# Adherence to Treatment in First Episode Psychosis: Acceptance, Refusal, or Ambivalent Process?

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### **ABSTRACT**

Drawing from the perspectives of 18 youth (characterized as adherent, ambivalent, nonadherent), 13 relatives and 8 clinicians, this qualitative study, using semi-structured individual interviews and a focus group, explores why individuals suffering from early psychosis accept or refuse treatment. Identity and relationships, understanding of the diagnosis and significance given to treatment are key themes. Varying degrees of ambivalence and nonadherence can be seen as normal stages of a process to rebuild their sense of self and construct their identity. A trusting relationship may facilitate gradual resolution of ambivalence, promoting the individuals' sense of ownership and empowerment in the context of treatment.

**Keywords:** early intervention, first-episode psychosis, schizophrenia, medication adherence, treatment adherence

# RÉSUMÉ

Considérant la perspective de 18 individus (adhérents, ambivalents ou non adhérents au traitement), 13 proches et 8 cliniciens, cette étude qualitative utilisant entretiens individuels semi-structurés et groupes de discussion, explore pourquoi les individus souffrant de psychose débutante acceptent ou refusent le traitement. L'identité et les enjeux relationnels, la compréhension du diagnostic et la signification donnée au traitement sont primordiaux. Différents degrés d'ambivalence et de non-observance semblent les étapes d'un processus visant à reconstruire le sens de soi et l'identité. Une relation de confiance faciliterait la

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résolution progressive de l'ambivalence, favorisant le sentiment d'appropriation et d'autonomisation dans le contexte du traitement.

**Mots clés :** intervention précoce, premier épisode psychotique, schizophrénie, observance à la médication, observance au traitement

Psychotic illness develops early in life and impacts various areas of functioning. Available pharmacological treatments are particularly effective in the early stages of psychotic illness (Cassidy, Norman, Manchanda, Schmitz, & Malla, 2010; Lieberman et al., 2003; Malla, Norman, Manchanda, & Townsend, 2002), although pharmacotherapy alone is not sufficient to insure recovery and needs to be combined with psychosocial interventions to improve outcomes (Breitborde, Moe, Ered, Ellman, & Bell, 2017). Nevertheless, nonadherence to pharmacological treatment, which is estimated to reach 50% in the first year after a first episode of psychosis (FEP; Coldham, Addington, & Addington, 2002; Mojtabai et al., 2002; Perkins et al., 2006; Rabinovitch, Bechard-Evans, Schmitz, Joober, & Malla, 2009), is an important risk factor of relapse and of poor clinical outcome (Coldham et al., 2002; Gitlin et al., 2001; Malla et al., 2002; McGorry & Killackey, 2002; Robinson et al., 1999; Velligan et al., 2009).

Originally defined as the act of conforming with medication prescription (Sackett & Haynes, 1976), adherence to pharmacological treatment is now considered to be more complex than that, integrating not only the individual's behaviour but also his/her attitude towards treatment (Weiden, Buckley, & Grody, 2007). A review of the literature reveals that medication adherence fluctuates with time (Kampman & Lehtinen, 1999; Marder, 2003; Mutsatsa et al., 2003) and can be characterized as a continuum (Marder, 2003; Rummel-Kluge, Schuster, Peters, & Kissling, 2008; Velligan et al., 2009). Moreover, psychosocial treatments are described as going hand in hand with pharmacological treatments, especially at the beginning of psychosis treatment, since psychosocial interventions adapted to individual's needs are particularly effective (Breitborde et al., 2017; Killackey, 2009) and can have a beneficial effect on adherence (Leclerc, Noto, Bressan, & Brietzke, 2015).

Since adherence to treatment seems to impact the clinical evolution of psychotic disorder, many studies have examined factors modulating it. They include factors that are inherent to the illness (e.g., symptom severity, co-morbidity), related to the medication (e.g., side-effects), associated with the social environment (e.g., therapeutic alliance with prescribing physician, family support), and linked with the individual's characteristics (e.g., insights, beliefs, attitude; Doyle et al., 2014; Fenton, Blyler, & Heinssen, 1997; Velligan et al., 2009). The subjective dimension of adherence has gradually gained more attention from researchers. Qualitative studies suggest that the decision to follow treatment recommendations would be influenced by the relationship with loved ones and the feeling that treatment can help to regain control over one's life (Usher, 2001; Roe, Goldblatt, Baloush-Klienman, Swarbrick, & Davidson, 2009). However, to the best of our knowledge, few studies have addressed the integrated understanding of adherence that takes into account the perspectives of the individual and also of his or her relatives (Beck, Cavelti, Wirtz, Kossowsky, & Vauth, 2011; Kikkert et al., 2006; Mutsatsa et al., 2003).

### **METHOD**

The purpose of this qualitative study is to understand the reasons why individuals with a first episode psychosis (FEP) accept or not the treatment that includes both pharmacological and psychosocial recommendations (such as psychoeducation, psychotherapy, and other group psychosocial interventions). Our qualitative, interpretative, descriptive study (Thorne, Reimer, & O'Flynn-Magee, 2004) intends to describe adherence in first psychosis and understand the phenomenon in depth and in all its complexity, while taking into account the perspective of individuals, their relatives, and clinicians involved in their care.

The study was approved by the Research Ethics Committee of the Centre hospitalier de l'Université de Montréal (CHUM). Study participants (individuals) were selected on the basis of the following inclusion criteria: age between 18 and 40 years, diagnosis of psychotic illness (schizophrenia spectrum and affective disorders, either bipolar or unipolar), and follow-up in a specialized early intervention clinic in the CHUM. Participants were selected after discussion with the treatment team. Two of the three researchers (LA, AAB) were also clinicians in the treatment team. Acute symptomatology, intellectual disability, and insufficient fluency in French were considered as exclusion criteria. In collaboration with the researchers, to insure optimal representation of the global first episode psychosis population, the clinical team selected potential participants on the basis of various characteristics that are likely to impact adherence or outcomes, such as diagnosis, length of follow-up, illness severity, number of past hospitalizations, education level, occupation, etc. This purposeful sampling method (Brinkmann, 2013; Marshall, 1996) generates maximal variation (Sandelowski, 2000). The potential participants were invited to participate in the study by the research assistant after being approached by their case-managers or psychiatrist. Informed consent was obtained from all the study participants by a research assistant not involved in the individual's treatment.

In previous literature, adherence levels have been considered on a continuum. Therefore, on the basis of clinical team consensus, participants were chosen according to their resemblance of the following three observed adherence profiles, each based on their main general attitude and behavior toward the treatment considering the whole duration of their follow-up:

- 1. *Nonadherent* (NAP): youths manifesting opposition to treatment including medication and/or follow-up (e.g., verbal refusal, missed appointments, not filling prescription). For the majority, a treatment order was issued by a judge on the basis of their incapacity to consent to treatment.
- 2. *Ambivalent* (AMP): youths presenting fluctuating attitudes and behaviours regarding treatment (e.g., sometimes refusing or accepting medication and/or follow-up).
- 3. *Adherent* (ADP): youths presenting attitude and behaviour showing acceptance of both medication and follow-up.

To increase validity of the results, the number of participants was determined according to the saturation principle of Grounded Theory (Sandelowski, 1995; Strauss & Corbin, 1994). Therefore, in our study, saturation was reached when the information that we got from new participants started to repeat itself. At that point, we decided to stop adding new participants because they would not add new information relevant to our research question. In our study, the saturation was obtained with six participants for each adherence profile.

The selected participants gave their consent for involving a relative of their choice in the study. The research assistant contacted the relative thereafter to explain the study and obtain signed consent. Clinicians on the specialized team where the two researchers (LA, AAB) worked were solicited for study participation.

Data were collected on clinic premises at the CHUM in two ways: semi-structured individual interviews (60–90 minutes) with youths, then with relatives and a focus group (90 minutes) with clinicians. The focus group was representative of different professionals on the care team (occupational therapist, social worker, nurse, psychiatrist). The aims of the focus group were first, to permit the exploration of clinician opinions on the research question, and second to inspire the elaboration of an interview guide for the youths' and relatives' individual semi-structured interviews.

The individual semi-structured interviews of young participants were performed first and then with the participating relatives by the research assistant and the researchers not involved in the individual's care. The same open questions were proposed to young participants and their relatives such as: "From your point of view, what are the reasons that influence your decision to follow or not the recommendations of your team?" and "Are there recommendations that are easier to follow?"

Both the focus group session and individual interviews were conducted in French, audio-recorded and then transcribed. Collected information was subjected to thematic content analysis (Thorogood & Green, 2009). The three researchers discussed all the aspects of data analysis. The researcher responsible for data analysis (LA) undertook repeated and careful readings of the 32 transcripts in French and, using QDA Miner software, identified relevant themes (e.g., identity issues related to the meaning of treatment) to which codes have been assigned (e.g., "identity" code). An analysis based on a recursive process (Braun & Clarke, 2006) allowed researchers to combine the different codes and revealed the emergence of recurring and significant themes with regard to our research question. The first versions of codification were discussed and the analysis adjusted according to the comments of the researchers to insure consistency of the thematic analysis. English translation of some quotes was conducted only for knowledge transfer activities and was reviewed by the three researchers and a linguistic reviewer.

# **RESULTS**

The sample included 39 participants. Eighteen of the 26 individuals who were asked to participate in the study agreed to do so. The characteristics of the participants are described in Table 1. Thirteen of 19 solicited relatives (12 parents and a friend chosen by the youths) participated along with eight of nine solicited clinicians.

Although our initial intention was to address the issue of adherence to treatment in its widest definition (including pharmacological and psychosocial interventions), for most youths in the study, the notion of "treatment" was spontaneously associated with medication. The results revealed that all of these youths experienced a certain level of ambivalence towards therapeutic recommendations that fluctuated with time. However, our study does not reveal any link between the length of the time involved in the EPI program and the adherence profile. Even individuals considered adherent or nonadherent by their treating team, reported having felt or were still feeling ambivalence about treatment. Some individuals could be adherent from the beginning and throughout the follow-up while others might stay ambivalent or nonadherent even after many

Table 1
Sociodemographic and Clinical Characteristics of Participants

Sociodemographic and Treatment Variables	Adherent $N = 6$	Non- adherent N = 6	Ambivalent $N = 6$	Total N = 18	Range
Age (years)	27.8	28.2	24.5	26.8	21.0-37.0
Gender n (%)					
Male	4 (66.7)	4 (66.7)	5 (83.3)	13 (72.2)	
Female	2 (33.3)	2 (33.3)	1 (16.7)	5 (27.8)	
Immigration status n (%)					
Non-immigrant	4 (66.7)	3 (50.0)	5 (83.3)	12 (66.7)	
1st generation immigrant	2 (33.3)	1 (16.7)	0	3 (16.7)	
2nd generation immigrant	0	2 (33.3)	1 (16.7)	3 (16.7)	
Diagnosis n (%)					
Schizophrenia	2 (33.3)	3 (50.0)	3 (50.0)	8 (44.4)	
Bipolar	3 (50.0)	1 (16.7)	1 (16.7)	5 (27.7)	
Schizoaffective disorder	1 (16.7)	2 (33.3)	2 (33.3)	5 (27.8)	
Clinical Global Impression scale (mean)	3.7	4.2	4.2	4.0	3.0 - 5.0
Education—years completed (mean)	13.0	12.5	12.0	12.5	7.0-17.0
Highest diploma obtained n (%)					
Primary school	1 (16.7)	1 (16.7)	2 (33.3)	4 (22.2)	
High school	3 (50.0)	3 (50.0)	1 (16.7)	7 (38.9)	
College	1 (16.7)	0	3 (50.0)	4 (22.2)	
University certificate	0	1 (16.7)	0	1 (5.6)	
Bachelor's or higher	1 (16.7)	1 (16.7)	0	2 (11.1)	
Current employment status n (%)					
Unemployed	1 (16.7)	3 (50)	1 (16.7)	5 (27.8)	
Employed	4 (66.7)	1 (16.7)	2 (33.3)	7 (38.9)	
Studies	1 (16.7)	0	2 (33.3)	3 (16.7)	
Work + studies	0	2 (33.3)	1 (16.7)	3 (16.7)	
Employment – Best in life n (%)					
None	1 (16.7)	1 (16.7)	2 (33.3)	4 (22.2)	
Short or unstable	0	2 (33.3)	1 (16.7)	3 (16.7)	
Sustained employment/studies	5 (83.3)	3 (50.0)	3 (50.0)	11 (61.1)	
Housing (%)					
Autonomous/room-mate	2 (33.3)	2 (33.3)	1 (16.7)	5 (27.8)	
Parents	2 (33.3)	2 (33.3)	3 (50.0)	7 (38.9)	
Supervised housing	2 (33.3)	2 (33.3)	2 (33.3)	6 (33.3)	
Duration of psychiatric treatment (mean. months)	43.3	37.0	27.8	36.1	6.0–129.0
Proportion of patients for whom medication is prescribed n $(\%)$	6 (100)	5 (83.3)	6 (100)	17 (94.4)	_
Currently receiving long-acting injectable antipsychotic n (%)	0	4 (66.7)	2 (33.3)	6 (33.3)	_
Previously received long-acting injectable antipsychotic n (%)	0	6 (100)	3 (50.0)	9 (50.0)	_
Community treatment order n(%)	0	5 (83.3)	0	5 (27.8)	
Number of hospitalizations (%)	1.2	2.8	2.2	2.1	1–6

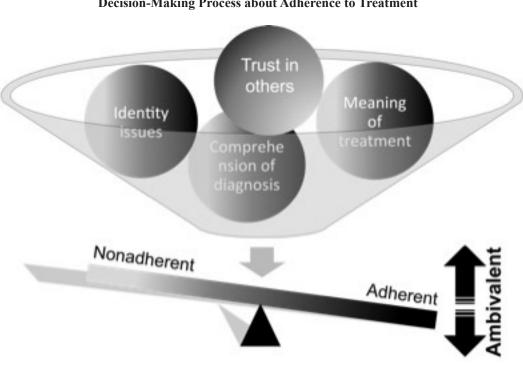


Figure 1

Decision-Making Process about Adherence to Treatment

years spent in the EPI program. The results suggested that only by resolving this ambivalence, can individuals make an informed decision about treatment. Regarding the medication, this decision can go either way and change over time. The key factor is the sense of agency that results from understanding the reasons behind the decision. Four themes stood out as having an impact on the resolution of the ambivalence: identity issues, relational issues, understanding of psychosis, and meaning of treatment (Figure 1).

# **Meaning of Treatment**

Although our initial intention was to address the issue of adherence to treatment in its widest definition (including pharmacological and psychosocial interventions), for most youths in the study, the notion of "treatment" was spontaneously associated with medication. Indeed, it is on this subject that the youths, whatever the adherence profile, had the most to say in relation to adherence issue.

Thus, nonadherent youths considered that medication altered their identity because of side-effects: "When I don't take medications... I feel less insecure, more intelligent" (NAP 101), and also because of the associated stigma: "It's all right to take aspirin for a headache, but taking antipsychotic medications is more taboo." (ADP 304). One participant went as far as saying "Taking medication is more painful than the illness itself" (NAP104).

Even if the ambivalent youths understood the indication of the treatment, the treatment goals remained vague for the majority of them and this had an impact on adherence:

I had to take it [the medication] to balance my nervous system... they told me it was for my well-being but I didn't really know what it was doing to me... I think the best way would have been to try to see how it went without medication. (AMP 201)

In contrast, adherent youths felt that that pharmacological treatment provided them with the stability necessary to complete projects, therefore allowing them to preserve their identity.

For their part, clinicians and relatives considered treatment in a comprehensive way:

The treatment... It's not just taking medication, but reorganizing your life, your social network, your work ... (clinician)

If the patient benefits from the treatment, he is more likely to be more and more adherent. (clinician)

Many participants observed that experiencing a relapse could raise the consciousness about vulnerability to psychosis:

I stopped taking antipsychotic medications after 2 years... It really got out of hand after that... That's when I realized I had to take the medications to live a stable and normal life... (ADP 304)

# **Identity Issues**

According to our results, identity issues seem to have a significant impact on adherence to treatment in first episode psychosis. Diagnosis of psychosis seemed to undermine individuals' identity because of the nature of the illness and associated stigma:

I think I was diagnosed as being schizophrenic... just mentioning the name of the disease is hard... being ill changes how people interact with me... they will treat me differently than someone in good health. (ADP 303)

The rejection of the treatment was even stronger if the diagnosis is perceived as an attack to self-esteem. The individual then confused "having" an illness and "being" the illness. He rejected the illness identity and at the same time, rejected the treatment, which he perceived as a threat to his identity.

Me, I don't want medication, because I don't want to be labelled as ill... People have prejudices towards that, so... of course it influences me. (NAP101)

... [with the medication] I thought I would become a zombie, a completely different person. (AMP 204)

Relatives also recognized that the diagnosis can be perceived as threatening to self-esteem and that this could have an impact on adherence:

He did not recognize the illness... the word "mental illness" has a terrible stigma attached to it, so if "I do not accept it...it does not exist." (relative PNO106)

Initial rejection of the diagnosis and treatment could persist in some youths. For others, this initial rejection was followed by a period of ambivalence, after which they began to perceive the illness as separate from their identity and the treatment as a way of regaining control of their lives:

I want to succeed in life and will take all measures... with the medication, I feel more in control... fewer things bother me... I'm more on top of things. (AMP 204)

For adherent individuals it was psychosis, not the treatment, that involved a loss of control:

When you lose control over your thoughts and your actions... you lose self-esteem. (AMP 205)

Ambivalence seemed to fade as the individual managed to redefine himself or herself as an individual outside of the illness while integrating treatment as "something necessary" (AP304) and "a way to take care of myself" (AP305).

Our results suggest that the strategies of identity reconstruction could be part of a continuum at the ends of which lay two opposing visions of the diagnosis of psychosis and its treatment. At one end, the diagnosis of psychosis (considered as a label) and its treatment are perceived as a threat to a person's identity; therefore, treatment is associated with loss of control. At the other end, the treatment is perceived as a way of gaining control over psychosis since the illness is perceived as a threat to identity.

# **Trust in Others**

All participants considered the concept of trust in others to be central in the acceptance or not of the therapeutic recommendations.

Treatment compliance in general—I see it as a triangle: the patient, the therapist and the parents. (clinician)

The patient must feel listened by all those who interact with him... if he doesn't feel listened, he will not go back to see the [therapist] or, if he is obliged [but still feels he is not listened], he will pretend to take the medication [but] nothing will happen... (clinician)

Adherent youths reported having accepted treatments, especially medication, not out of personal conviction at first but to please caring relatives:

I followed the treatment in spite of myself. I didn't believe in medication at first... my mother helped me so much... with time, I realized it was helping me... I accepted it and decided to continue. (ADP 305)

A relationship of trust helps youths in the early stages of psychotic illness to progressively face the illness and treatment. When relatives could not offer this type of support, youths seemed helpless because of the ambivalence:

... my mother was never really there... never did she lift a finger to tell me: don't you think you're not doing good?... I could have told myself that my mother was worried about me... it could have had an impact... (NAP 102)

Participants reported that trust in the treating team is built gradually on the following elements: listening, feeling a genuine interest in individuals' experiences, non-judgmental attitude, being considered as a person, help with concrete steps to make a return to normal life. Even youths most recalcitrant in their treatments said they appreciated being listened to "because psychosis is something very intimate" (NAP 106). For others, simply chatting with their case manager gave them the feeling of "not being sick anymore" (ADP 301).

From the clinician's point of view, considering "the patient as a 'normal' person with mental health difficulties" (clinician) can promote a bond of trust and thereby better compliance.

On the contrary, the vast majority of nonadherent youths and some ambivalent youths saw their relationship with their family as having an insignificant impact on adherence. And they perceived their relationship with the treating team, and especially with the physician, as contributing to their nonadherence because they did not trust them:

The psychological control of the psychiatrist was so important that I had to say I was agreeing to take the medication, that I was feeling better. (NAP 104)

Psychiatrists in general... they give you medication to put you to sleep. [They] will come and tell you "you are like that (psychotic)," but in the end you are much more than an illness. (NAP105)

In this regard, the majority of youths who stopped the medication did so without talking to their treatment team, partly for fear of the consequences such as hospitalization or injection but also because they wanted to make the decision by themselves.

### **Understanding of Diagnosis**

The vast majority of participating youths knew their diagnosis and treatment. However, even if they agreed with the principle that psychosis should be treated, most nonadherent and ambivalent youths felt little or no concern about the therapeutic recommendations and interpreted the given information in terms of their personal beliefs and identity issues:

They explained about neurotransmitters in workshops... you have too many in your brain when you have a psychosis... the medication... it cuts down... I only remember that I found it horrible to block a part of my brain. (NAP 105)

Among nonadherent youths, religious, spiritual, and psychological explanations of psychosis predominated:

I don't think it is neurotransmitters that don't do their job... in my opinion, a psychosis is due to imbalanced chakras.... (NAP106)

All relatives interviewed in the study referred to the explanatory biomedical model just like all adherent youths and some ambivalent ones.

If you were diabetic, you would go for treatment... but you... your illness is in your head... there are medications... you will be able to control your illness.... (relative AP 304)

If you have an illness (psychosis)... it is not a choice... it's like having a kidney disease.... (AP 302)

The majority of study participants reported that knowledge acquired in psychoeducation sessions had to be understood within their experience to be considered significant and to have an impact on adherence to treatment.

They explained what psychosis was... I analyzed what they said and compared it with my problem... I told myself that I was not in the psychosis state they were talking about... so... I could stop the medications to see what effect it would have on me. (AMP 301)

### **DISCUSSION**

This study sheds light on the issues related to adherence to treatment in the early stages of psychotic illness. The results confirm the concept of adherence as a continuum (Hunt, Jordan, Irwin, & Browner, 1989; Rettenbacher et al., 2004; Roe, Goldblatt, Baloush-Klienman, Swarbrick, & Davidson, 2009; Valenstein et al., 2004) and suggest the presence of ambivalence towards treatment, which reveals an ongoing negotiation with oneself and with others (Carder, Vuckovic, & Green, 2003; Gray & Deane, 2016; Hunt et al., 1989; Thorogood & Green, 2009; Usher, 2001). Indeed, even within the three "observance profiles," most individuals' position toward treatment seems to fluctuate.

It is notable that even though questions about the treatment defined it as a combination of pharma-cological and psychosocial treatments, participants spontaneously talked about the medication. It may be because they felt that the FEP program emphasized that aspect of the treatment. But the case could also be made that medication seems to crystallize identity and self-esteem issues. (Bjornestad et al., 2017; Hansen et al., 2018; Harris et al., 2017) Some patients go as far as to claim that "taking medication is more painful than the illness itself," an impression that has also been reported in other qualitative studies (Deegan, 2005; Roe et al., 2009). This may be explained by the fact that medication is closely related to agency; while some patients feel that taking medication gives them agency, others feel it deprives them of it.

Regarding the treatment as a whole, the data indicate that identity issues are fundamental to treatment adherence in the beginning of psychosis. Thus, for non-compliant youths, being treated for psychosis is closely associated with a sense of "loss of self" (Usher, 2001), while for adherent youth, it is the psychotic illness itself that is the source of alienation from their identity (Carder et al., 2003; Hon, 2012; Hunt et al., 1989).

The vast majority of nonadherent youths were able to acknowledge the theoretical value of treating psychosis. However, because they did not recognize themselves in the diagnosis of psychosis, they did not take ownership of therapeutic recommendations (Day et al., 2005; Gauthier, Corin, & Rousseau, 2008; Nageotte, Sullivan, Duan, & Camp, 1997; Weiden et al., 2007). As previously reported, individuals are particularly inclined to discuss their views of psychotic illness when it is in its early stages (Bensasson, Vassal, Linard, & Mnif, 2011; McGorry, 1992; Read, Mosher, & Bentall, 2004; Werbert & Levander, 2005).

Moreover, in our study, nonadherent youths seemed more eager to elaborate their explanatory model of psychotic illness (predominantly spiritual and psychological) than adherent youths. This elaboration on an explanatory model can give meaning to the psychotic experience and thus protect the self-esteem (Werbert & Levander, 2005; McGorry, 1992). However, in our study, relatives and clinicians seem less sensitive to the presence of these so-called "private theories" by Werbert and Levander (2005) and to their impact on adherence.

Testimonies of adherent youths suggest that ambivalence is a normal step in making decisions regarding treatment. What seems fundamental in this decision-making by youths is their capacity to identify with significant social roles outside the illness, on the one hand, and the perceived value of treatment in achieving life goals, on the other (Deegan, 2005; Hon, 2012; Roe et al., 2009; Usher, 2001; Weiden et al., 2007).

The relational dimension seems to be key to adherence because youths in the vast majority of cases appeared to have accepted treatment at first, not because of their personal conviction, but in the context of significant relationship with a relative or caregiver (Rabinovitch, Cassidy, Schmitz, Joober, & Malla, 2013;

Roe et al., 2009); for example, because the youths trust their relative or caregiver and value their opinion. The results indicate that the decision-making process is of varying duration and characterized by periods of ambivalence, treatment cessations, and, sometimes, even relapse. It appears that, through this process, youths may develop their own understanding of illness and what treatment means to them. The results also suggest that this learning process can only be realized in a relationship of trust (Bjornestad et al., 2017; Hansen et al., 2018; Kilkku, Munnukka, & Lehtinen, 2003; Roe et al., 2009; Tranulis, Goff, Henderson, & Freudenreich, 2011; Yeisen, Joa, Bjornestad, Johannessen, & Opjordsmoen, 2016).

If no relationship of trust is established or if it is insufficient, youths may feel helpless when faced with the significance of their psychotic experiences and associated treatments (Davidson & Strauss, 1992; Kilkku et al., 2003). It is noteworthy that most nonadherent youths in the study agreed that one of their relatives could be contacted. However, in total, only three relatives of nonadherent youths participated in the study, suggesting the ambivalence of relatives themselves, which probably could have had an impact on the youths' attitude toward treatment.

When the social network of youths is not supportive enough, the treatment team often assumes this role. In some cases, when the therapeutic relationship is not sufficient enough to foster adherence, a legal framework authorizing treatment against their wishes is then necessary. It is thus within this framework that the process of re-appropriation of treatment by individuals continues or not.

# **Study Strengths and Limitations**

This study enhances the comprehension of issues related to treatment adherence in the early stages of psychosis, notably through the perspective of the three relevant parties involved (youths, relatives, and clinicians). Exploring the perspectives of nonadherent youths and youths being treated against their wishes contribute additionally to this comprehension. Study trustworthiness is based on the fact that the main sources of information were the youths and their relatives and on the knowledge transferability (Graneheim & Lundman, 2004). Indeed, the goal of a qualitative study is not to obtain results that can be generalized empirically but to identify certain concepts that can help to better understand individual adherence to treatment in similar clinical situations (Fossey, Harvey, McDermott, & Davidson, 2002; Thorogood & Green, 2009).

Because the researchers were also clinicians, some biases have to be considered in data collection and analysis. However, their dual status allowed them to analyze data, particularly while taking into consideration the clinical reality of individuals in the early stages of psychosis.

Moreover, while discussions among the three researchers (LA, AAB, CR) were conducted throughout the data analysis process, blinded coding of transcripts by other researchers could have improved the reliability of the results.

Finally, the presence of residual symptoms in certain participants, such as delusional beliefs integrated in an explanatory model of their illness or experience, may have influenced the results. Nevertheless, from the perspective of a qualitative approach, the presence of these symptoms allowed access to the subjective experiences of participants. They are even richer because they testify to the clinical context in which adherence issues emerge.

A longitudinal study would allow better understanding of the process of adherence. Indeed, in such a design, the reasons for adherence and nonadherence would be explored at different moments of the individual's evolution.

### **CONCLUSION**

In terms of clinical implications, the results suggest a few avenues of intervention, mainly regarding the attitude of clinicians towards an individual's ambivalence. Thus, seeing ambivalence and nonadherence as part of a normal process allows clinicians to adopt an open attitude which, in turn, encourages dialogue with youths in the early stages of psychosis (Beisser, 1979; Bensasson et al., 2011; Weiden et al., 2007).

Indeed, since identity and relationship questions are at the core of adherence issues, clinicians should pay particular attention to youths as individuals as a whole, beyond the problem that brought them to consultation (Beisser, 1979).

This orientation in the clinical approach requires that clinicians first understand individuals and not try to convince them. By taking genuine interest in the way individuals understand their illness, in the significance they give to treatment, and in their quest for identity, clinicians should be accompanying individuals in reconstructing their identity, while tackling veritable issues influencing adherence (Kikkert et al., 2006; Read et al., 2004).

This approach can sometimes conflict with certain clinical requirements, since interventions are often made in youths with emerging psychosis in emergency situations sometimes involving coercive measures. However, even within these constraining frameworks, through attentive listening, clinicians can position themselves as individual allies, helping them to initiate a process of treatment re-appropriation that will allow them to overcome their illness.

### REFERENCES

- Beck, E. M., Cavelti, M., Wirtz, M., Kossowsky, J., & Vauth, R. (2011). How do socio-demographic and clinical factors interact with adherence attitude profiles in schizophrenia? A cluster-analytical approach. *Psychiatry Research*, 187(1–2), 55–61. doi:10.1016/j.psychres.2010.10.012
- Beisser, A. R. (1979). Denial and affirmation in illness and health. *American Journal of Psychiatry*, 136(8), 1026–1030. doi:10.1176/ajp.136.8.1026
- Bensasson, G., Vassal, L., Linard, F., & Mnif, S. (2011). Le comportement d'observance des patients atteints de schizophrénie: impact du diagnostic et du traitement. Analyse phénoménologique de trois attitudes. *L'Evolution psychiatrique*, 76(4), 641–657.
- Bjornestad, J., Davidson, L., Joa, I. et al. (2017). Antipsychotic treatment: Experiences of fully recovered service users. *Journal of Mental Health*, 26(3), 264–270.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101.
  Breitborde, N., Moe, A., Ered, A., Ellman, L., & Bell, E. (2017). Optimizing psychosocial interventions in first-episode psychosis: Current perspectives and future directions. Psychology Research and Behavior Management, 10, 119–128.
- Brinkmann, S. (2013). Qualitative interviewing. Oxford University Press.
- Carder, P. C., Vuckovic, N., & Green, C. A. (2003). Negotiating medications: Patient perceptions of long-term medication use. *Journal of Clinical Pharmacy and Therapeutics*, 28(5), 409–417.

- Cassidy, C. M., Norman, R., Manchanda, R., Schmitz, N., & Malla, A. (2010). Testing definitions of symptom remission in first-episode psychosis for prediction of functional outcome at 2 years. *Schizophrenia Bulletin*, *36*(5), 1001–1008. doi:10.1093/schbul/sbp007
- Coldham, E. L., Addington, J., & Addington, D. (2002). Medication adherence of individuals with a first episode of psychosis. *Acta Psychiatrica Scandinavica*, 106(4), 286–290.
- Davidson, L., & Strauss, J. S. (1992). Sense of self in recovery from severe mental illness. *British Journal of Medical Psychology*, 65(Pt 2), 131–145.
- Day, J. C., Bentall, R. P., Roberts, C., Randall, F., Rogers, A., Cattell, D., ... Power, C. (2005). Attitudes toward anti-psychotic medication: The impact of clinical variables and relationships with health professionals. *Archives of General Psychiatry*, 62(7), 717–724. doi:10.1001/archpsyc.62.7.717
- Deegan, P. E. (2005). The importance of personal medicine: A qualitative study of resilience in people with psychiatric disabilities. *Scandinavian Journal of Public Health Supplements*, 66, 29–35. doi:10.1080/14034950510033345
- Doyle, R., Turner, N., Fanning, F., Brennan, D., Renwick, L., Lawlor, E., & Clarke, M. (2014). First-episode psychosis and disengagement from treatment: A systematic review. *Psychiatric Services*, 65(5), 603–611.
- Fenton, W. S., Blyler, C. R., & Heinssen, R. K. (1997). Determinants of medication compliance in schizophrenia: Empirical and clinical findings. *Schizophrenia Bulletin*, 23(4), 637–651.
- Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian and New Zealand Journal of Psychiatry*, *36*(6), 717–732.
- Gauthier, A., Corin, E., & Rousseau, C. (2008). Au-delà des modèles de pratique: explorer la rencontre clinique en début de psychose. *L'Evolution psychiatrique*, 73(4), 639–654.
- Gitlin, M., Nuechterlein, K., Subotnik, K. L., Ventura, J., Mintz, J., Fogelson, D. L., ... Aravagiri, M. (2001). Clinical outcome following neuroleptic discontinuation in patients with remitted recent-onset schizophrenia. *American Journal of Psychiatry*, 158(11), 1835–1842. doi:10.1176/appi.ajp.158.11.1835
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, *24*, 105–112.
- Gray, R., & Deane, K. (2016). What is it like to take antipsychotic medication? A qualitative study of patients with first-episode psychosis. *Journal of Psychiatric and Mental Health Nursing*, 23, 108–115 doi: 10.1111/jpm.12288
- Hansen, H., Hjelen, Stige, S., Davidson, L., Moltu, C., & Veseth, M. (2018). How do people experience early intervention services for psychosis? A meta-synthesis. *Qualitative Health Research*, 28(2) 259–272.
- Harris, K., Brooks, H., Lythgoe, G., Bee, P., Lovell, K., & Drakr, R. J. (2017). Exploring service users', carers' and professionals' perspectives and experiences of current antipsychotic prescribing: A qualitative study. *Chronic Illness*, 13(4), 275–287.
- Hon, A. (2012). Factors influencing the adherence of antipsychotic medication (Aripiprazole) in first-episode psychosis: Findings from a grounded theory study. *Journal of Psychiatric Mental Health Nursing*, 19(4), 354–361. doi:10.1111/j.1365-2850.2012.01898.x
- Hunt, L. M., Jordan, B., Irwin, S., & Browner, C. H. (1989). Compliance and the patient's perspective: Controlling symptoms in everyday life. *Culture, Medicine and Psychiatry, 13*(3), 315–334.
- Kampman, O., & Lehtinen, K. (1999). Compliance in psychoses. Acta Psychiatrica Scandinavica, 100(3), 167–175.
- Kikkert, M. J., Schene, A. H., Koeter, M. W., Robson, D., Born, A., Helm, H., ... Gray, R. J. (2006). Medication adherence in schizophrenia: Exploring patients', carers' and professionals' views. *Schizophria Bulletin*, 32(4), 786–794. doi:10.1093/schbul/sbl011
- Kilkku, N., Munnukka, T., & Lehtinen, K. (2003). From information to knowledge: The meaning of information-giving to patients who had experienced first-episode psychosis. *Journal of Psychiatric Mental Health Nursing*, 10(1), 57–64.
- Killackey, E. (2009). Psychosocial and psychological interventions in early psychosis: Essential elements for recovery. *Early Intervention in Psychiatry*, 3(S17-S21). doi:10.1111/j.1751-7893.2009.00126.x
- Leclerc, E., Noto, C., Bressan, R., & Brietzke, E. (2015). Determinants of adherence to treatment in first-episode psychosis: A comprehensive review. *Revista Brasileira de Psiquiatria*. doi: 10.1590/1516-4446-2014-1539
- Lieberman, J. A., Phillips, M., Gu, H., Stroup, S., Zhang, P., Kong, L., & Hamer, R. M. (2003). Atypical and conventional antipsychotic drugs in treatment-naive first-episode schizophrenia: A 52-week randomized trial of clozapine vs chlorpromazine. *Neuropsychopharmacology*, 28(5), 995–1003. doi:10.1038/sj.npp.1300157

- Malla, A. K., Norman, R. M., Manchanda, R., & Townsend, L. (2002). Symptoms, cognition, treatment adherence and functional outcome in first-episode psychosis. *Psychological Medicine*, *32*(6), 1109–1119.
- Marder, S. R. (2003). Overview of partial compliance. Journal of Clinical Psychiatry, 64 Suppl 16, 3-9.
- Marshall, M. N. (1996). Sampling for qualitative research. Family Practice, 13(6), 522–525.
- McGorry, P. D. (1992). The concept of recovery and secondary prevention in psychotic disorders. *Australian and New Zealand Journal of Psychiatry*, 26(1), 3–17.
- McGorry, P. D., & Killackey, E. J. (2002). Early intervention in psychosis: A new evidence based paradigm. *Epidemiologia e Psichiatria Sociale, 11*(4), 237–247.
- Mojtabai, R., Lavelle, J., Gibson, P. J., Sohler, N. L., Craig, T. J., Carlson, G. A., & Bromet, E. J. (2002). Gaps in use of antipsychotics after discharge by first-admission patients with schizophrenia, 1989 to 1996. *Psychiatric Services*, 53(3), 337–339. doi:10.1176/appi.ps.53.3.337
- Mutsatsa, S. H., Joyce, E. M., Hutton, S. B., Webb, E., Gibbins, H., Paul, S., & Barnes, T. R. (2003). Clinical correlates of early medication adherence: West London first episode schizophrenia study. *Acta Psychiatrica Scandinavica*, 108(6), 439–446.
- Nageotte, C., Sullivan, G., Duan, N., & Camp, P. L. (1997). Medication compliance among the seriously mentally ill in a public mental health system. *Social Psychiatry and Psychiatric Epidemiology*, 32(2), 49–56.
- Perkins, D. O., Johnson, J. L., Hamer, R. M., Zipursky, R. B., Keefe, R. S., Centorrhino, F., ... Lieberman, J. A. (2006). Predictors of antipsychotic medication adherence in patients recovering from a first psychotic episode. *Schizophria Research*, 83(1), 53–63. doi:10.1016/j.schres.2005.10.016
- Rabinovitch, M., Bechard-Evans, L., Schmitz, N., Joober, R., & Malla, A. (2009). Early predictors of nonadherence to antipsychotic therapy in first-episode psychosis. *Canadian Journal of Psychiatry*, *54*(1), 28–35.
- Rabinovitch, M., Cassidy, C., Schmitz, N., Joober, R., & Malla, A. (2013). The influence of perceived social support on medication adherence in first-episode psychosis. *Canadian Journal of Psychiatry*, 58(1), 59–65.
- Read, J., Mosher, L. R., & Bentall, R. P. (2004). *Models of madness: Psychological, social and biological approaches to schizophrenia*. Psychology Press.
- Rettenbacher, M. A., Hofer, A., Eder, U., Hummer, M., Kemmler, G., Weiss, E. M., & Fleischhacker, W. W. (2004). Compliance in schizophrenia: Psychopathology, side effects, and patients' attitudes toward the illness and medication. *Journal of Clinical Psychiatry*, 65(9), 1211–1218.
- Robinson, D., Woerner, M. G., Alvir, J. M., Bilder, R., Goldman, R., Geisler, S., ... Lieberman, J. A. (1999). Predictors of relapse following response from a first episode of schizophrenia or schizoaffective disorder. *Archives of General Psychiatry*, 56(3), 241–247.
- Roe, D., Goldblatt, H., Baloush-Klienman, V., Swarbrick, M., & Davidson, L. (2009). Why and how people decide to stop taking prescribed psychiatric medication: Exploring the subjective process of choice. *Psychiatric Rehabilitation Journal*, 33(1), 38–46. doi:10.2975/33.1.2009.38.46
- Rummel-Kluge, C., Schuster, T., Peters, S., & Kissling, W. (2008). Partial compliance with antipsychotic medication is common in patients with schizophrenia. *Australia and New Zealand Journal of Psychiatry*, 42(5), 382–388. doi:10.1080/00048670801961107
- Sackett, D. L., & Haynes, R. B. (1976). *Compliance with therapeutic regimens*. Baltimore and London: The John Hopkins University Press.
- Sandelowski, M. (1995). Sample size in qualitative research. Research in Nursing and Health, 18(2), 179–183.
- Sandelowski, M. (2000). Whatever happened to qualitative description? Research in Nursing and Health, 23(4), 334–340.
- Strauss, A., & Corbin, J. (1994). Grounded theory methodology. *Handbook of qualitative research*, 17, 273–285.
- Thorogood, N., & Green, J. (2009). *Qualitative methods for health research*. London, England: SAGE Publications Ltd. Thorne S., Reimer S., & O'Flynn-Magee K. (2004). The analytic challenge in interpretative description. *International Journal of Qualitative Methods*, 3(1), 1–11.
- Tranulis, C., Goff, D., Henderson, D. C., & Freudenreich, O. (2011). Becoming adherent to antipsychotics: A qualitative study of treatment-experienced schizophrenia patients. *Psychiatric Services*, 62(8), 888–892. doi:10.1176/appi.ps.62.8.88810.1176/ps.62.8.pss6208\_0888
- Usher, K. (2001). Taking neuroleptic medications as the treatment for schizophrenia: A phenomenological study. *Australia and New Zealand Journal of Menttal Health Nursing*, 10(3), 145–155.

- Valenstein, M., Blow, F. C., Copeland, L. A., McCarthy, J. F., Zeber, J. E., Gillon, L., ... Stavenger, T. (2004). Poor antipsychotic adherence among patients with schizophrenia: Medication and patient factors. *Schizophria Bulletin*, 30(2), 255–264.
- Velligan, D. I., Weiden, P. J., Sajatovic, M., Scott, J., Carpenter, D., Ross, R., & Docherty, J. P. (2009). The expert consensus guideline series: Adherence problems in patients with serious and persistent mental illness. *Journal* of Clinical Psychiatry, 70 Suppl 4, 1–46; quiz 47–48.
- Weiden, P. J., Buckley, P. F., & Grody, M. (2007). Understanding and treating "first-episode" schizophrenia. *Psychiatric Clinics of North America*, 30(3), 481–510. doi:10.1016/j.psc.2007.04.010
- Werbert, A., & Levander, S. (2005). Understanding the incomprehensible: Private theories of first-episode psychotic patients and their therapists. *Bulletin of the Menninger Clinic*, 69(2), 103–136. doi:10.1521/bumc.69.2.103.66507
- Yeisen, R., Joa, I., Bjornestad, J., Johannessen, J., & Opjordsmoen, S. (2016). Use of medication algorithms in first episode psychosis: A naturalistic observational study. *Early Intervention in Psychiatry*, 10, 503–510 doi: 10.1111/eip.12203