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

de Haan, L.

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Chapter 3.1.

Introduction

Based on:

*Subjectieve ervaringen van patiënten met schizofrenie gerelateerd aan behandeling met antipsychotica*

*Ten Brink C, De Haan L, Knegtering H*

*Tijdschrift voor Psychiatrie, 1998, 40: 238-245*
Summary

Objective and Method: Review of literature concerning subjective experiences of patients related to treatment with antipsychotic medication.

Results: Since there is no generally accepted definition, I propose to operationalize subjective experiences of patients in response to treatment with antipsychotic medication as: all experiences patients report, whether positive or negative, at the physical, emotional and cognitive levels, related to treatment with antipsychotic medication.

Based on psychometric properties the Subjective Wellbeing on Neuroleptics and the Subjective Deficit Syndrome Scale are good candidates to assess subjective experiences of patients in response to treatment with antipsychotic medication.

Repeatedly a relationship has been found between subjective experiences of patients in response to treatment with antipsychotic medication and compliance with antipsychotic medication.

The relationship between subjective experiences of patients in response to treatment with antipsychotic medication and therapeutic effect is not clear. Not all studies revealed a correlation and moreover, the influence of subjective experience on therapeutic effect can also be explained by variations in compliance.

Conclusion: Subjective experiences of patients in response to treatment with antipsychotic medication is clinically relevant and deserves further research.
3.1.1. Definition of subjective experiences of patients related to treatment with antipsychotic medication

An Anglo-Saxon and a German school can be distinguished in the literature about subjective experiences of patients with schizophrenia (van den Bosch, 1993). In the Anglo-Saxon literature the focus is mainly on the subjective experience of patients during the acute psychotic phase. In the German tradition attention is given to subjective experiences that relate to – and form the operationalization of – the so-called basic disorders. These basic disorders affect subjective experiences of cognitive function, emotional reactions, energy, motor activities, physical sensations, perception, autonomic reactions and tolerance for stress. Delusions and hallucinations are viewed as secondary symptoms stemming from the basic disorders. Van den Bosch suggests that subjective experiences might be of greater importance for the validity of the diagnosis of schizophrenia than objectively perceivable symptoms (van den Bosch et al. 1988). Selten (1995) investigated the subjective experience of negative symptoms in schizophrenia. Subjective experiences accompanying schizophrenia is not the topic of this part of the thesis. The focus here is on subjective experiences which relate to the use of antipsychotic medication by patients with schizophrenic disorders.

There is no generally accepted definition of subjective experiences of patients in response to treatment with antipsychotic medication. Examples of definitions include: “subjective, non-observable symptoms, reported by patients who use neuroleptics” (Noll et al., 1991); “a changed subjective state after just a few doses of a neuroleptic” (Awad, 1993); “side effects concerning the motor-system, thinking and emotions that are difficult to objectify” (Naber, 1995).

Most authors describe negative experiences such as anxiety, gloominess, agitation, akinesia, cognitive disturbances, blurred vision, muscle contraction and "a zombie-like feeling.” Concepts used include "dysphoria" (van Putten 1974, van Putten and May 1978a, Singh and Kay 1979, van Putten and Marder 1987, Weiden et al. 1989, Emerich and Sanberg 1991), "subjective side-effects" (Noll et al., 1991) or "deficit syndrome" (Lewander, 1994). Some of these terms exhibit overlap with negative symptomatology in the context of schizophrenia ("deficit syndrome": Lewander, 1994), extrapyramidal side-effects ("akathisia": van Putten, 1975) or depression ("akinetic depression": van Putten and May, 1978b). Some authors use concepts that also provide scope for positive experiences such as a decrease in lability, being able to think clearly and being energetic. Examples include "subjective response to neuroleptics" (Awad, 1993), "subjective well-being under neuroleptics" (Naber, 1994) and "effects ascribed subjectively to neuroleptic medication" (Windgassen, 1992). The study by Windgassen (1992) into subjective experiences during treatment with clozapine reveals the importance of also recognizing positive experience aspects. He observed that patients who report
a predominantly negative subjective reaction have just as many negative, but fewer positive subjective experiences than patients who have a predominantly positive subjective reaction.

I will use a broad definition of the concept of subjective experiences in response to treatment with antipsychotic medication: all experiences patients report, whether positive or negative, at the physical, emotional and cognitive levels, related to treatment with antipsychotic medication. At the moment, there are insufficient research results to allow a narrower definition.

3.1.2. Assessment of subjective experiences of patients in response to treatment with antipsychotic medication

There are four scales available for measuring subjective experiences in response to treatment with antipsychotic medication: the "Van Putten and May" scale (Van Putten et al., 1978a, 1981), the Drug Attitude Inventory (DAI; Hogan and Awad, 1992) and the Subjective Well-being under Neuroleptics scale (SWN; Naber et al., 1994 and 1995; Dutch translation: de Haan and Dingemans, 1995), and the Subjective Deficit Syndrome Scale (SDSS; Jaeger et al. 1990, dutch translation de Haan, 1995).

The "van Putten and May" scale is the simplest. Not examined in terms of reliability, it is semi-structured, based on 4 items and can be used for acutely psychotic patients. The DAI-10 is not examined in terms of reliability and is a 10-item 2-point self-assessment scale. This scale also measures attitude toward medication and knowledge about relapse prevention, for that reason it is the least appropriate to measure subjective experiences of patients in response to treatment. In 1992, Hogan and Awad compared the DAI-10 and the "Van Putten and May scale" in order to test the validity of the concept of "subjective response to neuroleptics." The degree of similarities in identifying a "dysphoric" or "non-dysphoric" reaction is great, and the hasty conclusion is drawn that this is evidence of a valid concept. The SDSS is designed to assess a subjective syndrome dimension, not accounted for in traditional assessment of psychopathological states. The SDSS is not designed to be sensitive to influence of medication. The SWN (38 items), with good test-retest reliability and appropriate sensitivity to medication changes, is the most differentiated 6-point self-assessment scale, which measures both positive and negative experiences. The SWN has been used in several studies, including one randomised double-blind trial (Naber et al, 1994b 2001a, 2001b).

Recently a new instrument has been developed on the basis of statements made by patients about their experiences with antipsychotic medication (Wolters et al. 2001). The advantage of this instrument is that it is based on the articulation of the subjective experiences that patients associate with their
treatment with antipsychotic medication. Never before have the experiences of patients been so extensively inventorized in an instrument. There are also disadvantages connected with this instrument. The construction of the items was probably influenced by conceptions patients have about medication. In view of the explicit link posited between experience and the use of antipsychotic medication, this instrument is only applicable in double-blind comparative studies of antipsychotic medication. In open studies the ascertainment of subjective experiences will be influenced by specific conceptions of patients about a certain medication. Finally, the psychometric characteristics of this instrument are still unknown. If the instrument had been available at the moment when intake for our study began, we would certainly have made use of it.

A priority for research is assessment of the psychometric properties of instruments designed to measure subjective experiences of patients with schizophrenia (See chapter 3.2.).

3.1.3. **Relationship between subjective experiences of patients in response to treatment with antipsychotic medication and compliance**

Repeatedly associations have been found between a dysphoric reaction to medication, negative subjective experiences with medication and antipsychotics (AP) non-compliance (van Putten 1974, Van Putten et al. 1981, Hogan et al. 1983, Weiden et al. 1989, Naber et al. 1994). Because (subjective) side effects predicts AP non-compliance, compliance could be improved by selecting medication and dosage to avoid (subjective) side effects. However, randomised controlled trials comparing therapy compliance for different AP and dosages do not exist.

3.1.4. **Relationship between subjective experiences of patients in response to treatment with antipsychotic medication and therapeutic effect**

There are nine studies, differing strongly in terms of methodological approach, into the relationship between subjective experiences of patients in response to treatment with antipsychotic medication and therapeutic effect. In seven of these studies a favourable therapeutic effect is correlated with fewer negative subjective experiences (May e.a. 1976, van Putten and May 1978a, Singh and Kay 1979, van Putten e.a. 1981, Vinar e.a. 1984, Hogan e.a. 1985, Hogan and Awad 1992). In two of the studies, no correlation was found between subjective experiences of patients in response to treatment with antipsychotic medication and therapeutic effect (Ayers e.a. 1984,
Weiden e.a., 1989). Not all studies revealed a correlation and moreover, the influence of subjective experience on therapeutic effect can also be explained by variations in compliance. So the relationship between subjective experiences of patients in response to treatment with antipsychotic medication and therapeutic effect is not clear.
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