REVIEW ARTICLE

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Emergency care in case of acute psychotic and/or manic symptoms: Lived experiences of patients and their families with the first interventions of a mobile crisis team. A phenomenological study

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Abstract

Purpose: To explore the lived experiences of patients with a psychotic or bipolar disorder and their families with emergency care during the first contact with a mobile crisis team.

Methods: Open individual interviews were held with ten patients and ten family members. Content data-analysis was conducted.

Findings: Communication and cooperation was difficult in several cases. Personal crisis plans were not always used. Stigma was felt, especially when police-assistance was needed. A calm, understanding attitude was appreciated.

Practice Implications: Focus explicitly on communication with the patient, despite the acute condition, enhances the chance of cooperation. Taking time for contact is important.

KEYWORDS

bipolar, family members, mobile crisis team, patients, psychotic

1 | INTRODUCTION

In cases of acute mental health crisis, patients in many countries are typically referred to some sort of mobile, mental health, crisis team. A large part of the patients that need emergency care from a mobile crisis team are patients with acute psychotic and/or manic symptoms. 1,2 Most of the time, these patients are in a confused and disorganized state, often experiencing delusions and/or hallucinations. These symptoms can severely hamper attempts to communicate and interact with the patient, which can be further complicated by stress caused by the patients' distrust of mental health workers and others involved and the unpredictability of what is happening at that moment. The family and relevant others can also be under severe stress and exhaustion, which further complicates the activities in the emergency care for these patients.

The National Institute for Health and Care Excellence (NICE) guidelines for the treatment of patients with psychosis and schizophrenia³ and patients with bipolar disorder⁴ recommend the offering of crisis services 24 hr a day for the support of patients in crisis. Assessment

at home and further treatment in the community is first choice to be considered when possible, and before recommending admission to an inpatient unit.^{3,4} The NICE guidelines also recommend that assessment be conducted a) by an experienced health care professional who is qualified for crisis work, b) within 4 hr of referral, and c) include a comprehensive exploration of the situation. Providing clear information for the patient and caregivers is also important.⁵ The practice guideline of Health and Human Services (HHS)⁶ describes values and principles essential to any response to mental health emergencies. Nevertheless, standard procedures or protocols about the activities and attitude of professionals during the first contact with the patient and family members are not available. The activities of the mobile crisis team professionals are mostly practice based. Wheeler et al.⁷ describe in their review about Crisis Resolution Teams the diversity of these teams, and state that suggestions about optimizing these services are based on experience, personal views, and consensus processes. So far, little research has been conducted about the experiences of patients with acute psychotic and/or manic symptoms and their family members with the first

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contact with a mobile crisis team. The topic of this study is important because improving services is only possible if we take the lived experiences of these vulnerable patients and their family members into account.

A mental health crisis often has a great and long-lasting emotional impact for both patients and their families. In clinical practice, patients often complain about the lack of involvement into the communication with the professionals of the mobile crisis teams. Patients frequently experience this emergency care as threatening (as opposed to reassuring) and even traumatizing (as opposed to helpful). Systematic information on the experiences of these patients and their families during the first contact with the mobile crisis team has yet to be gathered.

In sum: The activities provided by mobile crisis teams during a mental health crisis are mostly practice based. Systematic information on the activities, attitude, and interventions provided by mobile crisis teams during the first contact is not available. The understanding of the perspectives of patients and family members is an important first step in describing the context of interventions. The aim of the present study was therefore to explore the lived experiences of patients with a psychotic or bipolar disorder and their families with emergency care during the first contact with a mobile crisis team.

2 | METHODS

A qualitative, phenomenological study design was used to explore the lived experiences of patients and their families. Qualitative research focuses on the lived experiences, interactions, and language of human beings. Phenomenology seeks to describe the common meaning for several individuals of their lived experiences of a phenomenon, which leads to a description of the universal essence. ¹⁰

Professionals working in teams from four mental health organizations providing treatment for outpatients with psychotic and bipolar disorders in the Netherlands were asked to inform their patients about this study. Variation in age, gender, and diagnosis of the participants was pursued. Patients were asked if they would be willing to participate; if interest was showed they were given further, written information about the study. They were contacted one week later by phone to answer any questions. When the patient agreed to participate, an interview appointment was scheduled. All patients who were initially informed about the study were asked to share the written information that they had been provided with a family member in order to recruit family members for participation in the study as well. When it became clear that very few family members became available using this procedure, we turned to the organizations for patients with schizophrenia and patients with a bipolar disorder for the recruitment of family members.

Written, informed consent was provided by all participants before the interview was conducted.

2.1 | Inclusion criteria for patients

Age > 18 years.

- An Axis I Diagnostic and Statistical Manual of Mental Disorders IV diagnosis of a psychotic disorder or bipolar disorder.
- Experienced a crisis with psychotic and/or manic symptoms, and were visited by the mobile crisis team during the past 2 years.
- Able to speak understandable Dutch.
- A stable condition, according to him/herself and a professional, at the time of the interview.

2.2 | Inclusion criteria for family members

- Age > 18 years.
- Present during the visit of the mobile crisis team when their family member had a crisis with psychotic and/or manic symptoms during the past 2 years.
- Able to speak understandable Dutch.

For each group of participants, the target sample was set at 10 participants. For qualitative studies, no rigid rules apply as to the minimum number of participants.

2.3 | Ethical considerations

The proposal for this study was approved by the Dutch Central Committee on Research Involving Human Subjects and by the Scientific Research Committee from the mental health organizations involved in the study. Each participant received both oral and written information on the study. An informed consent form was signed prior to the start of the interview.

2.4 Data collection

The participants were interviewed individually, starting with the question: How did you experience the (last) crisis in which you or your family member had acute psychotic and/or manic symptoms and a mobile crisis team intervened? After each of the open interviews, a brief impression of the interview was written in the study logbook. The interviews were audio-recorded and later transcribed verbatim.

2.5 | Data analysis

Within the same time frame, two separate sets of data analysis were performed: one for the data from patients and one for the data from family members. The MAXQDA 2007 computer program (VERBI GmbH, Berlin, Germany) was used for the analyses. To start with, the entire interview was read and reread along with the information in the logbook. Sentences in the interview texts associated with the research question were selected and coded. The first interview for each group was coded by two investigators independent of each other. The coding was discussed until consensus was reached. The first author then went on to code the remainder of the interviews. Discussion within the research team during the course of the data analysis helped refine the categories in the separate analysis. The process of data collection and data analyses was interfering. Attention was taken that the coding

categories could always be traced back to the original data. Certain categories were relevant for the coding of the data from both the patients and the family members. We therefore decided to describe the outcomes of the analyses as a whole and thus combine those categories that overlapped for patients and family members. Quotes from the interviews were added to the text of the findings.

3 | FINDINGS

Sixteen crises were analyzed with information coming from 10 patients and 10 family members who were interviewed between April 2013 and November 2014. For further demographic information, see Table 1.

Six themes emerged from the data with similarities in the information provided by the patients and family members for four of these themes: the experience of the crisis, experiences with the emergency care provided by the mobile crisis team, experiences with the crisis professionals, and the role of the outpatient treatment team. "Stigma" was an additional theme among the patients. And "family members as caregivers" was an additional theme among the family members.

3.1 | Experience of the crisis: "Feeling trapped"

Patients reported feeling trapped in psychotic thoughts and inner confusion during the crisis, which made communication with others during the crisis quite difficult.

Yes, I was caught up in delusions. I was stuck in myself and iust couldn't speak with others at that moment. (patient 08)

Patients also mentioned experiencing feelings of suspicion during the crisis.

I lived in a fantasy world...I was paranoia and thought people would come and get me.... That kind of things... (patient 04)

Both patients and family members reported seeing that things were going wrong but found seeking professional help not easy because most patients were ambivalent about this. Family members reported feeling very worried and frustrated as they saw the situation worsen and heard the patient deny that professional help was needed. They felt powerless.

I did ask my eldest brother to come too, just to feel more safe. The whole evening, we tried to convince him to go see a doctor. (family member 21)

Both patients and family members reported experiencing such feelings as despair, helplessness, shame, and sadness during the crisis.

Another crisis, again. Why don't we have control? With all our strength and that of her too... we have insight into the disease... and still this happens. Yes, it's hard. And sometimes we blame ourselves... (family member 16)

Although patients reported not being able to remember everything that happened during the crisis, some of them did recall the sincere commitment of a family member. In a number of the crisis situations,

the family member experienced the behavior of the patient as becoming dangerous and therefore had to call the police. Police involvement to secure safety was experienced as intrusive and hard to witness and accept for the family members. The family members emphasized that the patient was ill and should therefore not be treated as a criminal.

He did not want to open the door [for the police]. Then they forced the door open and got ahold of him. This was very traumatic for him and also for all the other people who were around. It was in the middle of the night and everybody was upset. (family member 19)

3.2 | Experiences with the emergency care of the mobile crisis team: "A bumpy road"

It often took a long time for the mobile crisis team (sometimes together with the police) to arrive, according to both patients and family members. As a result, and as they saw the situation — often quickly — deteriorate, the family members were left to feel helpless and still in need. Placement in police custody pending assessment by a crisis team, however, was experienced as very inappropriate by both patients and family members.

The police took control at such a moment. I felt like a criminal. Which was idiotic because I had not done anything wrong. I had not stolen anything or something like that. (patient 05)

The way the mobile crisis team acted was sometimes unclear to both patients and family members. In many of the crisis situations, both the patients and the family members reported not knowing who they were speaking with or the profession of that person.

I do not know if they are doctors...or nurses? It could be... I do not know who they are. (patient 03)

In general, the family members felt sufficiently informed about the diagnosis and the reasons for the activities and interventions conducted.

They explained to us what was going on, what the diagnosis was, and which decisions they made...(family member 21)

Those patients who sought professional help during an early stage of the crisis reported that the crisis team did not always understand the call for help and that they thus felt that the crisis team did not always take them seriously.

They should not think: "Oh she's talking calmly and clearly so she's okay." If I say, I myself, that things are going wrong and that I do not feel good, then they should listen to me! And not just send me away... (patient 04)

Those family members who received a follow-up call to see how they were doing reported this as highly appreciated.

Afterwards it is important to hear what's going to happen next. They also asked what we needed... I could tell my own story as well.... (family member 01)

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TABLE 1 Demographic information



3.3 | Experiences with the crisis professionals: "Closing the gap"

A number of patients experienced no communication with the crisis team about their condition, and about the decisions being made. According to the patients, they had no influence at all. They felt powerless.

Other people have the power over you. I could not say what was wrong with me. And even if I could, they decided what to do. At such a moment, I am at the mercy of that power, of the mental health institution. That's how it is... (patient 05)

Other patients told us that the professionals from the crisis team were kind and they felt reassured by them; also that they felt heard and taken seriously. They felt at ease.

That professional talked to me in a quiet and normal way. Just like a normal person, that was really nice (patient 09)

The attitude of the crisis professionals was described most of the time as calm, empathic, and understanding.

They came to my house, and they were very friendly. Very friendly and very reassuring. That calmed me (patient 03)

In contrast to what patients told about not being asked about their condition, family members reported frequently being asked about the condition of the patient. Also they were informed about the viewpoint on the problems and their plans and interventions. That gave confidence.

They took us apart to explain to us what was going on and which interventions might be used. He could go home, but that would not change his situation, which was unstable. Or he could voluntarily go to a hospital... (family member 21)

Family members mentioned that they thought that it was essential that the emergency care provided for the patient was in concordance with the needs and the severity of the crisis.

The psychiatrist explained the need for forced hospitalization. On the one hand that was threatening, but the way he told it was okay... he acted well... (family member 21)

Family members also mentioned that attention to their own emotional state — as people closely involved— was important.

3.4 \mid The role of the outpatient treatment team: "Being prepared"

Fourteen of the patients involved in a crisis were already in treatment at an outpatient treatment organization when the crisis developed. If there was a crisis plan formulated and discussed earlier by the patient and a professional from the outpatient treatment team, this was reported to help some of the patients and their family members during the crisis: they knew what to do and who to call. This was experienced as reassuring.

We are doing better all the time! We are not unsure about what to do anymore: We have the telephone numbers, we know who we have to call, what to do.... That is something you have to learn. (family member 16)

Most patients, however, said they did not know what was in their crisis plan or whether the mobile crisis team had used their crisis plan or not.

The communication with and support of the professionals from the outpatient treatment team, especially during the crisis situation, was mentioned as very important by both the patients and family members. The patients said that they probably would have followed the advice of a familiar professional from the outpatient treatment team if the professional had been available at the time of the crisis.

A conversation between the crisis team, my therapist, and me: that would have been helpful. The most important people would have been together then and could have shared all the information. (patient O1)

3.5 | Stigma: "Feeling humiliated"

Patients reported that they felt treated like a criminal when the police took them into police custody pending assessment by a crisis team. They experienced the stay as horrible.

I felt so helpless. It was a sort of desperate feeling; I could do nothing about it. You lose your freedom; you are just left sitting in a cell at the police station. (patient 01)

These patients felt stigmatized. People in the neighborhood saw them being taken off in a police car, sometimes in handcuffs. All such patients felt that they were treated as a crime suspect and therefore being picked up rather than being cared for as a patient.

I thought I had done something wrong. I was given some sort of blue overall, and they said I should put it on. (patient 10)

Family members told how they tried to take responsibility for the condition of the patient during crisis, even when the situation got dangerous. They felt they acted more and more as caregivers instead of as a family member.

Of course we try to do as much as we can by ourselves. I ask for help at the last moment. Simply because I want to solve our own problems. (family member 17)

Most of them described feeling incapable of doing anything as the crisis evolved at times. They reported feeling that they could not handle the situation any longer. When finally the crisis team arrived they felt great relief.

My partner [patient] wasn't well. Totally not well. And I.. I was at my wits' end, physically and mentally... (family member 19)

They also reported feeling a conflict of interest during crisis: they did not want to damage the confidence of the patient but, at the same time, they saw the need for professional help. This was experienced as very uncomfortable.

I have to be careful not to lose the confidence of my son. He still trusts me. (family member 20)

4 | DISCUSSION

In this study, we explored the lived experiences of patients with acute psychotic and/or manic symptoms, and their families during the first contact with a mobile crisis team.

The main findings of this study are: most patients reported feeling trapped in psychotic thoughts and inner confusion during crisis, whereby communication was difficult. Family members mentioned how powerless they were to handle the situation any longer. In general, the family members felt heard by the professionals of the crisis team. According to the participants it often took a long time for the mobile crisis team to arrive. Calmness, empathy, and understanding on the part of the professional were experienced as essential by both patients and family members. Most of the patients did not know if the crisis team had used their crisis plan. Some participants reported they used the plan, which was experienced as helpful. Patients often felt stigmatized when the mobile crisis team was called in to help and especially when the police had to get involved. Family members felt great relief when the mobile crisis team stepped in since they felt overloaded when the crisis evolved.

Some of the participants in this study experienced a lack of communication and contact with the involved professionals, others felt understood and heard. Participants in general described their confused and disorganized state and quite a lot of them experienced that the activities and interventions of the professionals did not fit with this condition. These experiences do not give a clear, unambiguous picture of the way professionals carry out the first contact. Roberts and Ottens¹¹ describe stages in a crisis intervention model, in order to come via assessment, rapport, and collaboration to stabilization, resolution, and mastery. The first stage handles biopsychosocial assessment and establishes rapport. For professionals of the mobile crisis team conducting the first contact especially with patients with psychotic and/or manic symptoms, there is nevertheless still little guidance on how to interact with these patients. The stories of the participants seem to endorse a hypothesis as: "when professionals are able to find a tailored way of working, suitable for that specific case, the chance of collaboration enhances."

When the crisis occurred for the first time, both patients and family members were particularly in need of information on the activities and interventions being considered and decisions being made by the mobile crisis team during this first contact. This is in line with the advised values and principles mentioned in the practice guideline of HHS.⁶ For patients already in treatment, early involvement of the family in this treatment is important; this provides possibilities to enhance cooperation with patients and family members during crisis. ¹²

Participants in this study underlined that the already existing contact with the community mental health team was important for them, even during crisis. But when crisis occurred, they often had to deal with unknown professionals, like those from the mobile crisis team. A personal crisis plan or relapse prevention plan helped some patients, and their family members, to know what to expect from professionals during crisis. Participants in this study told they did not know whether the professionals of a mobile crisis team used the personal crisis plan of the involved patient in the first contact with the patient and family members. This is in sharp contrast with the recommended role of a crisis plan or relapse prevention plan at all stages of treatment. 3.4,13–15 The same applies to continuity in the long-term relationship between professional, patient, and family members. 12

Most of the patients referred to stigma in relation to the need for emergency care. Some were afraid of being stigmatized while others already felt stigmatized. In both cases, label avoidance was mentioned as a reason for not seeking professional help in case of acute psychotic and/or manic symptoms. Others felt stigmatized following the first contact with a mobile crisis team; many mentioned feeling treated like a criminal, especially when the police was involved to secure safety. On the one hand, particularly family members told that the assistance of the police sometimes was needed for the purpose of safety; also patients and family members were clear that police interference should be as minimal as possible because patients need care, and no stay in a police station. In a policy paper between the Dutch Association of Mental Health and Addiction Care and Dutch National Police force, 16 (Convenant Politie-GGz Nederland), closer cooperation between these two was recommended to make sure that patients get the emergency care they need as soon as possible and that assessments takes place in a secure and appropriate location, not being a police station. In England the Mental Health Crisis Care Concordat¹⁷ describes how patients, family, and responding services can work together to make sure that immediate mental health support at a time of crisis is available at any moment in the right way.

4.1 | Study strengths and limitations

Participants in this study were drawn from both urban and rural regions of the Netherlands and mobile crisis help was provided by teams coming from a variety of mental health organizations within the Netherlands. In addition, the data is rich, which increases the credibility of the findings reported here.

A potential limitation of the present findings is the possibility of selection bias. It is not clear if the patients who agreed to participate in the study are representative of the more general group of patients with acute psychotic or manic symptoms requiring the emergency care of a mobile crisis team. Patients may obviously have decided against participation in the study because they did not want to be confronted with the crisis situation yet again. The recruitment method also excluded patients who did avoid further treatment after the contact with the mobile crisis team. All participating patients were in mental health treatment. Maybe they are a specific group, motivated to receive help and having some insight in their problems. Recall bias is a second potential limitation, as in many retrospective studies.

The time between the experienced crisis and the interview for this study ranged from 6 to 24 months. It is thus unclear if the patients relied upon their own memories or on what others have told them: cognitive dysfunctioning may have influenced the recollections of the interviewed patients. Nevertheless, the retrospective design was chosen deliberately, suitable to the research question. Finally, the majority of the data analyses was conducted by one individual, but the findings were regularly discussed within the research team to enhance the confirmability of the findings.

4.2 | Implications for nursing practice

The chances of cooperation during crisis enhance when the professionals of the mobile crisis team focus explicitly on communication with the patient with acute psychotic and/or manic symptoms, despite the confused and disorganized condition of the patient, and possible delusions. Taking time to gather information about the patients' condition and the opinion and wishes of the patient and family members, described in a crisis plan, could contribute to less stigmatization and escalation. The crisis plan needs to be used on the spot during the first contact. Repeated information about activities and interventions has to be given to make the patient and family members understandable for which care is given with what reason. Future research should strive to gain insight into the activities, interventions, and experiences of the professionals of a mobile crisis team and other professionals involved during the first contact with the patient. So a more complete picture can be obtained, including the perspectives of all people involved.

CONFLICT OF INTEREST STATEMENT

The authors report no actual or potential conflict of interest.

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