

# Becoming Adherent to Antipsychotics: A Qualitative Study of Treatment- Experienced Schizophrenia Patients

Constantin Tranulis, M.D.

Donald Goff, M.D.

David C. Henderson, M.D.

Oliver Freudenreich, M.D.

**Objective:** Discontinuation of antipsychotic medication is a pervasive clinical problem in the treatment of patients suffering from psychosis. The aim of this study was to complement a largely quantitative body of research by focusing on patients' perspectives on the topic. **Methods:** In-depth semistructured interviews were conducted with 20 persons who have schizophrenia spectrum disorders. Narratives were elicited on illness and medication use and emphasized key turning points, such as periods of nonadherence and illness relapses. **Results:** Respondents had extensive experience with antipsychotic treatment (15±12 years of treatment). Nineteen (95%) reported at least one extended period of nonadherence. A complex picture of medication use or refusal emerged from patients' descriptions. An array of external factors influenced initiation of medication and treatment maintenance: pressure from family or clinicians, secondary benefits from initiating and maintaining treatment, and a variety of coercive measures. Moreover, personal factors transcended rational models in deciding whether to take medication; patients' responses stressed the importance of trust, emotional reactions, and subjective experiences with medication and stigma. **Conclusions:** These findings call into question the validity of a purely voluntaristic model of the use of antipsychotic medication. Its use was part of a long and painful fight with a debilitating disorder, and off-medication periods were essential parts of a learning process. (*Psychiatric Services* 62:888–892, 2011)

Poor medication adherence is a vexing clinical problem for many chronic disorders in medicine, including schizophrenia (1). Rates of antipsychotic medication nonadherence are reported to average between 41.0% and 49.5%, depending on the definition of adherence (2). Long-term antipsychotic adherence

rates are low; for example, in one study, only 11.6% of 2,655 patients in an administrative sample treated with first-generation antipsychotics achieved one year of uninterrupted antipsychotic drug therapy (3).

A rich quantitative literature identified over 200 risk factors related to medication nonadherence, including

lack of insight, negative attitudes toward medication, perceived treatment efficacy and tolerability, and past nonadherence (2,4). In contrast to quantitative methods, qualitative research, with its focus on subjective experience, allows an in-depth study of the dynamic and subtle interplay of factors operating at the level of the individual (5). However, qualitative inquiries in the area of antipsychotic nonadherence are scarce. One qualitative exploration of patients', caregivers', and professionals' views on medication adherence highlighted a lack of shared understanding of what determines medication adherence, thus stressing the necessity of developing a mutual understanding and a strong therapeutic alliance (6). In another study, the exploration of the subjective meaning of antipsychotic medication exposed the tension between external social control and contemporary values of autonomy and self-control (7).

In this qualitative study, we explored the disparity between the recommendation of continuous-maintenance antipsychotic treatment for patients with schizophrenia and the clinical reality of frequent discontinuations. By focusing on experienced patients found to clinically benefit from antipsychotic medication and judged to need maintenance antipsychotic medication, we wanted to explore what is at stake for patients with regard to taking antipsychotic medication and learning about the need for adherence from their own perspective.

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*Dr. Tranulis is affiliated with the Department of Psychiatry, University of Montreal, Montreal, C.P. 6128 succursale Centre-ville, Montréal, Québec H3C 3J7, Canada (e-mail: constantin.tranulis@gmail.com). The other authors are with the Schizophrenia Program, Massachusetts General Hospital, Boston, and Harvard Medical School, Boston, with which Dr. Tranulis is also affiliated.*

## Methods

### *Patients and recruitment*

We conducted a qualitative study of use of antipsychotic medication among patients with schizophrenia spectrum disorders. Participants were referred from a community mental health center outpatient clinic affiliated with the Massachusetts General Hospital Schizophrenia Program. Patients had to be clinically stable and to have more than one year of exposure to antipsychotic medication. In the clinicians' judgment, all referred patients needed maintenance treatment with antipsychotics. Clinicians were asked to refer patients regardless of patients' attitudes toward medication, their insight into illness, or their eloquence or narrative skills. When patients expressed interest in the study, the treating clinician referred them to the interviewer, stressing the confidentiality of the research and the external position of the interviewer. The local ethics committee approved the study, and informed written consent was obtained from all participants, including an assessment of competency to give consent. No patient refused the study, nor was any patient considered unfit for it. Participants were recruited between December 2007 and May 2008.

### *Data collection and analysis*

Study participants were interviewed by the first author, who used a semi-structured interview that was audio-taped and then fully transcribed. The interview consisted of three parts. The first part used the Indiana Psychiatric Illness Interview to elicit a global illness narrative (8). This was intended to promote a trusting atmosphere, to position the study in a broader perspective than a clinical encounter, and to offer a personalized and deeper context for the later, more specific questions on medication. The second part used a medication-oriented modification of the Turning Point/Period Interview (medication-TPI) (9). The medication-TPI elicits narratives about medication use and focuses on the evolution of attitudes, meanings, and practices that concern antipsychotic medication. The medication-TPI was divided into five sec-

tions: a timeline of medication use, the first use of antipsychotic medication, stopping medication, resuming medication, what matters in using medication, and future plans regarding medication. With the use of the ten-item Drug Attitude Inventory (DAI), the third part collected structured data on attitudes toward medication (10), compliance over the past year (11), and present compliance (doses missed during the past week). Present symptom levels were assessed with the Brief Psychiatric Rating Scale (BPRS) (12).

Ethnographic notes taken by the interviewer and a chart review complemented the audiotaped interview. We also summarized the timeline and the illness and medication narratives for each participant. Data were analyzed with NVivo8.0, and when necessary, we went back to the audiotape data to verify the meaning and the verbal information related to specific statements.

Analyses were performed with the use of inductive principles based on narrative analysis and grounded theory (13). A tree-style coding structure was developed by using an iterative process to identify codes in a transcript, applying the codes to additional transcripts, and comparing the result to the global narrative extracted from each participant. The ethnographic notes and chart reviews were used to complement and verify the validity of the obtained coding scheme. The material was shared and discussed by two of the authors. Overarching themes were then extracted, compared again with the narrative data from the interviews, and enriched and developed further by qualitative details and descriptions of the respondents.

## Results

We recruited 20 participants. Seventeen (85%) were male. The mean±SD age of the participants was 39±14. Seventeen (85%) were single, one (5%) was married, one (5%) was divorced, and one (5%) was in a common-law relationship. Fourteen (70%) were impoverished, rating their household income in the lower fifth quintile. Seven participants lived in supported or supervised housing,

seven with family or roommates, and six lived independently. The mean education level was 12.2±2 years.

Fourteen (70%) participants had chart diagnoses of schizophrenia, and six (30%) had diagnosed schizoaffective disorder. The sample showed significant residual symptoms (BPRS of 40±9; possible scores range from 16 to 112, with higher scores indicating more severe symptoms). The duration of antipsychotic medication treatment was 15±12 years (range one to 34 years). Eighteen (90%) participants received antipsychotic monotherapy; eight (40%) were taking clozapine, and most received additional psychotropic medications. The relatively low antipsychotic polypharmacy might be explained by the use of clozapine for refractory symptoms and the academic teaching setting. Participants' attitude toward medication as measured by the DAI was positive (5.5±4.3, with possible scores ranging from -10 to 10 and higher scores indicating a more positive attitude toward medication). Thirteen (65%) participants reported good adherence over the past year (all concordant with the chart review), five stopped their medication for more than one week during past year, and two had stopped taking it for one to seven days at a time in the past year. Over the past week, one participant reported not taking any antipsychotics, and the 19 (95%) others reported not missing any pills over the past week.

All participants completed the interview in one session that lasted 33–123 minutes (average of about 45 minutes). Respondents produced rich and complex narratives about their illness and medication use, including acknowledged periods of nonadherence, disagreements with clinicians, and motivations to take medication that were at odds with the psychoeducative discourse to which they had been heavily exposed.

Each participant told multiple illness narratives, tapping several meta-narratives available in the local cultural environment and also in more idiosyncratic worldviews, the latter heavily influenced by psychotic experiences. Notably, only four of 20 (20%) participants indicated a com-

plete acceptance of the biomedical explanatory model for their mental illness. Echoing the illness narrative literature (14–16), narrative disruptions and cognitive dissonance were common (such as “I feel like I’m pretty normal, except that I take medication and sometimes I wonder why”). These illness narratives offered a perspective on the worldview and the relative place of psychiatric care and medication use in their life.

The medication-TPI revealed that nearly all participants (N=19, 95%) had stopped their antipsychotic medication for extensive periods in the past. The narratives regarding antipsychotics (and, notably, mood stabilizers) were strikingly different from those about other psychotropic medications, which were seen as less dangerous, more positive, more helpful, and more efficient in rapidly soothing anxiety or insomnia, giving energy, and brightening the mood (antidepressants). Three (15%) participants stressed the importance of having control over some of these medications: “I also have Ativan [lorazepam] PRN. I don’t take it very often, ‘cause that’s the way I assert my control. I choose when to take it. . . . And then I don’t have to fight about the Zyprexa [olanzapine].”

#### *First antipsychotics: passivity and pressures*

First contact with antipsychotic medication took place in a crisis, when individuals were experiencing significant confusion. When asked why they took medication the first time, 12 (60%) participants looked puzzled and explained that it was offered to them. This passivity ranged from a prevalent attitude of “trusting” doctors (“Because I was trusting that they knew what they were—I decided just to go along with it”) to trusting a family member’s advice (“At first I didn’t want to take it ‘cause I didn’t know what was going on. I didn’t even know where I was. But my mom was there and she was telling me, you know, you should take it. You’ll feel better—that kind of thing. So I trusted them through my mom.”). In fewer cases there was an implicit and subtle obligation to comply (“In the problem with mental health is, they tell you,

‘Here.’ And they put it [the medication] on the table in front of you, and it’s kind of like there.”) or even a direct, tremendous pressure: “[M]y mom really wanted me to take the—whatever they were going to give me—and I think the people there really wanted me to take it or something. So, I mean everybody was just really—I mean if it were up to me, I wouldn’t have even been there. I would have just been back at my house, but I was there, so I relented, I guess. . . . It did seem like a lot of pressure.”

Taking medication during hospital stays was related to the same perceived external pressure and to the pragmatic goals of getting out of the hospital: “So I was compliant with medication throughout my hospitalization. . . . Still skeptical, I think . . . when you’re in the hospital, it’s best to take your medication. You tend to get out faster [laughter] if you do that.”

#### *Continuation without perceived need: external pressures*

Twelve (60%) participants stopped taking antipsychotic medication because they didn’t perceive a need for continuing it. However, family and friends externally reinforced adherence to outpatient treatment, as one respondent described: “I was living with Mom, and she was fairly vigilant and insistent that I take the medication as a condition of living with her.” Another participant described it this way: “Basically [I am taking medication] so I can still live with my mom. . . . If I didn’t take my medication, I don’t think she’d want me living with her—not because of any particular reason, just because I’m not taking my medication and she just really wants me to.” This participant was the only one who claimed he had never stopped his medication in his 22 years of treatment.

The social network could also have opposite effects on compliance: “My boyfriend told him that he couldn’t work with me anymore, cuz I got sick from the medication, and he poured it all down the toilet, and he called the doctor and he said, ‘Dr. N., you’re fired.’ . . . I called Dr. N., and he said, ‘Well, come back when he’s more amiable.’”

#### *Subjective benefits: persevering in spite of side effects*

Although side effects were cited as reasons to stop medication by seven (35%) respondents, it is noteworthy that when they felt a clear benefit from the medication, they were able to bear the side effects for years: “I didn’t think there was any help for me or any hope for me. You know, I didn’t think there was anything out there that could cure my ‘goop,’ my strange feelings. . . . And it took three months—I stayed on the Thorazine, and after three months, the goop went away slowly, and it was finally gone within a matter of three months. And ever since then, I never went off of my medication again except for one night at a time a couple of times. And that’s the reason why, to this very day, I always take my medication.”

#### *Threats to self-esteem*

Seven (35%) participants linked antipsychotic medication to self-esteem and stigma. This ranged from simple links (stopping the medication “helps me think I am not crazy”) to longing for premorbid “normal” states (“I would stop medication, I would not [think I was] going to need it, and then I will be like I was before, when I was 14. . . . I don’t want to have that name of schizophrenia”) and subtler issues of agency and personal value (“They would think that just the pill itself is what’s helping me be a person. And I mean, that’s not the case. Whether I took it or not, I still have value”).

Periods of nonadherence were related to symptom relapse and aggressive or disruptive behaviors. Relapses exerted a direct toll on participants’ lives and self-esteem. Moreover, the painful process of mourning a drug-free, “normal” state compounded the effects of illness on self-esteem. This can be difficult to accept even for therapists, as eloquently explained by one participant, who had to abandon medical training because of her illness: “Nobody ever told me I’d be taking meds for the rest of my life. The one I saw [as an] outpatient, that’s a professor at Harvard, . . . I said to him after my fifth episode: ‘Will I be taking medication for the rest of my life?’ And he said, ‘No.’ I felt like nobody was being honest with me.”

### *Learning from nonadherence*

Eight (40%) participants reported awareness of direct benefit only after contrasting periods of treatment and nonadherence: "So I'd say to myself, 'I don't want to damage my body in any way, like my organs or anything, so I just won't take this.' . . . and then I'd find out that I needed it when the voices would come back."

Learning happened at a personal pace, sometimes fast: "I tried to go without it. They had me on a couple of Navane. . . . But I was feeling—you know how it's a chemical imbalance in you head? I could feel the chemicals in my head for some reason . . . for about a week, and I said, 'I've gotta start taking 'em.' And I started taking them the way I should have been. And in about a week and a half, I was okay. . . . So I said, 'Well, I've gotta take it for the rest of my life.' So I might as well take it, you know. That's the way I've got it figured."

And sometimes learning was not as fast as expected by others: "I have found stability, and I understand that I need to take my meds. But I wish people weren't so hard on me when I was off my meds. . . . I was talking [to my therapist] about how I was a slow learner. It took me a long time to figure out that I needed the meds."

### **Discussion**

In our sample, most participants initially did not choose to take antipsychotics freely but initiated treatment in a passive and oftentimes clearly imposed context, through pressure from either clinicians or family. This imposed compliance was also described in other qualitative studies of medication experiences in schizophrenia (17–19) and is related to more or less explicit social contracts linking social reintegration to adherence to medication (7). The collected narratives highlight the importance of trust in the early acceptance of treatment and reveal that a voluntaristic model was not how participants experienced those periods of crisis. These data do not fully support the self-medication hypothesis (20).

After regaining control over their lives, those who abandoned treatment expressed a desire to feel "normal again," suggesting that voluntary

nonadherence might be, from a subjective perspective, a tentative attempt to enhance self-esteem and to avoid internalizing the stigma of mental illness. This was echoed in a recent qualitative study of nonadherent patients with severe mental illnesses: "The decision to stop taking medication appeared to be an effort to regain what had been robbed from them by the medication—their perspective, preference, choice, right for self-determination and sense of self" (19).

Respondents stressed that treatment-free periods, including deleterious relapses of psychosis, are "a necessary part of the healing process." Once they learned the importance of antipsychotic medication through this "naive scientist" method (21), they often decided to stay in treatment despite severe adverse effects.

In an earlier theoretical paper, we proposed five descriptive prototypes of patients in regard to medication adherence; these prototypes were based on attitude toward drugs and a "medication worldview" (22). This study suggested that a prototype approach has face validity (that is, we were able to identify the prototypes) but needs to incorporate a dynamic aspect of learning (in other words, patients are not confined to one prototype over time but move from one to another according to their subjective experiences, phase of treatment, and interactions with clinicians and family or friends).

A potential limitation of this study concerns the risk of false self-reports of adherence. However, 19 (95%) participants reported extended periods of nonadherence, easily verbalized disagreements with clinicians, and motivations at odds with social desirability expectations. Hence, while this is a legitimate concern for present or future adherence evaluations, it is less of a concern for the main objective of this study, namely past adherence behaviors.

The qualitative design we used cannot refute or confirm a specific adherence model. However, it can complement quantitative studies and inform clinical practices. We have depicted here the lived experience of a sample of patients in clear need of maintenance therapy and with a

mostly severe and relapsing psychotic illness. This description might not apply to persons with single psychotic episodes, less impairing symptoms, or other diagnoses.

### **Conclusions**

The passivity and mostly informal coercion described here raise both ethical and clinical questions regarding the best practices for addressing adherence to antipsychotics. In particular, informed consent and collaborative decision making are still elusive targets, especially in the acute phases of treatment.

This study suggests that long-term adherence to antipsychotic medications must be learned through personal experience. The fact that periods of nonadherence seemed to be unavoidable in most cases and sometimes had positive effects on long-term adherence behaviors needs further study and consideration, particularly for the formulation of treatment guidelines and the development of clinical interventions.

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## First-Person Accounts Invited for Column

Patients, family members, and mental health professionals are invited to submit first-person accounts of experiences with mental illness and treatment for the Personal Accounts column in *Psychiatric Services*. Maximum length is 1,600 words.

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