Patients' perspectives. Subjective experiences and attitudes of patients with recent onset schizophrenia

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General Introduction
Background

The title “Patients’ Perspectives” refers to various successive facets in the treatment of patients with recent-onset schizophrenic disorders. Before a treatment is started, patients, who at that moment do not experience themselves as such, have ideas about the nature of their problems as well as an opinion about the need for treatment. These ideas often lead to a delay in the first treatment. An important question is whether this delay has consequences for the prognosis (the perspective) of patients. During treatment with antipsychotic medication the experiences of patients (subjective experiences and obsessive-compulsive symptoms) account partly for their well-being and therapy compliance.

The title “Patients’ Perspectives” therefore indicates: 1) the opinion of patients about the disorder and about the treatment; 2) the prospects of patients in connection with delay in treatment; 3) the experience of patients with the treatment (subjective experiences and obsessive-compulsive symptoms as possible side-effects of antipsychotic medication).

The perspective of patients has a prominent place in the influential movement of “Evidence-Based Health Care.” “The needs and preferences of patients and clients” in addition to “the best available evidence” are important factors in achieving Evidence-Based Health Care. This study will focus primarily on the needs and preferences of patients and clients and to a lesser extent on the best available evidence regarding the treatment of patients with recent-onset schizophrenic disorders. These two factors represent two different research perspectives: “The best available evidence” is a factor in which the question about effectiveness is important (the positivist perspective). A positivist researcher believes there is a world of “objective” reality, which can be observed and measured. “The needs and preferences of patients and clients” is a factor in which the subjective reality of the patients is important (the naturalistic perspective). A naturalistic researcher will argue that there is no single objective reality, and that we all construct our own, subjective reality. A naturalistic researcher will therefore focus on feelings, experiences, and thoughts (RCN Institute, 1999).
Experiences of a patient

November 1993
Something strange has been going on since last month. There are certain people, I'm not sure who they are or what they want, who are watching me. Sometimes I think they are following me in a car, but I've never seen clearly who it is. At first I doubted that I was really being watched, but since last week I know for sure. I hear them talking late at night. I went outside to see if there were lights on at the neighbors, but there weren't. That made me all the more worried – they're sitting in the dark and I can hear them clearly. Maybe they have ways to listen in on me. Maybe they want to confuse me with their talk. My mother says she hears no sounds coming from the neighbors. But she hardly listens either. She wants me to go to school again, but I'm not interested. Not in the subjects and not in my classmates. I can't concentrate well anyway. I first want to know for sure what is going on.

January 1994
Every time I go outside I hear voices clearly; they threaten me, call me names. It's a terrible feeling. In my room it's better. I've started smoking more pot; that calms me down. But I do have constant hassles with my father and mother. I really want to move out but the way things are going that won't be possible. My mother wants to take me to the family doctor, but I don't want to go. Stop smoking pot, he'll say. They won't believe me when I tell them about the voices. Sometimes I think, could there be something wrong with my head - it's as if I can't think well anymore. I lose my train of thought.

February 1994
My father makes me sick. Always making a fuss – about smoking pot, that I should look for a job. Sometimes I hear my father's voice when he isn't at home.

March 1994
I'm locked up in an isolation ward. Yesterday I had a fight with my father. I had enough of his watching me and sending me messages. He was also looking at me in a strange way. It was self-defense. My mother called the police, they took me to the police station and then a doctor came. I got an injection and they locked me up. I feel strangely groggy and there's a vague feeling of panic inside me. If I walk around I feel a little better. I want to get out of this hospital as soon as possible. They say I'm confused; maybe they're right, but I want to work it out myself.
April 1994
I’m not taking those pills anymore. I feel dull, thinking is hard, as if everything is less clear than it used to be. The doctor said I would have less trouble with voices. Maybe I don’t hear them quite as much, but they are still there every day. They say I have a psychosis. If they leave me in peace I’ll do better.

July 1994
I have a room in the house of a distant relative. But things aren’t going well. I’m less upset by the voices I hear, but I still can’t concentrate. A nurse at the RIAGG (Regional Institute for Psychiatric Outpatient Care) says things will improve if I take antipsychotic medicine. Maybe I do have to give those pills another try. But if I feel so miserable again I’ll stop.

October 1994
Although the nurse at the RIAGG is a really nice guy, I’ll never go back to him. I took pills for a while but I didn’t feel well. I still can’t concentrate and nothing matters to me anymore; my energy is gone. I continually hear the voices. The psychiatrist says I have schizophrenia. So they can pigeonhole me and write me off. If I sleep during the day, I’m less bothered by other people. I don’t like it if others decide what’s going to happen.

July 1997
A lot has happened. I was hospitalized involuntarily one more time. Things weren’t going well with me. Now I have different pills. I have less trouble with voices and I feel less agitated. It’s hard getting up in the morning.
Structure of the thesis and questions

This thesis consists of four parts. The topics of research are briefly described below.

Part I. Attitudes of patients concerning psychosis and treatment

The first part focuses on the conceptions of patients who become psychotic for the first time – their ideas about psychotic symptoms as well as about the psychiatric treatment and the need for help. A difference in views between patients and caregivers can lead to a delay in treatment of a first psychosis. The opinions and needs of patients play an important role, both in the delay in treatment and in bringing about cooperation in the treatment. Part I consists of two chapters, which address the questions printed in italics.

1.1. Attitudes of patients concerning the first psychotic episode and the start of treatment

*What opinions do patients have about the first psychotic episode and about the initiation of treatment, and how do these opinions relate to delay in treatment?*

1.2. Preferences for treatment during a first psychotic episode

*What kind of help do patients consider important when they first become psychotic, and are there differences in the priorities of patients, family members and professional caregivers?*

Part II. Duration of untreated psychosis and outcome

The second part investigates whether the delay in treatment of a psychosis affects the short-term and long-term prospects. Early treatment of a first psychotic episode might improve the prognosis of schizophrenia in the long term. It is of clinical importance to study this hypothesis because the duration of the untreated psychosis can in principle be shortened. Part II consists of four chapters, which address the questions printed in italics.

2.1. Introduction

*What is known about the clinical course of schizophrenia during the five years following a first hospitalization? Is there a pathogenetic hypothesis that would explain a relation between treatment delay and course? What is known in the
literature about the relation between the duration of untreated psychosis and the course of schizophrenia?

2.2. Early intervention, social functioning and psychotic relapse of patients with recent-onset schizophrenic disorders
Are there indications that early intensive intervention is associated with improvement in psychopathology and social functioning in the short term?

2.3. Duration of untreated psychosis and the long-term course of schizophrenia
Is the duration of untreated psychosis related to the prognosis in the long term?

2.4. Duration of untreated psychosis and outcome of schizophrenia: delay in intensive psychosocial treatment versus delay in treatment with antipsychotic medication
Is delay in intensive psychosocial intervention a better predictor of the course than delay in treatment with antipsychotic medication?

Part III. Subjective experiences of patients with schizophrenia related to antipsychotic medication

The third part deals with the subjective experiences of patients with antipsychotic medication. These experiences probably have an effect on therapy compliance. Psychometric properties of two instruments for measuring subjective experiences are examined. Attention is then given to the relation between subjective experiences and biological aspects of the treatment.

Part III consists of three chapters, which address the questions printed in italics.

3.1. Introduction
What is known about subjective experiences of patients with schizophrenia during treatment with antipsychotic medication? Is therapy compliance related to subjective experiences during the use of antipsychotic medication?

3.2. Psychometric properties of the Subjective Well-being under Neuroleptics Scale (SWN) and the Subjective Deficit Syndrome Scale (SDSS)
What is the psychometric quality of two instruments (SWN and SDSS) used to measure subjective experiences during use of antipsychotic medication?
3.3. Subjective experience and striatal dopamine D₂ receptor occupancy in patients with schizophrenia stabilized on olanzapine or risperidone

Are subjective experiences related to dopamine D₂ receptor occupancy by antipsychotic medication?

3.4. Subjective experience and D₂ receptor occupancy in patients with schizophrenia, treated with low dose Olanzapine or Haloperidol; a randomized double-blind study

Is there evidence for the hypothesis that D₂ receptor occupancy between 60% and 70% in patients with recent onset schizophrenia results in optimal subjective experience?

Are there differences in subjective experience during treatment with low-dose olanzapine or haloperidol?

Part IV. Obsessive-compulsive symptoms associated with antipsychotic medication in patients with schizophrenia

Obsessive-compulsive symptoms occur in patients with schizophrenia and are often experienced as troublesome. It is possible that obsessive-compulsive symptoms develop or are exacerbated during the use of certain antipsychotic medications. This part describes two studies concerning the relation between the use of certain antipsychotic medications and obsessive-compulsive symptoms. Part IV consists of three chapters, which address the questions printed in italics.

4.1. Introduction

How frequently do obsessive-compulsive symptoms occur in patients with schizophrenia, and what is known about the relation between the use of antipsychotic medication and obsessive-compulsive symptoms?

4.2. Clozapine and obsessions in patients with recent-onset schizophrenia and other psychotic disorders

Do obsessive-compulsive symptoms occur more frequently during the use of clozapine than during the use of other antipsychotic medications?

4.3. Obsessive-compulsive symptoms during treatment with olanzapine and risperidone, a prospective longitudinal study of 113 patients with recent-onset schizophrenia or related disorders

Is there a difference in the severity of obsessive-compulsive symptoms in patients who are treated with olanzapine and patients who are treated with risperidone?
References

RCN Institute (1999), Evidence-based Health Care, unit 2; Chiltern Press, Luton