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

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Citation for published version (APA):
de Haan, L. (2002). Patients' perspectives. Subjective experiences and attitudes of patients with recent onset schizophrenia

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Chapter 3.2.

Psychometric properties of the Subjective Well-being under Neuroleptics scale (SWN) and the Subjective Deficit Syndrome Scale (SDSS)

_In press Psychopharmacology_

Lieuwe de Haan, Martijn Weisfelt, Peter Dingemans, Don Linszen, Luuk Wouters
Summary

Objective: To examine the internal consistency, test-retest reliability, sensitivity to medication change and concurrent validity of two instruments: the Subjective Well-being under Neuroleptics (SWN) and the Subjective Deficit Syndrome Scale (SDSS).

Methods: Both instruments were administered at admission and after six weeks of medication stabilization in 105 consecutively admitted patients diagnosed with DSM-IV diagnoses of recent-onset schizophrenia, schizophreniform disorder or schizoaffective disorder.

Results: Almost all patients are capable of reproducing their subjective experience in a consistent way before as well as after medication stabilization. The internal consistency of both instruments is high. The test-retest reliability is high if medication is not changed, especially for the SWN. The SWN is sensitive for changes in medication or dosage. The short form of the SWN (SWN-20 items) has comparable psychometric qualities as the original instrument (SWN-38 items). The concurrent validity of the SWN and the SDSS is good, indicating that both tests measure the same concept.

Conclusions: The assessment of subjective experience with the SWN (both versions) may be used in evaluating differential effects of anti-psychotics and dose on subjective well-being.
3.2.1. Introduction

Antipsychotic medication is effective in treating positive symptoms of schizophrenia and in preventing psychotic relapse. Research of subjective experiences of patients during treatment with antipsychotic medication is limited: only 13% of the studies on the effectiveness of antipsychotic medication pay attention to subjective experiences of patients (Collins et al. 1991). The limited research may be attributed to the lack of consensus about the concept of subjective experience. There is also the rigid idea that patients with schizophrenia are unable to explore subjective experience in a valid or reliable way.

There are indications that subjective experience of antipsychotics is relevant for compliance (Van Putten 1974; Van Putten et al. 1981; Weiden et al. 1989; Naber et al. 1994). Differences in subjective experience during use of typical and atypical antipsychotic drugs are found (Naber et al. 1995, 2001). Subjective well-being cannot reliably be predicted by means of psychopathology and the low correlations between improvement in psychopathology and subjective well-being underline how much psychiatrists and patients differ in their evaluation of treatment with antipsychotic medication (Naber et al. 2001). A relationship between subjective experience and D₂ receptor occupancy by antipsychotic drugs as measured with SPECT was recently demonstrated (De Haan et al. 2000).

Instruments designed to measure subjective experience during use of antipsychotic drugs usually are explicit in assuming a relationship with antipsychotics. This may confound the assessment of subjective experience by attitudes of patients towards medication. It may even be assumed that neither patients nor clinicians are capable in differentiating subjective experience of the disorder proper and other aspects of the treatment, such as medication. We therefore propose to operationalize ‘subjective experience’ as constituting aspects of mental or physical state which patients report regardless of etiological attributions: the latter should be assessed independently.

We selected two instruments designed to measure the subjective experience of patients: the Subjective Well-being under Neuroleptics (SWN, Naber et al. 1995, 2001) and the Subjective Deficit Syndrome Scale (SDSS, Jaeger et al. 1990) because of their reported psychometric qualities. We report on: the internal consistency (the property of the different items of an instrument to be positively correlated) test-retest reliability (the property of producing equivalent results when used for the same subject on different occasions), sensitivity to medication-change (the property of producing different results when medication is different on different occasions) and concurrent validity (the property of both instruments of producing equivalent results). We will
also investigate the psychometric properties of the recently developed 20-item version of the SWN. Our study aims to replicate abovementioned research on psychometric properties of the SWN (both versions) in a group of young patients with recent onset schizophrenia (mostly first-episode).

3.2.2. Materials and methods

Subjects
Inclusion criteria for this study were: written informed consent, diagnosis of recent onset schizophrenia or a related disorder according to DSM-IV criteria, age between 16 and 28, and being able to understand and speak Dutch. Exclusion criteria were: diagnosis of a primary alcohol- or drug-related psychosis, a known neurological or endocrine disease or mental retardation. Included were 105 consecutively admitted patients to the Adolescent Clinic for Schizophrenia (Academic Medical Center, Amsterdam, The Netherlands). The diagnosis at admission according to DSM-IV was made by three psychiatrists and a research psychologist with the use of all possible information (medical records, interviews with patients and with parents) based on longitudinal, clinical, hetero-anamnestic assessment (Longitudinal Expert Assessment of Diagnosis procedure; Spitzer and Williams 1985): 92 patients were diagnosed as having schizophrenia, 8 had schizoaffective disorder and 5 had schizophreniform disorder. The demographic characteristics of the study sample are as follows: mean age at admission: 21.09 years (SD=2.88), 21 females, 84 males.

Instruments

Subjective Well-being under Neuroleptics scale
The SWN is a 38 items and 6 point Likert type self rating scale referring to the subjective experience in the past 7 days. Sample questions: "I am full of energy and life", "I feel very comfortable in my body". Naber et al. (1994) found a 5 factor solution of the scale, which was interpreted as: emotional regulation, self-control, mental functioning, social integration, and physical functioning. Analyses of the SWN (patients with schizophrenia, n=216) showed good practicability, reliability and sensitivity. In addition it was found that only 4% of the patients were inconsistent in their ratings, that all 37 patients on stable medication were consistent in rating their subjective experience and that the 16 patients whose medication was changed in the study period also significantly changed on their SWN factor scores (Naber et al. 1994,1995). Recently a 20-item version of the SWN was developed, based on reliability analyses. Items with a low item-test correlation were dropped. The internal consistency of both the short and long version is comparable and the versions were found to be highly correlated. (Naber et al. 2001).
We translated the "Selbstbeurteilung der befindlichkeit unter neuroleptischer therapie" (SWN-38) into Dutch. This version was retranslated in German by a Dutch speaking psychiatrist who's native language is German. This retranslation was reviewed by the principal author of the original scale and with use of his comments the final Dutch translation was made. We want to stress that in the Dutch translation of this instrument the possible relationship of subjective experience with medication is not mentioned.

Subjective Deficit Syndrome Scale
The SDSS consists of 19 (patient's) complaint items which are rated on basis of a semi structured interview covering the past 7 days. The scale is intended to measure the patient's self-reported complaints only, and not the interviewer's judgement of the patient's distress. Patients are asked "Do you have trouble concentrating?", "Do you get tired easily?" or "Have you lost the ability to enjoy things?". If a complaint is endorsed, its severity is elicited by asking the patient how disturbing the complaint is, and it is then rated on a 4 point scale. Jaeger et al. (1990) found (patients with schizophrenia, n=166) that subjective experience was reliable assessed with the SDSS: interrater reliability ranged from .97 to .99 (ICC).

Since the SDSS is less complicated at face value than the SWN, we expected that this instrument would be better applicable in patients in a florid psychotic state.

The SDSS was translated into Dutch, retranslated independently into an English version and checked with the original version. This retranslation was found to be identical to the original instrument.

During a pilot study of 20 acutely psychotic patients it was found that two items could not be assessed without serious interference from the interviewer". When presented with these items most patients indicated that they did not understand the question or were reluctant to answer. The concerned items were: "Tolerance for conflicts/external events" and "Sensitivity to weather". These two items were left out during this study.

PANSS and MADRS
Psychopathology was assessed with the positive and negative syndrome scale (PANSS) (Kay et al. 1989) based on information collected in a semi-structured interview (SCI-PANSS) and with the Montgommy Asberg Depression Rating Scale (MADRS) (Montgommy Asberg 1979). Psychopathology rating were performed by trained and experienced raters, independently from the SWN and SDSS assessment.

Procedure
In the first week (T1) of the admission each participant was administered the SWN and the SDSS. At stabilization (medication type and dosage stable for a period of 6 weeks) the SWN and the SDSS were readministered (T2). Psychopathology was rated at T1 and T2. Patients using co-medication in
addition to antipsychotic medication (T1 and/or T2) or patients for whom T2 assessment was missing were not included in analyses (n=14).

Statistical analysis

Internal consistency
Internal consistency was tested using Cronbach's coefficient alpha.

Test-retest reliability and sensitivity to medication change
The test-retest reliability of both instruments was tested in the group without change in medication.
In order to determine the reliability of patient's assessment with the SWN the difference between the item scores on the positively and the negatively formulated items was computed. (The SWN consists of 38 items, divided in 12 singular items and 26 dual items. The dual items consist of 13 positive and 13 negative formulated items, describing each complaint in a positive and a negative manner.)
The sensitivity to medication change for the SWN (38 item and 20 item versions) and the SDSS were examined by comparing differences in mean scores: at T1 and T2 between subgroups (patients with versus without changes in medication or dosage and between T1 and T2 within groups (paired samples test).

Concurrent validity
Concurrent validity was examined by comparing the Pearson correlation coefficients between the test outcomes of the SWN and SDSS before and after medication stabilization.

Indication of predictive validity
We assume that lower scores on the SWN (implying worse subjective well-being) and a higher score on SDSS (also implying worse subjective well-being) are associated with the independent decision of the treating clinician to change medication. Significant differences in the SWN and SDSS scores at baseline between patients with no change in medication and those with later change of medication is of interest. We suggest that if the self-rating of subjective experience of those patients whose medication is changed, indicate a reduced well-being, the change of medication is an adequate clinical decision. This implicates that self-assessment of subjective experience of patients has clinical validity. We want to stress that treating clinicians were not aware of the rating of subjective experience of their patients.

Relationship with psychopathology
The Pearson correlation coefficients between SWN, SDSS scores and PANSS-sub scales' rating and MADRS were computed to check the relationship between subjective experience and psychopathology.
3.2.3. Results

Eight Patients used co-medication in addition to antipsychotic medication (T1 and/or T2) and of six patients a T2 assessment was missing (three patients refused, two patients were lost to follow-up and assessment of one patient was missing due to administrative failure) These fourteen patients were not included in analyses. We found neither significant differences in demographic and psychopathological characteristics of excluded (n=14) and included (n=91) patients, nor differences for these groups on total score or subscale scores of the SWN and total score of SDSS.

Internal consistency
The results of the internal consistency analysis using Cronbach's alpha of the SWN (both versions) and SDSS is shown in table 1.

Table 1. Cronbach α’s for the SWN and subscales and for the SDSS at both assessments (n=91) [number of items of SWN-38 / number of items of SWN-20]

<table>
<thead>
<tr>
<th></th>
<th>T1 Cronbach α</th>
<th></th>
<th>T2 Cronbach α</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SWN-38</td>
<td>SWN-20</td>
<td>SWN-38</td>
<td>SWN-20</td>
</tr>
<tr>
<td>SWN total score [38/20]</td>
<td>.95</td>
<td>.93</td>
<td>.95</td>
<td>.93</td>
</tr>
<tr>
<td>Physical functioning [7/4]</td>
<td>.88</td>
<td>.84</td>
<td>.86</td>
<td>.80</td>
</tr>
<tr>
<td>Social integration [8/4]</td>
<td>.85</td>
<td>.82</td>
<td>.85</td>
<td>.84</td>
</tr>
<tr>
<td>Mental functioning [8/4]</td>
<td>.84</td>
<td>.68</td>
<td>.82</td>
<td>.63</td>
</tr>
<tr>
<td>Self-control [6/4]</td>
<td>.68</td>
<td>.56</td>
<td>.76</td>
<td>.64</td>
</tr>
<tr>
<td>Emotional regulation [8/4]</td>
<td>.78</td>
<td>.68</td>
<td>.77</td>
<td>.59</td>
</tr>
<tr>
<td>SDSS total score [17]</td>
<td>.87</td>
<td></td>
<td>.88</td>
<td></td>
</tr>
</tbody>
</table>

T1: in the first week of admission
T2: at stabilization (medication type and dosage stable for a period of 6 weeks)

Test-retest reliability and sensitivity to medication change
Total score and correlation at T1 and T2 (SWN, both versions, SDSS) in the group with stable medication and in the group with change of medication are shown in table 2 (page 122).
Table 2. Mean total score at T1, T2 and correlation between mean total score at T1 and T2 for the SWN and SDSS in the group with stable medication and in the group with a change of medication between T1 and T2

<table>
<thead>
<tr>
<th></th>
<th>Stable medication and dosage</th>
<th>Change medication or dosage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
<td>30</td>
<td>61</td>
</tr>
<tr>
<td><strong>SWN-38</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean SWN score T1 (SD)</td>
<td>162.1 (32.4)</td>
<td>139.9 (29.6)</td>
</tr>
<tr>
<td>Mean SWN score T2 (SD)</td>
<td>163.4 (32.2)</td>
<td>154.4 (27.5)</td>
</tr>
<tr>
<td>Correlation T1 and T2</td>
<td>0.84</td>
<td>0.67</td>
</tr>
<tr>
<td><strong>SWN-20:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean SWN score T1 (SD)</td>
<td>86.0 (18.5)</td>
<td>75.0 (16.8)</td>
</tr>
<tr>
<td>Mean SWN score T2 (SD)</td>
<td>86.4 (18.1)</td>
<td>82.7 (15.2)</td>
</tr>
<tr>
<td>Correlation T1 and T2</td>
<td>0.86</td>
<td>0.62</td>
</tr>
<tr>
<td><strong>SDSS:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean SDSS score T1 (SD)</td>
<td>19.8 (13.1)</td>
<td>27.4 (12.4)</td>
</tr>
<tr>
<td>Mean SDSS score T2 (SD)</td>
<td>17.2 (11.7)</td>
<td>20.6 (11.8)</td>
</tr>
<tr>
<td>Correlation T1 and T2</td>
<td>0.70</td>
<td>0.52</td>
</tr>
</tbody>
</table>

The mean absolute difference between the positively and the negatively formulated items of the SWN-38 at T1 and T2 were respectively 0.69 (SD 0.49) and 0.66 (SD 0.50). Only 1 patient at T1 and 3 patients at T2 had a mean difference of 2 or more. This means that patients produce mean different scores of about a half between the 6 possible responses when they assess their subjective experience on items describing each complaint in a positive and a negative manner. (For example when a patient marks "much" (score 5) in response to the statement "My body is a burden to me" and marks "much" to the statement "My thinking is difficult and slow" then their responses on the positively formulated statements: "I feel very comfortable with my body" and "I find it easy to think" are "a little" (score 2) and "not at all" (score 1). Their responses "should have been" two times "a little" to ensure complete consistency.)

Correlations between T1 and T2 assessments were higher in the group with stable medication than in the group in which medication was changed.

We found no significant differences between mean scores on subscales, total score of SWN, (both versions) or total score of SDSS at T1 and T2 in the group with no change in medication (n=30). Differences between mean scores on SWN (scale and subscales of both versions) at T1 and T2 in the group with change in medication (n=61) are shown in table 3 (page 123). Difference between mean total score on SDSS
at T1 and T2 in the group with change in medication (n=61) is −6.8 (SD=11.9, p<0.000).

Table 3. Differences between mean scores of scale and subscales of the SWN (both versions) at T1 and T2 in the group with a change in medication or dosage (n=61)

<table>
<thead>
<tr>
<th></th>
<th>Difference T2-T1, SWN-38</th>
<th></th>
<th>Difference T2-T1, SWN-20</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>p</td>
</tr>
<tr>
<td>Total score</td>
<td>14.5</td>
<td>23.3</td>
<td>0.000</td>
</tr>
<tr>
<td>Physical functioning</td>
<td>2.7</td>
<td>5.5</td>
<td>0.000</td>
</tr>
<tr>
<td>Social integration</td>
<td>3.5</td>
<td>5.5</td>
<td>0.000</td>
</tr>
<tr>
<td>Mental functioning</td>
<td>3.2</td>
<td>7.2</td>
<td>0.001</td>
</tr>
<tr>
<td>Self-control</td>
<td>2.4</td>
<td>4.5</td>
<td>0.000</td>
</tr>
<tr>
<td>Emotional regulation</td>
<td>2.4</td>
<td>5.8</td>
<td>0.002</td>
</tr>
</tbody>
</table>

Concurrent validity
The correlation between the total score on the SWN-38 item version and the total score on the SDS at T1 is −0.83 (n = 91, p<0.01) and at T2 −0.80 (n=91, p<0.01). The correlation between the total score on the SWN-20 item version and the total score on the SDS at T1 is −0.81 (n = 91, p<0.01) and at T2 −0.78 (n=91, p<0.01). (Correlations between the 38 item version of the SWN and the 20 item version was .98 for the total score and varied from .93 to .97 for the subscale scores.)

Indication of predictive validity
Differences in mean total score of SWN-38 item version at T1 between patients with no change in medication (n=30) and patients with change in medication (n=61) was: 22.2 (SD=6.8, p=0.002, independent samples test, two tailed). Differences in mean total score of SWN-20 item version at T1 between patients with no change in medication (n=30) and patients with change in medication (n=61) was: 11.0 (SD=3.9, p=0.006, independent samples test, two tailed). Differences in mean total score of SDS at T1 between patients with no change in medication (n=30) and patients with change in medication (n=61) was: -7.5 (SD=2.8, p=0.01, independent samples test, two tailed). All subscale scores of the SWN-38 item version differed significantly in patients with no medication change versus patients with medication change (p<0.02).

Relationship with psychopathology
Correlations between the SWN total score (both versions), SDS and PANSS-subscalses and MADRS total score (n=91) are shown in table 4 (page 124).
Table 4. Correlations between the SWN total score (both versions), SDSS and PANSS-subscalaes and MADRS total score (n=91) (two-tailed level of significance *P<0.05; **P<0.005; ***P<0.001)

<table>
<thead>
<tr>
<th>SWN-38 at T1</th>
<th>SWN-38 at T2</th>
<th>SWN-20 at T1</th>
<th>SWN-20 at T2</th>
<th>SDSS at T1</th>
<th>SDSS at T2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive score</td>
<td>-10</td>
<td>-.20*</td>
<td>-.09</td>
<td>-.20*</td>
<td>.15</td>
</tr>
<tr>
<td>Negative score</td>
<td>-.33**</td>
<td>-.24*</td>
<td>-.38**</td>
<td>-.22*</td>
<td>.35**</td>
</tr>
<tr>
<td>Global score</td>
<td>-.26*</td>
<td>-.54***</td>
<td>-.46***</td>
<td>-.51***</td>
<td>.39**</td>
</tr>
<tr>
<td>Total score</td>
<td>-.48***</td>
<td>-.52***</td>
<td>-.50***</td>
<td>-.52***</td>
<td>.42***</td>
</tr>
</tbody>
</table>

1Correlations are given between psychopathology ratings (PANSS and MADRS) assessed at T1 and ratings of subjective experience at T1; and between psychopathology ratings assessed at T2 and ratings of subjective experience at T2.

3.2.4. Discussion

This study was undertaken to examine the internal consistency, test-retest reliability, sensitivity to medication-change and concurrent validity of the SWN (two versions) and the SDSS. From this study it may be concluded that the internal consistency of both instruments is high and that patients reliable assess their subjective experience, independent of whether or not the patient is stabilized on antipsychotic medication. The applicability is very high in this sample of patients. This indicates that patients suffering from schizophrenic disorders are capable of representing their subjective experiences independent of their state of psychopathological and medication stabilization. Actually the measure of internal validity of the SWN 38-item and 20-item version is very high (0.95-0.93). This may indicate that one item could be sufficient because they all measure the same concept. At least it indicates that further shortening of the SWN might be possible.

The test-retest reliability of the scores on the SWN and the SDSS in the group without changes in medication or dosage is good. The SWN is sensitive to changes in medication and dosage. These findings indicate that the SWN (both versions) can be used to measure the relationship between subjective experience and antipsychotic medication.

The correlation between the SWN and the SDSS is high, indicating that the concurrent validity is high and that both tests measure the same concept.

Patients whose medication was not changed had a significant higher level of subjective well-being on both tests, at admission, compared to the patients who’s medication is adjusted. These findings give an indication of the predictive validity of both instruments. Perhaps this can be of future use in identifying high-risk and low-risk patients regarding subjective unwell-being, need for medication change or future non-compliance.
We found higher correlations between PANSS global scale and scores on SWN and SDSS than Naber et al. (2001). Moreover we found moderately to high correlations between SWN and SDSS scores and depression as assessed with MADRS. This indicates that patient’s assessed subjective experience is related to objectively assessed affective state, but not to positive symptoms as assessed with the PANSS. However, only 25% of the variance of rater based assessment of depression is predicted by self-rated subjective experience.

The short form of the SWN is the most practical without loosing important aspects of psychometric quality. The internal consistency of the subscales mental functioning, self-control and emotional regulation is somewhat lower than the internal consistency of these subscales in the original version. Our study replicates the findings concerning the psychometric properties of the short form by Naber et al., 2001 in a younger group of patients with recent onset schizophrenic disorders.

In the use of both the SWN and the SDSS we found the SWN to have advantages over and above the SDSS. The structure of the items in the SWN makes it possible to test the consistency after one assessment. Moreover, the SWN has higher correlations in the stable group than the SDSS and the SWN is more sensitive to medication change. The SWN and SDSS appeared to be equal applicable in patients in a florid psychotic state.

On the basis of the results of this study we conclude that the assessment of subjective experience with the SWN and the SDSS, not confounded by attitudes of patients to medication, can be used in evaluating differential effects of type of medication and dose on subjective well being. Subjective unwell-being related to treatment with antipsychotic medication diminishes quality of life and might be a risk factor in future non-compliance. Subjective experience of patients should be one of the outcome measures in clinical trials of antipsychotic drugs.
References


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