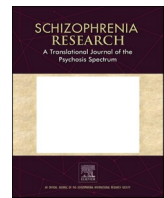


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Schizophrenia Research

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## Extension, translation and preliminary validation of the Northhoff Scale for Subjective Experience in Catatonia (NSSC)

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### ARTICLE INFO

#### Keywords:

Catatonia  
Subjective experience  
Clinical rating scale  
ICD-11

### ABSTRACT

**Background:** In the last two decades, much neuroscientific research has been done on the pathomechanisms of catatonia. However, catatonic symptoms have mainly been assessed with clinical rating scales based on observer ratings. Although catatonia is often associated with strong affective reactions, the subjective domain of catatonia has simply been neglected in scientific research.

**Methods:** The main objective of this study was to modify, extend and translate the original German version of the Northhoff Scale for Subjective Experience in Catatonia (NSSC) and to examine its preliminary validity and reliability. Data were collected from 28 patients diagnosed with catatonia associated with another mental disorder (6A40) according to ICD-11. Descriptive statistics, correlation coefficients, internal consistency and principal component analysis were employed to address preliminary validity and reliability of the NSSC.

**Results:** NSSC showed high internal consistency (Cronbach's alpha = 0.92). NSSC total scores were significantly associated with Northhoff Catatonia Rating Scale ( $r = 0.50, p < .01$ ) and Bush Francis Catatonia Rating Scale ( $r = 0.41, p < .05$ ) thus supporting its concurrent validity. There was no significant association between NSSC total score and Positive and Negative Symptoms Scale total ( $r = 0.26, p = .09$ ), Brief Psychiatric Rating Scale ( $r = 0.29, p = .07$ ) and GAF ( $r = 0.03, p = .43$ ) scores.

**Conclusion:** The extended version of the NSSC consists of 26 items and was developed to assess the subjective experience of catatonia patients. Preliminary validation of the NSSC revealed good psychometric properties. NSSC is a useful tool for everyday clinical work to assess the subjective experience of catatonia patients.

### 1. Introduction

Catatonia is a serious psychiatric disorder that can be characterized by different motor, affective and cognitive-behavioral symptoms (Gazdag et al., 2017; Hirjak et al., 2020a; Hirjak et al., 2020b; Ungvari et al., 2010). Catatonia occurs in 9–17 % of patients with acute mental disorders (Rasmussen et al., 2016; Rosebush and Mazurek, 2010; Sienaert et al., 2014) and a large number of studies on pathomechanisms of catatonia have been published in recent years (for reviews see also (Cattarinussi et al., 2022; Foucher et al., 2022; Hirjak et al., 2020a; Walther et al., 2019)). From a clinical perspective, catatonia patients can experience a variety of very distressing symptoms and according to authors' clinical experience, catatonia patients often feel anxious and

some of them might provide an explanation why they are not able to move and do not respond to any verbal or non-verbal cues, as if they were frozen in place (Dawkins et al., 2022). In akinetic catatonia, schizophrenia spectrum (SSD) and mood disorders, patients often experience their catatonic symptoms closely related to the psychotic experience and individual delusional content (Dawkins et al., 2022). Patients often report that they have had to adopt the catatonic state of immobility or rigidity and mutism in order to cope with their psychotic experience. Some patients also report they took over bizarre poses on purpose to cope with ego disturbances, which is a prominent symptom of SSD. However, some patients are not aware of their inability to terminate movements, therefore posturing (Northhoff, 2002; Plateka and Gallup, 2002). During this phase, some patients may feel disconnected

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<https://doi.org/10.1016/j.schres.2023.06.002>

Received 31 March 2023; Received in revised form 7 June 2023; Accepted 8 June 2023

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from their own body, helpless and as if they were in a trance-like state. Others suffer from a pronounced amnesia for this episode (Northoff et al., 1996). Therefore, a self-rating scale assessing catatonic experience could provide an opportunity for psychiatrists and psychotherapists to engage in conversation with the patient about the illness, which can help the patient feel more comfortable discussing their symptoms and staying adherent.

However, only little attention has been paid to the examination of subjective experience in catatonia patients (Clarke, 2018). We can only speculate about the reasons for this clinical and scientific gap: First, it can be assumed that clinicians and researchers were mainly concerned with treating the severe motor symptoms and their somatic side effects such as pneumonia, malnutrition and dehydration (Karl et al., 2023). Second, affective symptoms were not addressed in catatonia patients for a long time, as the diagnosis was exclusively given to patients with mutism, stupor and other bizarre motor phenomena. This is supported by the fact that the majority of clinical rating scales only marginally mentions affective symptoms (Hirjak et al., 2022; Northoff and Hirjak, 2022; Northoff et al., 2021; Sienaert et al., 2011), although there is existing evidence that affective symptoms play a crucial role in catatonia. In particular, catatonia patients often experience very intense feelings such as anxiety, anger, sadness, despair, etc. (Kline et al., 2022; Northoff et al., 1998). The dysfunction in the orbitofrontal cortex (OFC) (Hirjak et al., 2019) and the amygdala (Fritze et al., 2022a) in particular can contribute to the inability to adequately interpret negative stimuli from in- (e.g. bizarre thoughts) and outside (difficult interactions and perceptual disturbances) of the patient and to react with intensive emotions. Furthermore, catatonic symptoms are often present in mood disorders and vice versa (Dunayevich and Keck Jr., 2000; Grover et al., 2015; Jacobowski et al., 2013; van den Amele et al., 2015).

Third, there are only two self-rating instruments assessing subjective experience of catatonia patients. In 1996, Georg Northoff introduced a self-assessment-scale developed for catatonia called the *Northoff Scale for Subjective Experience in Catatonia* (NSSC) (Northoff et al., 1996). This scale contains 14 items that are measured with a continuum-based approach, by drawing the subjective experience on a line. According to Northoff et al. (Northoff et al., 1996), catatonic patients are often unaware of the prominent motor symptoms they are experiencing and rather do not report insight into akinetic states. What appears counter-intuitive is that catatonia patients barely reported their experience of motor symptoms, but rather described their experience of affective and cognitive-behavioral symptoms as intense and distressing (Northoff et al., 1996). Some patients also described mortal agony and fear. This led to the assumption that catatonia patients cluster in an emotive and a non-emotive subtype. Besides the NSSC, only one additional instrument has been developed so far that assesses self-reported catatonia symptoms (Dell'Osso et al., 2022). The Catatonia Spectrum (CS) introduced by Dell'Osso et al. (Dell'Osso et al., 2022) consists of 74 items divided into 8 domains and was developed to measure catatonic symptomatology across the different diagnostic categories of catatonia in DSM-5 (e.g. catatonia associated with another mental disorder, catatonic disorder due to another medical condition, catatonia without specification (Tandon et al., 2013)).

To fill the above mentioned clinical and scientific gap, this study had three main aims: First, we modified the original German version of the NSSC published in 1996 (Northoff et al., 1996) from its continuum-approach into a Likert-scale to improve the application of the questionnaire in clinical practice. Further, the original NSSC scale was extended to include other important items that are mentioned in the clinical rating scales such as Northoff Catatonia Rating Scale (NCRS) (Northoff et al., 1999) or Bush Francis Catatonia Rating Scale (BFCRS) (Bush et al., 1996) and ICD-11 (<https://icd.who.int/browse11>). The scale was then translated into English language to provide information about the subjective experience to a broader field of patients and scientists. Second, this study sought to examine a preliminary reliability and validity of the NSSC in a sample of catatonia patients according to

ICD-11. In particular, we examined whether the scale can be used to accurately measure the severity of the patient's subjective experience of catatonic symptoms. Finally, we sought to map the three catatonia domains of the NCRS (e.g. motor, affective and behavioral) on the subjective level and to replicate previous findings of the NCRS and the original version of the NSSC.

## 2. Methods

### 2.1. Patients and recruitment

We examined a total of 28 right-handed (Oldfield, 1971) subjects fulfilling the ICD-11 criteria of catatonia associated with another mental disorder (6A40). This study is part of a larger prospective study focusing on white matter microstructural alterations underlying catatonia (whiteCAT) (for rationale and study protocol see (Hirjak et al., 2023b)). Exclusion criteria were: (1) age < 18 or >64 years; (2) history of brain trauma or neurological disease (especially movement disorders); (3) alcohol/substance dependence within 12 months prior to participation; or (4) if the patients had MRI contraindications. (5) Medical conditions potentially affecting central nervous system function, as well as cardiovascular or metabolic diseases in patients with SSD and mood disorders were excluded by physical examination, laboratory control, electrocardiography (ECG), electroencephalography (EEG) and magnetic resonance imaging (MRI). (6) Further, no severe complication of catatonia, such as dehydration or electrolyte disorders, as indicated by laboratory findings were detected in any of the patients on the day of MRI investigation within the whiteCAT study.

The local Ethics Committee (Medical Faculty at Heidelberg University, Germany) approved the whiteCAT study (study number: 2021–613). We obtained written informed consent from all study participants after all aims and procedures of the study had been fully explained.

### 2.2. Extension of the German version of NSSC

We have followed the steps below to extend the German version of the NSSC developed and published by Northoff et al. (Northoff et al., 1996): First, we modified the scoring system and developed new ratings based on a Likert-scale for each item, because the initial German version of the NSSC could not represent the entire width of the severity of the subjective complaints due to its dimensional approach (GAB, SF and DH). Second, we conducted a systematic search using PubMed and the terms “catatonia” and “subjective” or “subjectivity” to identify any existing scales and studies in order to determine the items and ranges of ratings used. Third, to cover the whole spectrum of subjective experience of catatonia patients, we (GAB, DH and SF) searched within the NCRS (Northoff et al., 1999), BFCRS (Bush et al., 1996) and ICD-11 (<https://icd.who.int/browse11>) to identify additional symptoms/items that were applicable to measure the patient's subjective experience of catatonia. Finally, we consulted the new items with experts in the field (GN, KMK and RCW) to ensure the items and ratings were clinically relevant, concise and well applicable.

Thus the extended version of the NSSC contains 26 items in total, item #1 serves as a classifier if the patients can remember the acute catatonic period (2: “very well”, 1: “partially”, 0: “not at all”), item #26 assesses subjective affective valence about the acute catatonic state. Patients were asked if they found the acute phase “very pleasant”, “tolerable” or “horrible”, since there is evidence in the literature that some catatonia patients report rather pleasant feelings during the catatonic phase (Northoff et al., 1996). 24 items are considered for data analyses, scored on a three point Likert-scale with values from 0 to 2 (0 = abnormality absent, 1 = abnormality definitely present, but moderately and occasionally present with possibility of interruptions, 2 = abnormality constantly and severely present without any possibility of interruption) thus leading to a total score ranging from 0 to 48. The three

point Likert-scale was chosen in accordance with the response format of the NCRS to make the results more comparable. Only patients with at least a “partial” memory of the acute catatonic phase are considered for further analysis. All items are concise, easily understandable and cover the three catatonia domains (e.g. motor, affective and cognitive-behavioral) as defined in the NCRS.

### 2.3. Translation of the German version of NSSC

The translation of the extended German version of the NSSC followed three steps: First, we sought to ensure that the language is appropriate for the patient population suffering from catatonia and that all 26 items (symptoms) are clearly communicated. The extended German version of the NSSC was discussed among the authors of this study and was shown to two medical students to rate its understandability. Second, we wanted to ensure that the extended German version of the NSSC is accurately translated. Therefore, we selected a team of translators with experience in translating clinical rating scales and asked for their feedback. Third, the translated German version of the NSSC was retranslated into English language by two bilingual persons. A back translation of the English final version revealed no relevant deviations from the original German work. For the final version of the NSSC see supplementary material.

### 2.4. Clinical assessment

All participants were examined during in- or outpatient treatment after partial remission of acute psychopathological symptoms at Central Institute of Mental Health (CIMH) in Mannheim, Germany. All relevant study procedures (e.g. psychometric testing, motor assessment and MRI examination) were completed within 3 days. For a better comparability among studies, the daily doses of antipsychotic medication were converted to olanzapine equivalents (OLZ) (Leucht et al., 2015). All patients considered for further analysis were diagnosed with catatonia (Catatonia associated with another mental disorder - 6A40) according to ICD-11. In the ICD-11, three or more of the following symptoms in any of the three domains (decreased, increased or abnormal psychomotor activity) are required for the diagnosis of catatonia: *Decreased* psychomotor activity (e.g., staring, negativism ambivalence, mutism and stupor), *increased* psychomotor activity (e.g. extreme hyperactivity or agitation without reason with aimless movements and/or uncontrollable, extreme emotional reactions; impulsivity such as sudden, inappropriate behavior without provocation; combativeness - striking others, usually in an untargeted manner, with or without risk of injury), or *abnormal* psychomotor activity (e.g., grimacing, mannerisms, rigidity, and catalepsy, echoic phenomena, verbigeration and waxy flexibility). For a valid diagnosis it is important to emphasize, when evaluating increased psychomotor activity, multiple symptoms of increased psychomotor activity are only counted as one of the three required symptoms to meet the criteria for catatonia. Severity of catatonic symptoms was assessed by the German version of the NCRS (Hirjak et al., 2017). The NCRS measures the presence and severity of motor (13 items), affective (12 items), and behavioral (15 items) catatonic symptoms. We also used the BFCRS to assess severity of 23 catatonia symptoms since it is the most commonly used catatonia ratings scale (Hirjak et al., 2023a). We used the modified and extended German version of the NSSC to assess the subjective experience of catatonia patients. In general, for the assessment of NSSC, catatonia patients should be able to give informed consent and to answer the questionnaire despite their psychopathological symptoms (e.g. akinesia and/or amnesia). Catatonia patients should state how they are currently experiencing their catatonic symptoms or have experienced them within the last 7 days. We deliberately did not choose a longer time period, e.g. 14 days, because patients might not remember their symptoms exactly and this would lead to a possible bias in relation to NCRS or BFCRS.

The evaluation of psychopathological symptoms and global functioning was performed with Positive and Negative Syndrome Scale

[PANSS] (test-retest reliability across a 3- to 6-month inpatient phase [ $r = 0.80, 0.68, \text{ and } 0.60$ ]; (Kay et al., 1987)) (Kay, 1990), Brief Psychiatric Rating Scale [BPRS] (reliability:  $r = 0.78, p < .001$ ; (Andersen et al., 1986)) Global assessment of functioning [GAF] (inter-rater reliability:  $r = 0.26$ ; (Grootenboer et al., 2012)) (DSM-III-R., 1989). Anxiety symptoms were assessed with the state-trait anxiety inventory [STAI] (test-retest reliability:  $r = 0.77$  to  $0.90$  for trait anxiety,  $r = 0.22$  to  $0.53$  for state anxiety; (Spielberger et al., 2001)). Experience of loneliness was assessed with German version of UCLA loneliness scale [UCLA] (split-half reliability:  $r = 0.85$ ; (Döring and Bortz, 1993)).

### 2.5. Data analysis

#### 2.5.1. Clinical and demographic characteristics

Initially, a descriptive analysis for demographic and clinical data in catatonic patients (Table 1) was performed.

#### 2.5.2. Internal consistency

To assess reliability on the item level, Cronbach's Alpha was calculated as incorporated in SPSS version 26.

#### 2.5.3. Criterion and divergent validity

For criterion and divergent validity, a Spearman's correlation (two-side) was run to determine the relationship between NSSC, psychopathological symptoms (NCRS, BFCRS, PANSS, STAI and BPRS), experience of loneliness (UCLA loneliness scale) and global functioning (GAF) in catatonia patients.

#### 2.5.4. Factor structure

We used SPSS for Windows version 26. First, we used the Bartlett's test for sphericity to verify whether a data reduction technique can actually compress the data in a meaningful way. In case the Bartlett's test is significant, we will proceed with a data reduction technique such as principal component analysis (PCA). We used PCA with varimax rotation to map the three catatonia domains of the NCRS (e.g. motor, affective and behavioral) on the subjective level and to replicate previous

**Table 1**

Demographic and clinical variables in patients with catatonia ( $n = 28$ ) according to ICD-11 (as of May 2023).

Variable	Mean	Standard deviation
Age	38.04	15.11
Gender (m/f)	17/11	
Education (years)	12.79	2.78
Olanzapine equivalents	6.05 (M = 1, IQR = 13.07)	8.28
NSSC total	13.04	9.25
NSSC motor	2.14	3.19
NSSC affective	6.96	3.93
NSSC behavioral	3.93	3.22
NCRS total score	9.86	4.23
NCRS motor score	1.68	1.41
NCRS affective score	4.82	2.60
NCRS behavior score	3.36	1.61
BFCRS total score	3.29	2.71
PANSS total score	68.39	14.01
PANSS positive score	14.14	6.26
PANSS negative score	19.43	6.09
PANSS general score	34.82	6.59
BPRS total score	41.31	9.60
GAF score	43.39	10.48
STAI total score	50.59	12.52
UCLA total score	52.71	8.36

M = median, IQR = Interquartile range, NSSC=Northoff Scale for Subjective Experience in Catatonia; NCRS=Northoff Catatonia Rating Scale; PANSS=Positive and Negative Symptoms Scale; BFCRS=Bush Francis Catatonia Rating Scale; BPRS=Brief Psychiatric Rating Scale; GAF Global Assessment of Functioning; STAI=State-trait anxiety inventory, UCLA = loneliness scale.

findings of the NCRS. A three-factor model was specified a priori in which 24 items of the NSSC loaded on separate, but correlated factors. The threshold for inclusion of an item in one factor was 0.48, lower coefficients were not shown. This threshold allowed for the grouping of each NSSC item exclusively in one of the three dimensions, leaving no unassigned items. Lowering the threshold, the individual items were grouped in more than one of the three dimensions. Increasing the threshold, more items were left unassigned. Subsequently, we estimated the dimension scores for each patient by adding the values of the items included in each factor. Finally, we used the Kaiser-Meyer-Olkin measure of sampling adequacy to examine the sample adequacy for further analysis of factor structure and conducted the PCA.

3. Results

3.1. Clinical and demographic characteristics

Demographic and clinical characteristics of the study group comprising 28 subjects with catatonia according to ICD-11 (17 male/11 female) are shown in Table 1.

3.2. Internal consistency

For the analysis of reliability, Cronbach's alpha was calculated to examine the internal consistency of the NSSC. Cronbach's alpha was 0.92 for the entire NSSC with 24 items which shows satisfying internal consistency of the NSSC.

3.3. Criterion and divergent validity

There was a strong, positive correlation between NSSC and psychopathological symptoms (NCRS, BFCRS, PANSS, BPRS and STAI), which was statistically significant (for details see Table 2). There was no significant correlation between NSSC and global functioning (GAF) and UCLA loneliness scale total score.

3.4. Factor structure

First, the Bartlett's test for sphericity revealed significant results ( $p < .001$ ). Second, PCA with varimax rotation revealed that the three NSSC factors corresponding to the three catatonia domains in the NCRS explained 61.04 % of the total variance. However, the Kaiser-Meyer-Olkin measure of sampling adequacy was 0.58, which indicates that the sample adequacy for further analysis of factor structure is barely acceptable (Hutcheson and Sofroniou, 1999).

4. Discussion

The main aim of this study was to introduce the first clinical instrument in the English-speaking world for the specific assessment of subjective experience in catatonia patients. Three main findings emerged: First, we modified, extended, and translated the original German version of the NSSC (Northoff et al., 1996) to provide a clinically feasible instrument to examine the subjective experience of catatonia patients. Second, the extended version of the NSSC showed excellent internal consistency. Third, the NSSC showed significant positive correlations with psychopathological symptoms as assessed with well-established clinical rating scales in catatonia patients.

Catatonia is a psychomotor disorder characterized by prominent motor but also affective and behavioral symptoms. However, subjective experience of catatonia patients has been previously neglected by researchers and clinicians. To date, besides the study by Northoff et al. (Northoff et al., 1996), only one study by Zingela et al. (Zingela et al., 2022) examined the subjective experience of catatonia patients following a qualitative approach. Zingela et al. (Zingela et al., 2022) showed that the subjective experience of catatonia patients is mainly

Table 2 Correlations between extended version of the Northhoff Scale for Subjective Experience in Catatonia (NSSC), psychopathological rating scales and global functioning.

Variable	NSSC t	NSSC m	NSSC a	NSSC b	NCRS t	NCRS m	NCRS a	NCRS b	BFCRS t	PANSS t	PANSS p	PANSS n	PANSS g	BPRS	GAF	STAI	UCLA I
NSSC t	0.86**																
NSSC m	0.92**	0.66**															
NSSC a	0.92**	0.66**	0.677**														
NSSC b	0.50**	0.49**	0.43**	0.42*													
NCRS t	0.31*	0.45**	0.10	0.31*	0.49**												
NCRS m	0.42*	0.38*	0.40*	0.36*	0.88**	0.16											
NCRS a	0.36*	0.42*	0.41*	0.254	0.78**	0.15	0.56**										
NCRS b	0.36*	0.29	0.41*	0.29	0.33*	0.49**	0.35*	0.42*									
BFCRS t	0.41*	0.49**	0.29	0.30**	0.39**	0.20	0.43*	0.15	0.33*								
PANSS t	0.26	0.37*	0.07	0.30**	0.46**	0.41*	0.39*	0.22	0.432**	0.77**							
PANSS p	0.14	0.16	0.07	0.15	0.20	-0.07	-0.15	-0.22	0.02	0.60**	0.10						
PANSS n	0.37	0.39*	0.24	0.536*	0.57**	0.09	0.568**	0.31	0.39*	0.84**	0.58**	0.26					
PANSS g	0.29	0.45*	0.11	0.27	0.53**	0.29	0.49**	0.40*	0.40*	0.86**	0.77**	0.26	0.87**				
BPRS	-0.03	-0.02	0.08	0.02	-0.38*	0.01	-0.37	-0.42*	-0.12	-0.38*	-0.25*	-0.34*	-0.34*	-0.42*			
GAF	0.56**	0.38**	0.68**	0.41**	0.30	0.00	0.23	0.40*	0.21	-0.15	-0.18	-0.32	0.15	0.02	0.27		
STAI	-0.07	-0.17	-0.02	-0.02	-0.07	-0.30	-0.07	-0.03	0.03	0.02	-0.05	0.00	0.09	0.01	0.14	0.20	
UCLA I																	

Correlation table of subjective experience of catatonia, psychopathological symptoms and global functioning. Pearson correlation r values (one-tailed) were determined using SPSS 26. Abbreviations: NSSC = Northhoff Scale for subjective experience in Catatonia (t = total, m = motor, a = affective, b = behavioral); NCRS = Northhoff Catatonia Rating Scale (t = total, m = motor, a = affective, b = behavioral); PANSS = Positive and Negative Symptoms Scale (t = total, p = positive, n = negative, g = global); BFCRS = Bush Francis Catatonia Rating Scale; BPRS = Brief Psychiatric Rating Scale; GAF = Global Assessment of Functioning; STAI = State-Trait Anxiety Inventory; UCLA I = UCLA loneliness scale.

\*  $p < .05$ .  
\*\*  $p < .01$ .

characterized by overwhelming anxiety, fear, and depression, thus corroborating the early study by Northoff et al. (Northoff et al., 1996). The authors concluded that symptoms such as changing emotions, anxiety, panic, and depression often cause catatonic patients to withdraw from interactions with others. Particularly noteworthy about the study by Zingela et al. (Zingela et al., 2022) is that it also describes recommendations - beyond benzodiazepines and antipsychotics - for managing catatonia patients with prominent suffering and distress. This is indeed something new, because the treatment of catatonia has so far been limited to medication only. This study demonstrates the need for psychotherapeutic and psychosocial interventions for patients with catatonia, sometimes to convince these patients not to abstain from fluid, food, and medication intake, especially when negativism is present. Another recent study by Dawkins et al. (Dawkins et al., 2022) used a narrative approach searching healthcare records to examine subjective experience in catatonia. Analyzing 1456 validated diagnoses of catatonia across a wide range of demographic groups, diagnoses and treatment setting, the authors showed that there are three subtypes of catatonia patients, namely parakinetic, hypokinetic and withdrawal type. However, this study was able to identify only 68 patients with phenomenological data (e.g. statements about the time during the catatonic episode), including 49 contemporaneous and 24 retrospective accounts. Of these patients, 35 % expressed severe anxiety, with the majority (72 %) of these patients providing a plausible explanation for the catatonia symptoms based on their experience of hallucinations, delusions, and non-psychotic complaints. This is also in accordance with the clinical experience of the authors that the majority of patients have an explanation for their akinesia or hyperkinesia. Overall, the three studies mentioned (Dawkins et al., 2022; Northoff et al., 1996; Zingela et al., 2022) show how important it is to record subjective symptoms in catatonia in order to establish therapeutic options for this group of patients beyond drug treatment.

To address the current sparse evidence on subjective experience of catatonia, we decided to introduce the first clinical instrument for the assessment of subjective experience in catatonia patients. For this purpose, we looked at the original version of the German NSSC and considered how we could improve it to make the rating system easier for clinicians and researchers as well as patients. We decided to use the Likert-scale for each item. In addition, we noticed that the original German version of the NSSC did not cover all symptoms of the NCRS. Although it was not possible to translate all 40 symptoms of the NCRS into items examining subjective experience, we attempted to translate as many of the 40 catatonia symptoms as possible into the NSSC. The modification, extension and translation of the original German version of the NSSC was successful and the scale was well received by colleagues and students. Furthermore, the first 28 catatonia patients according to ICD-11 were examined by our newly developed instrument. Based on patients' narrative, the NSSC was also well accepted by most severely ill patients (s. Table 1 for psychopathological ratings).

Furthermore, in the sample of 28 catatonia patients, we were also able to obtain preliminary reliability and validity results. First, the NSSC showed excellent internal consistency. Second, NSSC showed significant positive correlations with NCRS total score as well as with affective and behavioral subscores. Interestingly, the NSSC did not show a significant correlation with NCRS motor subscale. This finding is also in line with the study by Northoff et al. (Northoff et al., 1996) that showed the most catatonia patients are unaware of their prominent motor symptoms during the acute catatonic state. Northoff et al. (Northoff et al., 1996) suggested that this might be explained by different catatonia subgroups. On one side, there is an emotive subtype experiencing rather intensive affective symptoms. On the other side, the other subtype is rather characterized by strong ambivalence, ambitendency and blockade of the will and thus also motor symptoms such as akinesia, stupor and flexibilitas cerea. However, the exact relationship between the two catatonia subtypes and NCRS as well as other psychopathological symptoms needs to be examined within future studies. In addition, the NSSC

showed significant correlations with BFCRS total score, that also can be considered as an indicator for adequate criterion validity, because the BFCRS (23 items) is the far most commonly used clinical rating scale for catatonia (Hirjak et al., 2023a). However, catatonia patients included in this study had slightly lower BFCRS scores compared to other studies (Dutt et al., 2011; Walther et al., 2022). There are two possible explanations for this: First, our patients must have been able to give informed consent and undergo clinical and MRI assessment to be included in the whiteCAT study. Therefore, they were no longer acutely severely ill, but were in partial remission of their psychopathological symptoms. Second, we also recruited patients with mood disorders and affective catatonic symptoms. Because the ICD-11 also includes affective catatonic symptoms, patients in the present study met the criteria for catatonia according to ICD-11 by the presence of affective catatonic symptoms, although only 1 point can be scored for affective symptoms. However, because the BFCRS hardly measures affective catatonic symptoms, it is possible that the BFCRS total scores in our sample were lower than in other studies that mainly included SSD patients (Dutt et al., 2011; Walther et al., 2022).

Looking at other psychopathological symptoms, we identified positive correlations with PANSS global subscore. These findings indicate that catatonic experience is related to general psychopathology. However, we did not identify any significant correlations between NSSC and PANSS positive and negative subscales. This result contrasts with our recent study by Fritze et al. (Fritze et al., 2022b), which found a significant correlation between PANSS negative and NCRS total scores after controlling for age, gender, and OLZ. It may be that this relationship will reach statistical significance in a larger patient sample. Furthermore, it may also be that the subjective experience of catatonia patients is not related to negative symptoms. This said, catatonia patients have much more intense emotions than patients with predominantly negative symptoms. Still, this is a very interesting finding, as from a clinical point of view it is often challenging to distinguish catatonia from negative symptomatology, especially when patients show symptoms such as negativism, withdrawal, mutism, stupor or akinesia. Clinical differentiation and the correct diagnosis are indeed very important with regard to therapy and prognosis. Possibly, the NSSC is suitable as a clinical tool to distinguish these two clinical entities. Furthermore, the construct of subjective experience in catatonia is different from other constructs that are also present in our study (e.g., loneliness after social withdrawal and global functioning).

What is somehow surprising is that we did not identify any significant association between NSSC and GAF score. Since we found an association between NCRS total and GAF score, similar to the study by Sambataro et al. (Sambataro et al., 2020), we might speculate that there is no correlation between the often fluctuating subjective experience of catatonic symptoms and the global level of functioning, which is rather a stable measure. At this point, the question of the relationship between subjective experience and objective assessment by clinical or scientific personnel also arises.

#### 4.1. Strengths and limitations

The strength of this study is that it shows preliminary data on the assessment, reliability and validity of a self-report-questionnaire for the examination of subjective experience in catatonia. This is somehow unique because there is no such self-report instrument for catatonia patients so far. Due to the fact that our sample is rather small at this early stage of data collection, our aim is to replicate these findings in a much larger sample size to improve statistical power. Upon completion, this study on subjective experience in catatonia will stimulate the discussion regarding which cognitive-behavioral-therapy(CBT)-based psychotherapeutic interventions might be suitable for partially remitted catatonia patients suffering from anxiety, negativism, negative affect, impulsivity, and aggression, respectively and address these patients' needs.

This study has also limitations: First, we did not differentiate

between catatonia patients with schizophrenia spectrum disorders and mood disorders according to ICD-11. It may therefore be that the subjective experience of these two groups of patients will differ. Second, some of our patients have taken benzodiazepines in addition to antipsychotics. Psychotropic drugs and benzodiazepines in particular, can affect the subjective experience of particular catatonic symptoms. However, benzodiazepines are often life-saving and necessary to break through mutism and stupor so that patients can talk and move again and participate in scientific trials at all. In addition to relevant covariates such as age, gender, and duration of illness, the daily dose of antipsychotic and anxiolytic medication should also be considered as a covariate in statistical analyses. Third, we did not calculate the test-retest reliability. However, the test-retest reliability of a test procedure measures the consistency of the result over time and assumes longitudinal stability of the data. We refrained from calculating test-retest reliability because we do not assume longitudinal stability of the data, but rather expect catatonic symptoms and their subjective experience to improve over time dependent on the treatment as usual (TAU) that could lead to underestimation of the actual reliability. Fourth, we did not include patients with catatonia associated with a general medical condition, since our study population was exclusively recruited in psychiatric hospital and psychiatric outpatient treatment. Fifth, the Kaiser-Meyer-Olkin measure of sampling adequacy indicated a barely acceptable sample adequacy. Therefore, we refrained from interpreting the factors/component loadings at this early level of data collection since it is dependent on sample size in relation to the number of items of the questionnaire (Buehner, 2011). Still, we are confident that once we have recruited >60 catatonia patients, a factor analysis will also be statistically possible (as recommended by (Buehner, 2011)). Finally, the present study only presents cross-sectional analyses. Since the NSSC is collected as part of the longitudinal whiteCAT study, it is also planned to examine the NSSC and its changes (e.g. increase or decrease of NSSC total score) over time in the future.

## 5. Conclusion

The data supports the feasibility of giving more insight into the subjective experience in catatonia to a broader field of clinicians and researcher by using a quantitative approach. This study underscores the potential of gaining more knowledge about the subjective experience during catatonic states in order to adjust tailored treatment options to the patients' needs.

## CRedit authorship contribution statement

DH and GAB: original idea and design of the study. DH, GAB, GN, KMK and RCW: modification, extension and translation of NSSC. DH, GAB, SF, MK, JD, SV, JK: patient recruitment and examination. DH, GAB, SF and SV: statistical analyses and interpretation of results. DH and GAB: first draft of the manuscript. All authors: discussion of the topic, writing and manuscript revision.

## Role of the funding source

This work was supported by the German Research Foundation (DFG, grant number DFG HI 1928/5-1 and HI 1928/6-1 to D.H.). The DFG had no further role in the writing of this manuscript and in the decision to submit the paper for publication.

## Declaration of competing interest

The authors have declared that there are no conflicts of interest in relation to the subject of this study.

## Appendix A. Supplementary data

Supplementary data to this article including the NSSC can be found online at <https://doi.org/10.1016/j.schres.2023.06.002>.

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