**Basic self-disturbances in first treated psychosis -
A seven-year follow-up study**
An exploration of stability, impact on recovery and sense of coherence

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Acknowledgment.

In 1994 I started in my first job as a nurse in a recently opened unit for young people with symptoms of schizophrenia spectrum disorders. This was also the start of my interest in young people with psychotic disorders and the phenomenology of psychosis. And this is probably the reason why I twenty-six years later complete a PhD study on first-treatment psychosis patients where phenomenology is an essential basis for the research. It is mainly psychiatrists and psychologists that have conducted earlier research in this field. So when I was invited to join the current study as a PhD-student, I asked myself: "Do I have something to add? And if I have, what can I add based on my professional background?"

During my education, I had an interest in reading nurse theory and nurse ethics, with an especial interest for theories based on phenomenology. I think this has influenced me in how I am as a nurse and my attitude towards other people. For me, it is essential to meet "the others" as equally as possible and listen to their stories/their narratives about their life in a non-judgmental way. I think this was a strength when I met the participants, asked many questions, listened to many answers both verbally and non-verbally, and transferred this into a number in a statistical matrix.

Later in my career I have developed an interest in salutogenic thinking and Antonovsky's theory of "Sense of coherence". Salutogenesis is concerned with *what makes people stay healthy*, as opposed to *what makes them sick* (pathogenesis) (Antonovsky, 1987). The theory of Basic Self-disturbance (BSDs), with its aim of a better understanding of the patients' experiences, thus echoed the thoughts that had inspired me.

The present study is a follow-up study of a study of patients coming to their first treatment for a psychotic disorder, established in 2007 by the Network for Early Stage Psychosis research in South-Eastern Norway, under the management of Professor Ingrid Melle. My current supervisor, Elisabeth Haug, did her PhD thesis and the main work with this baseline study together with Unni Bratlien, M.D. PhD. The study was funded by the research unit at Innlandet Hospital Trust and the Eastern Norway Health Authority through the Network for Early Stage Psychosis Research and was based at the Department of Acute and Psychosis Treatment, Reinsvoll, Division of Mental Health at Innlandet Hospital Trust.

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At last, I am grateful to all the participants who shared their experiences with self-disturbances and psychosis during extended interviews, laboratory tests, and neurocognitive tests. Your contributions have been valuable.

List of papers

The present thesis is based upon the papers listed below.

- Paper 1 Svendsen, I. H., Øie, M. G., Møller, P., Nelson, B., Melle, I., & Haug, E. (2018). **Stability in basic self-disturbances and diagnosis in a first treated psychosis: A seven year follow-up study**. *Schizophrenia Research*, 202, 274-280. doi:10.1016/j.schres.2018.07.011
- Paper 2 Svendsen, I. H., Øie, M. G., Møller, P., Nelson, B., Haug, E., & Melle, I. (2019). **Basic self-disturbances independently predict recovery in psychotic disorders: A seven year follow-up study**. *Schizophrenia Research*, 212, 72-78. doi:10.1016/j.schres.2019.08.009
- Paper 3 Svendsen I.H., Øie M.G, Møller P, Nelson B, Melle I, Haug E. (2020). **Basic self-disturbances are associated with Sense of Coherence in patients with psychotic disorders**. *PLoS ONE* 15(4): e0230956. <https://doi.org/10.1371/journal.pone.0230956>

Summary

Basic self-disturbances (BSDs) selectively aggregate in schizophrenia spectrum disorders and are considered core features of schizophrenia spectrum disorders. BSDs are present in the prodromal, early psychotic and chronic phases (Haug, Lien, et al., 2012; Henriksen & Parnas, 2014; Nordgaard & Parnas, 2014; Sass & Parnas, 2003). Earlier studies have shown BSDs as stable phenomena in schizophrenia spectrum disorders (Nordgaard, Handest, et al., 2017; Nordgaard, Nilsson, Saebye, & Parnas, 2017).

This study is a seven-year follow-up of a study of young patients (median age 22 years) recruited in their first treatment of a psychotic disorder. At both baseline and follow-up, the participants went through an extensive diagnostic and clinical evaluation. BSDs were measured by the Examination of Anomalous Self-Experience (EASE) manual. Fifty-six (62%) of the initial 90 patients participated in the present study, and include 35 patients with a disorder in the schizophrenia spectrum (Schizophrenia) and 21 patients with a psychotic disorder outside the schizophrenia spectrum (Non-schizophrenia). Data from both the diagnostic groups are included in the study.

The primary purpose of the study was to contribute to more knowledge about the phenomenon of BSDs over the first treated years of psychotic disorders. We here wanted to study to what extent BSDs are stable phenomena over time. We also wanted to study to what extent the level of BSDs at baseline could predict clinical and diagnostic changes at follow-up. Also, we wanted to explore the associations between BSDs at both baseline and follow-up and objective measures of mental health (criteria for recovery) and subjective experience of health (Sense of Coherence (SOC)).

In study 1, I examined the stability of BSDs from baseline to follow-up and looked at the differences between the diagnostic groups of schizophrenia and other psychotic disorders (non-schizophrenia). We further investigated the association between the level of BSDs at baseline and diagnostic changes at follow-up. The findings showed that participants in the schizophrenia group had statistically significantly higher levels of BSDs at both baseline and follow-up than the non-schizophrenia group, but also a statistically significant reduction in BSDs from baseline to follow-up. Based on the theory of BSDs as core features in schizophrenia, and findings from earlier studies exploring the stability of BSDs, the level of BSDs was less stable than expected. The participants in the non-schizophrenia group had a

stable, low level. Study 1 also focused on the small group of participants in the non-schizophrenia group experiencing a relatively high level of BSDs at baseline. The hypothesis was that high baseline level of BSDs in non-schizophrenia patients could predict changes to a schizophrenia spectrum disorder later on. However, we did not find any changes in the diagnostic group for any of the participants. This diagnostic stability from baseline to follow-up compared to other first treatment studies may be based in a long duration of untreated psychosis (DUP) before service entry in our participants.

In the second study, we examined the association between BSDs, at baseline and follow-up, and recovery. We used Andreassen's "Remission of Schizophrenia Working Group" (RSWG) criteria as a definition of stable remission, with the addition of achieving good social and occupational function as criteria for recovery. We found that recovery at follow-up was predicted by an absence of a schizophrenia diagnosis, by low baseline level of BSDs and a further reduction of BSDs from baseline to follow-up. The change in BSDs was the strongest predictor of recovery in our dataset, even after adjusting for premorbid adjustment and duration of untreated psychosis, and the findings were not confounded by diagnosis.

In the third study, the aim was to explore the association between BSDs and the subjective experience of health, based on Antonovsky's theory of Sense of Coherence (SOC) in a cross-sectional study of the follow-up data. We found an independent statistically significant association between a high level of BSDs and low level of SOC, even after controlling for clinical symptoms, level of functioning and diagnostic category. Since this is a cross-section study, we do not know the direction of the association. However, since BSDs are considered linked to the more basic levels of the self than SOC, the findings may be taken to suggest that the level of BSDs influences the level of SOC (and not vice versa).

In summary: As shown in study I, BSDs are less stable in the schizophrenia group than generally assumed, with a statistically significant reduction from baseline to follow-up. We also found an association between a high level of BSDs and high levels of clinical symptomatology at both baseline and follow-up. Studies II and III investigated the possible impact of BSD levels on different aspects of mental health. They indicated that initially low level of BSDs and a reductions in BSDs increase the chances of attaining recovery (study II) and low level of BSDs increase the possibility to experiencing subjectively good mental health (study III).

Abbreviations

BS	Basic Symptoms
BSABS	Bonn Scale for the Assessment of Basic Symptoms
BSDs	Basic self-disturbances
CDSS	Calgary Depression Scale for Schizophrenia
CTQ	Childhood Trauma Questionnaire
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders Fourth Edition
DUP	Duration of Untreated Psychosis
EASE	Examination of Anomalous Self-Experience
GAF	Global Assessment of Functioning Scale-Split version
GAF-F	Global Assessment of Functioning Scale-Functioning subscale
GAF-S	Global Assessment of Functioning Scale-Symptom subscale
GRR	General Resistant Recourses
ICD	International Classification of Diseases and Related Health Problems
Non-SZspect	Psychotic disorders outside the schizophrenia spectrum
PANSS	Positive and Negative Syndrome Scale for Schizophrenia
RSES	Rosenberg Self-esteem Scale
RSWG	Remission in Schizophrenia Working Group
SCID-I	Structured Clinical Interview for DSM-IV Axis I disorders
SCI-PANSS	Structured Clinical Interview for the PANSS
SIHF	Sykehuset Innlandet Helseforetak (Innlandet Hospital Trust)
SFS	Social Function Scale

SOC	Sense of Coherence
SZSpect	Schizophrenia spectrum disorders
TOP	Thematically Organised Psychosis Research Study
W/F	Wallwork and Fortgang's five-factor model (PANSS)

1 Background

Schizophrenia and schizophrenia spectrum disorders are ranked among the leading contributions to the total burden of disease worldwide. This *group of* severe mental disorders have a significant influence on morbidity and disability. They often have an onset in adolescence or young adulthood, with often debilitating clinical symptomatology and significant negative influence on social- and occupational capacity (James et al., 2018; Rössler, Joachim Salize, van Os, & Riecher-Rössler, 2005).

There has been growing interest in an approach that not only counts the different symptom "criteria", but also focuses on the description of symptoms and the subjective experience of symptoms and related phenomena. Of particular interest is the theory that disturbances in the basic sense of self are a marker of vulnerability for schizophrenia spectrum disorders and a core phenomenon in schizophrenia (Parnas & Henriksen, 2014). Ten years ago, our group conducted a study where the aim was to increase knowledge about basic self-disturbances (BSDs) in the early stages of psychosis. To do this, we included all patients referred to their first adequate treatment for broadly defined psychotic disorders (including schizophrenia - and psychotic bipolar spectrum disorder) from two neighbouring Norwegian counties served by the same hospital trust. The main findings from the baseline study were that level of BSDs differentiated between schizophrenia and both bipolar and other psychoses, with significant more BSDs in the schizophrenia group (Haug, Lien, et al., 2012). In patients with schizophrenia, there were statistically significant associations between BSDs several clinical measures, including social dysfunction (Haug et al., 2014) and suicidality (Haug, Melle, et al., 2012).

The study raised several new questions concerning both BSDs and its role in the clinical development of psychotic disorders: To what extent are BSDs stable over time? To what extent does BSDs at start of treatment predict diagnostic changes over a more extended period? To what extent do BSDs at baseline predict the course of clinical symptoms? To what extent does BSDs influence the experience of health and the ability to recover from a psychotic disorder? Based on this, the study group planned a follow-up study aimed at answering these questions. The follow-up was carried out in 2015-2016. This thesis is based on data from both the baseline study and the follow-up study.

1.1 Short introduction to the historical background of phenomenology in schizophrenia

1.1.1 Phenomenology

The term phenomenology comes from the Greek *phainómenon* “that which appears”, and *lógos* “study”. Phenomenology is thus the study of “phenomena»; the appearances of things, the ways we experience things and the meanings things have in our experience. The term has, at least, three different uses in psychiatry. The first is the straight forward observation of signs and symptoms by an observer. The second refers to descriptions of subjective experience, for instance, using patients' description of their subjective experience as the basis for classification. The third is linked to the philosophical school of phenomenology, with its focus on the essential features of aspects of human consciousness (Nelson, Yung, Bechdolf, & McGorry, 2008).

Edmund Husserl (1859-1938) is seen as the founder of the philosophical school of phenomenology. In his conception, the primary concern is to study the structures of consciousness and the phenomena that appear in acts of consciousness (Smith, 2018). Phenomenology attempts, in its most basic form, to make it possible to study topics that usually are seen as subjective objectively. These include consciousness, judgement, perceptions, and emotions. An essential element in this theory is that consciousness is always consciousness of something and directed towards things in the world, i.e. intentionality (Sass & Parnas, (2003). Phenomenology proposes that our basic sense of self and sense of immersion in the world exist at the same time and are inseparable. Our experiences appear to us as *our* experiences. Our awareness of what the person sitting next to us says takes place with the implicit background that it is *we* who are aware of and listen to this person. "Since phenomenology aims at understanding the structures of human subjectivity, it forms a framework for understanding the subjective dimension of psychopathology" (Nelson et al., (2008).

Stanghellini et al. (2019) emphasise six reasons why phenomenological psychopathology is important in psychiatry. 1) It is a framework for approaching mental illness, where the patient's subjective experience is prioritised. 2) It has a function as a bridge between human sciences and clinical sciences within psychiatric knowledge. It can clarify experiential traits and constructions, and provide tools that can facilitate successful diagnosis. 3) It "gives the word" to the patients instead of assessing their abnormalities according to pre-structured

interviews. 4) It attempts to describe the diversity of experiential alteration, and help us to shed light on the structure, meaning and the importance of the issue. 5) It connects understanding with caring in a dialogical framework, where the clinician and the patient cooperate in co-construct meaningful narratives for the patient. 6) It aims to bridge understanding and causal explanation in research and clinical settings, through an accurate description of the phenomenon, which is important before we can arrive at a satisfying explanation.

Schizophrenia and schizophrenia spectrum disorders are in particular characterised by severe alterations of subjective experiences, through symptoms that include loss of the sense of inhabiting one's own actions, thoughts, feelings, impulses, bodily sensations, or perceptions: Thought insertion or withdrawal; thought broadcasting; delusions of control; influence- or passivity symptoms; and hallucinatory voices commenting or discussing the patient in the third person (Sass & Parnas, 2003). Phenomenological psychopathology has thus had particular importance for the understanding of schizophrenia.

1.1.2. The concept of schizophrenia

Emil Kraepelin (1856-1926), a German psychiatrist, is considered a pioneer in the classification of severe mental disorder, based on this dividing psychotic disorders into dementia praecox (schizophrenia) and manic-depressive psychosis (bipolar disorder) (Angst, 2002). His main argument for the division was empirical and based on the better course and outcome of manic-depressive psychosis. Kraepelin however considered "loss of inner unity of consciousness" ("orchestra without a conductor") to be a core feature of dementia praecox, (Kraepelin, 1985; Sass & Parnas, 2003).

Paul Eugene Bleuler (1857-1939) was the first to coin the term "schizophrenia", as a combination of *schizo* "divided" and *phreno* "mind". Bleuler claimed that what constituted schizophrenia was not one unitary disorder, but that it included several states; "the schizophrenias". He further divided the symptoms of schizophrenia into primary and secondary symptoms. The primary symptoms were seen as fundamental to the disorder, and they included autism, ambivalence, affect disturbance, association disturbances and depersonalisation. While the following theories limit these primary symptoms to four (the four "A's"), Bleuler himself did not specifically emphasise any of these symptom groups. He stated that there is always a particular affliction ("Spaltung") of the self in schizophrenia, and this loss of intact self is the most characteristic for schizophrenia (McNally, 2009; Sass,

Pienkos, & Nelson, 2013). This splitting is not splitting in the form otherwise seen in multiple personality disorder. Here, it infers to a fundamental splitting of the self. It takes the form of a loss of the feeling of activity or the ability to direct thoughts. According to Bleuler, the hallucinations, delusions and flamboyant catatonic features constituting a psychotic episode, were secondary symptoms of schizophrenia - the reaction of a sick psyche to internal - or external stress (McNally, 2009). Also, while Kraepelin envisaged dementia praecox as an organic and most probably degenerative disorder, Bleuler had a broader approach to the illness and stated that schizophrenia not necessary had a bad prognosis (Hoenig, 1983).

Eugene Minkowski (1885 – 1972) was trained by Bleuler. He developed Bleuler's theory further by claiming that it was not enough to have a list of symptoms describing what constituted the core of schizophrenia. A background theory of the nature of mental life was also needed to understand these clinical features (Parnas, 2011). Minkowski's theory received contributions from the psychiatrist and philosopher Karl Jaspers (1883-1969), who systematically described changes in the subjectivity of people with psychiatric disorders such as schizophrenia.

Both Karl Jaspers and another German psychiatrist, Kurt Schneider (1887-1967,) claimed that the *form* of symptoms rather than their contents should be the basis for diagnosis. For example, the fact that a patient hears voices in his head talking about him is more important than what the voices say. Based on this, Schneider grouped psychopathological phenomena which were characterised by influence, passivity and control, into the group of *first-rank symptoms* (Bürge, 2011; Jansson, 2018; Jaspers, 1923).

1.1.3 Diagnostic classification systems.

The work of Kraepelin and Schneider has had a particular influence on the format of psychiatric diagnostic classifications in the WHO International Classification of Disease (ICD) and the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM). The first edition of ICD that included mental disorders came in 1949, while the first edition of DSM came in 1952 (American Psychiatric Association, 2020; World Health Organization, 2019). These earlier editions of the diagnostic systems had an underlying theoretical basis that included the phenomenology of schizophrenia and other psychoses (Parnas, 2011). Based on problems caused by the lack of common definitions of mental disorders, both diagnostic systems were reviewed and revised in the 1970ies. The revisions were based on descriptive, operationalised and primarily atheoretical definitions of

psychiatric disturbances (Andreasen, 2007). There was however a strong emphasis on Schneider's first-rank symptoms for the diagnosis of schizophrenia. The reorganisation of the diagnostic systems was based on consensus between experts and not products of conceptual analyses or knowledge about biological markers (Jansson & Parnas, 2006). The use of operationalised criteria from DSM-III onwards has made the DSM into the mostly used diagnostic classification in research, even if the ICD is the most used in clinical settings outside of North America.

In 1858 the English neurologist John Hughlings-Jackson formulated the concept of positive and negative symptoms based on phenomena occurring due to a brain injury at a primitive level (positive symptoms), or loss of brain function (negative symptoms). Later definition of positive and negative symptoms is an amplification of these initial ideas (Yudofsky & Hales, 2004). The concept of positive and negative symptoms of schizophrenia has achieved significant influence, especially in Anglo- American psychiatry. In the fourth edition (DSM-IV) and ICD-10, positive and negative symptoms, together with symptoms of disorganisation, were given further importance as criteria for schizophrenia. The DSM-5, introduced in 2013, removed the emphasis on bizarre delusions and commentary auditory hallucinations for a diagnosis of schizophrenia. Since these terms covered parts of the first rank symptoms, this change is a further step away from phenomenological psychopathology (Sass & Byrom, 2015). The ICD-11 will come into effect in 2022 and will be even more similar to DSM than previous editions. The main difference between DSM-5 and ICD-11 is the role of functional impairment, which is mandatory for a diagnosis of schizophrenia in DSM-5 but not in ICD-11 (Gaebel, 2015).

1.2 Diagnostic classification in DSM-IV

In the baseline study, the diagnostics were based on the DSM-IV. To be able to compare data, we also used DSM-IV in the follow-up study.

1.2.1 Schizophrenia spectrum disorder

To receive a diagnosis of schizophrenia according to the DSM-IV, the patients have to meet two or more of the following criteria (Criterion A): Delusions, hallucinations, disorganised speech or behaviour, grossly disorganised or catatonic behaviour, and negative symptoms

(affective flattening, reduced speech or poverty to speech and inability to initiate and persist in goal-directed activities) with a duration of one month, or shorter if successfully treated. The patients must also have a significantly reduced social and occupational function (Criterion B). Also, continuous signs of the disturbance must persist for at least six months (Criterion C), affective disorders must be ruled out (Criterion D), and the disturbance must not be due to the effects of substance use or a medical condition (Criterion E).

If the patients have bizarre delusions (delusions that are against the law of nature or are not a part of the patients' culture), hearing two or more voices talking to each other or having voices commenting, it is sufficient to have one of these criteria to meet the A criterion for schizophrenia in DSM-IV (American Psychiatric Association, 1994).

Schizoaffective disorder requires that the A, B and duration criteria for schizophrenia are met, that episodes of psychosis overlap with mood episodes for a substantial portion of the entire period of illness. At the same time, psychotic symptoms are also present outside of the mood episode (American Psychiatric Association, 1994). Schizophreniform disorder has the same A, D and E criteria as schizophrenia, but the duration of the illness is shorter than six months, and functional decline is not required.

1.2.2 Bipolar disorders

Bipolar disorders are characterised by episodic symptoms of mood disturbances that are depressive, manic or hypomanic. Bipolar I Disorder as it is the only bipolar disorder that was included in the current study.

The essential feature of Bipolar I Disorder is the occurrence of one or more manic episodes or mixed episodes, most often combined with one or more major depressive episodes (American Psychiatric Association, 1994).

Mania is a period with abnormally elevated, expansive, or irritable mood, lasting one week or shorter if hospitalisation is required. According to DSM-IV three or more of the following symptoms must be present: inflated self-esteem or grandiosity decreased need for sleep, talks more than usually, subjective experience of racing thoughts and flights of ideas, distractibility, increase in goal-directed activity or psychomotor agitation, excessive involvement in plausible activities that have a high potential for painful consequences. The symptoms must not be due directly to a medical condition or effect of a substance, and the

disturbance must lead to impaired function, psychotic symptoms or hospitalisation to prevent harm.

Mixed episodes meet both criteria for a manic episode and major depressive episode (except for duration), nearly every day in at least one week (American Psychiatric Association, 1994).

1.2.3 Other Psychoses

Delusional disorder is characterised by non-bizarre delusions (delusions about situations that can occur in real life) of at least one month's duration. If hallucinations are present, they have to be associated with the delusions. The function is not markedly impaired, and the behaviour is not odd or bizarre. The delusions are not due to the effect of a substance or general medical condition (American Psychiatric Association, 1994).

Psychotic Disorder NOS (Not Otherwise Specified) includes psychotic symptomatology and is used when there is inadequate or contradictory information, or the psychotic symptoms do not meet criteria for any specific Psychotic Disorder (American Psychiatric Association, 1994).

1.3 Basic self-disturbances

1.3.1 Schizophrenia - more than DSM criteria?

As stated above, the current diagnostic systems do not reflect the growing interest in phenomenology in schizophrenia (Mishara & Schwartz, 2013). Phenomenologists are criticising lack of acknowledgement of what is considered core disturbances of the disorder, as described in classic psychopathological literature. This is a consequence of mainly addressing symptoms that are easily recognisable but usually seen as constituting "secondary" psychotic symptoms and not the primary vulnerability. This focus makes the systems not well suited for recognising disturbances in the very early course or the disorders, before the onset of the psychotic symptoms (Moller & Husby, 2000; Parnas, 2011; Sass, Parnas, & Zahavi, 2011). The organisation of the diagnostic systems is also criticised because their emphasis on a high degree of inter-rater reliability may come at the cost of a low degree of validity (Andreasen, 2007). Also, while DSM-III and IV manuals were not meant to be textbooks of psychiatry, they are often used as such. Many clinicians, students and researchers consequently do not have enough knowledge about other potentially important

and interesting signs and symptoms that are not included in the diagnostic manuals (Andreasen, 2007).

The introduction to the chapter Schizophrenia and other psychotic disorders in the DSM-IV manual states that "...psychotic symptoms are not necessarily considered to be fundamental core features of these disorders..." (American Psychiatric Association, 2000, page 297). This statement is, however, not reflected in the following diagnostic criteria. Phenomenologist has emphasised, that to understand the concept of schizophrenia, we need to look at the phenomenological core gestalt of the disorder. "(T) the core properties are not fluctuating state phenomena (psychotic symptoms) but trait features, reflecting its phenomenological structure" (Parnas, 2012, page 68). Schizophrenia is seen as belonging to a spectrum of conditions that share important trait factors, but where the profiles of the phenomena varies in intensity and quality. Within this framework, we also need to take into consideration the totality of the patient's expression and experiences, and the clinical symptoms and signs cannot be seen independent of the context (Parnas, 2012).

1.3.2 Historical background of the concept of self-disturbances

Altered self-experience has been described from different sources, including existential psychiatry, psychoanalysis, phenomenology, psychosocial rehabilitation and dialogical psychology (Lysaker & Lysaker, 2010). The history and development of theories about the altered self are tightly interwoven with the history of schizophrenia. Kraepelin pointed to the "loss of inner unity of consciousness". Bleuler suggested that depersonalisation was a fundamental symptom of schizophrenia, together with autism, ambivalence, affective disturbance and associations' deficits (the four A's). Focus on depersonalisation and the fundamental splitting associated with the "four A's" were however more or less set aside for decades after Bleuler's original theories – especially outside German and French psychiatry (McNally, 2009). Later pioneers in continental psychiatry, including Kurt Schneider, Henrich Rümke, Josef Berze, Wolfgang Blankenburg and Eugene Minkowski, did, however, emphasise subtle changes or alterations in the basic self, as e.g. depersonalisation, as symptoms of schizophrenia (Parnas, 2011; Parnas & Handest, 2003).

From the 1970ies onward, Gerd Huber, Joachim Klosterkötter and their colleges in Western Germany made significant contributions through their work on self-experienced sub-clinical disturbances, called Basic Symptoms (BS). BS are conceptualised as nonpsychotic affective, cognitive, perceptual, motor and bodily disturbances, out of which many are seen as specific

to schizophrenia (Klosterkötter, Ebel, Schultze-Lutter, & Steinmeyer, 1996; Parnas & Handest, 2003; Schultze-Lutter, 2009). The Bonn Scale for the Assessment for Basic Symptoms (BSABS) was made to assess the patient's own experience of BS and is designed as a comprehensive mapping tool with a thorough description of BS (Gross, Huber, Klosterkötter, & Linz, 1987). Studies using the BSABS showed that in schizophrenia patients in remission, the level of self-disturbances was significantly higher than in patients with a bipolar disorder (Parnas, Handest, Sæbye, & Jansson, 2003). The same was found in a study comparing 151 patients with either schizophrenia in first remission, patients with a schizotypal disorder and patients with other psychotic disorders outside schizophrenia spectrum (affective illness, obsessive-compulsive disorder, anxiety, eating disorder and personality disorder). Patients with schizophrenia here had a higher score on the BSABS, compared to patients with a schizotypal disorder and patients with diagnoses outside the schizophrenia spectrum (Handest & Parnas, 2005), and a 5-year follow-up of the same sample, showed a high level of persistence of self-disturbances measured with BSABS in the same groups (Nordgaard, Handest et al., 2017).

A later study of genetic high-risk individuals by Raballo, Saeby and Parnas (2011), using selected parts of the BSABS, also showed a significantly higher level of self-disturbance in patients with a high risk of a schizophrenia spectrum disorder. Two other Scandinavian studies also revealed significant disturbances in subjectivity in the prodromal phase of schizophrenia (Moller & Husby, 2000; Parnas, Jansson, Sass, & Handest, 1998). These two independent studies were the start of a research cooperation where senior psychiatrists from three European countries collaborated in constructing the Examination of Anomalous Self-Experiences (EASE) manual. The EASE is partly overlapping with the BSABS, but the EASE does only assess disorders of the self. BSABS also includes other manifestations that may occur with schizophrenia, such as neurovegetative symptoms (e.g. sleep disorders), affective-dynamic disorders (e.g. reduced stress tolerance to daily tasks, increased impressionability), and compensatory behaviour (Gross et al., 1987; Parnas, Moller, et al., 2005). The EASE will be described in more detail in paragraph 1.3.4.

1.3.3 The phenomenology of basic self-disturbances

Understanding the concepts of self, subjectivity, and self-awareness is necessary to understand the concept of basic self-disturbances (BSDs). The experience of being a person and the sense of self is automatic and thus not explicitly conscious in a state of mental health.

Phenomenological theory gives us the possibility to investigate the self at different levels of organisation. Theoretically, the self can be seen as organised into hierarchical levels, either as two levels or as three levels. In the following, I will mainly use the concept of two levels; that is the narrative self and the basic- or pre-reflective self. These levels are separated but closely interlinked (Gallagher, 2000; Zahavi, 2005). Some theorists further divide the narrative self into a narrative level and a reflective level, thus resulting in the three levels of the self (Parnas & Handest, 2003).

The narrative self exists on a reflective and articulated level. The narrative self is the experience of the self as having particular characteristics, personality traits, values and history (Gallagher 2000; Sass & Parnas, 2003; Zahavi 2005). It refers to the personality, “what I like”, “what I do”, to education, experience, behaviours, and vulnerabilities. It is at this level that we talk about “self-esteem” and “self-image” as psychological concepts.

The basic or pre-reflective self refers to an unconscious and implicit level of selfhood; an inter-subjectivity that makes the person feel like a whole, with a core that is “me, and an anchor of all “my “experiences: “*I am experiencing*”, “*I am feeling*” and “*I am thinking*”, “It's *my* experiences, feelings and thoughts”. “I exist, and I am the same person over time.” (Parnas & Handest, 2003; Zahavi, 2002). *Subjectivity* is strongly linked to the pre-reflective self and is seen as the nucleus of being a person. Subjectivity is an automatic and unconscious experience that thoughts, feelings, body movements and acts are coming from *me*. This ownership is also called “ipseity” or “mineness” (Sass & Parnas, 2003). This “mineness” constitutes a basic form of self-awareness, which forms the background for where the conscious activity takes place (Nelson et al., 2009).

When subjectivity is threatened, this ownership is disturbed. BSDs are anchored in the pre-reflective self. BSDs can start as brief changes in the subjectivity and from there develop towards the formation of delusions. The phrasings describing this process may range from a simple statement such as “I do not feel like myself” or “I am not me”, to “I am losing myself”, “I have a strange feeling as if I was an alien. I am almost not existing”, “I am becoming a monster” or “I am not a human” (Parnas & Sass, 2011). BSDs can also intensify into hallucinations (e.g., audible thoughts become external voices) or symptoms of disorganisation (e.g. brief problems finding the right word develops to total muteness). Some BSDs can, also if they increase in severity, be interpreted as behavioural signs of negative

symptoms (e.g., a slight feeling of emotional distance to others leads to withdrawal and isolation).

The following statement from a person with psychosis captures an example of this: "It feels as if the thoughts are not mine." In this experience lies the seed of delusions. Many will try to make sense of these strange feelings and construct a model of explanation: "If they are not my thoughts – who do they belong to?" A reorganisation of the consciousness can thus result in psychotic symptoms that follow patterns and trajectories guided by specific changes of ipseity and the act of awareness; "Someone other than me is controlling my thoughts. There are aliens in my brain!" (Parnas, 2003; Parnas & Handest, 2003; Sass & Parnas, 2003).

Studies have confirmed high levels of BSDs in prodromal/Ultra High Risk (UHR) (Comparelli et al., 2016; Koren, 2013; Koren, Lacoua, Rothschild-Yakar, & Parnas, 2016; Koren et al., 2017; Nelson, Thompson, & Yung, 2012; Parnas et al., 2011; Raballo et al., 2016), early psychotic (Haug, Lien, et al., 2012; Nordgaard & Parnas, 2014) and chronic phases of schizophrenia (Raballo et al., 2011). A study based on the concept of BSDs indicated that the presence of BSDs predicts transition to psychotic disorder in an ultra-high-risk (UHR) population (Nelson et al., 2012). Several other studies show a selective aggregation of BSD in schizophrenia (Haug, Lien, et al., 2012; Raballo et al., 2011) and support that BSDs are core features in schizophrenia (Haug, Lien, et al., 2012; Nordgaard, Handest, et al., 2017; Nordgaard, Nilsson, et al., 2017; Parnas & Handest, 2003; Parnas & Henriksen, 2014; Raballo et al., 2011).

A recent addition to the theory of BSDs is the view that some disturbances are fundamental to schizophrenia (primary BSDs), this includes a confusion between self and world, and a disturbed first-person perspective (Sass, Pienkos & Nelson, 2013; Sass & Borda, 2015).

Other disturbances may occur as a defensive reaction to traumatic life events and are seen as secondary BSDs. Especially depersonalisation (e.g. self-alienation) and derealisation (e.g. change in the experience of the environment) are disturbances seen in stressful situations and usually vanish when the stress disappears (Borda & Sass, 2015; Sass & Borda, 2015; Sass, Borda, Madeira, Pienkos, & Nelson, 2018).

1.3.4 The Examination of Anomalous Self-Experiences (EASE).

The current study used the EASE manual (Parnas, Moller, et al., 2005) to assess BSDs. The EASE-manual was developed as a specific clinical instrument allowing a comprehensive mapping of BSDs. The manual is organised in five Domains containing 57 items and several sub-items that guide the mapping. The five Domains are 1) Cognition and stream of consciousness, 2) Self-awareness and presence, 3) Bodily experiences, 4) Demarcation and transitivity, 5) Existential reorientation (see appendix for EASE Item Key List).

Domain 1 - Cognition and stream of consciousness

This domain assesses changes in “(A) normal sense of consciousness as it continues over time, flowing, inhabited by the subject and introspectively transparent (immediately or directly given) in a nonspatial way” (Parnas, Moller et al., 2005, p. 204). The domain has 17 items assessing changes in how the thoughts appear to the person. The focus is not *what* the person is thinking, but *how*. Normally, thoughts should not be experienced as unfamiliar and strange or located at one place in the head or somewhere in the body. Some patients experience that their thoughts have an acoustic or auditory quality, sometimes they can be so loud that it appears as others are able to hear their thoughts. Some experience uncertainty about the source of their thoughts. Changes in the speed of thoughts and the experience of having many different thoughts at the same time are among other changes in cognition and stream of consciousness assessed in this domain.

Domain 2 - Self-awareness and presence

A normal sense of being (existence) involves automatic unreflected self-presence and immersion in the world (natural, automatic, self-evident). It implies that the sense of the self and the sense of immersion in the world are inseparable (Parnas, Moller, et al., 2005). This notion indicates that changes in the sense of self will leave its imprint on the sense of immersion in the world, and vice versa. With normal experiences of self-awareness and presence, we are directly conscious of our thoughts, feelings, and perceptions as our own, with no experience of distance between the sense of self and the one that is experiencing the world. This domain contains 18 items and assesses disturbances such as a diminished sense of basic self and distorted first-person perspective, sometimes described as a feeling of lack of an inner nucleus. Diminished clarity of transparency, depersonalisation, and a diminished sense of vitality and loss of "common sense" are other disturbances assessed in Domain 2.

Changes in self-awareness and presence can be the experience of alienation from oneself and others. Some ask themselves; "Do I really exist?" or "Am I the only human...or am I an alien?" These experiences and thoughts may result in existential loneliness.

Domain 3 - Bodily experiences

This domain explores the experience of psychophysical unity and coherence. Usually, we experience our body as both a psychical object and an abstract subject at the same time, in an unproblematic interplay between the mind and the body. This domain contains nine items and assesses phenomena as abnormal changes in the body. Some patients experience that part of, or their whole body feels unfamiliar, even if there are no visual changes. Some report that they feel as if parts of their body are changed bizarrely (e.g. arms are getting thinner or shorter). When looking in a mirror, some patients say they experience that their face or part of it has changed or feels unfamiliar. Some avoid mirrors because they are afraid of what they can see in it. A misfit between body and mind was expressed by one patient as: "It feels as my head and body are not really connected; the body does not feel like a part of me".

Domain 4 - Demarcation/transitivism

This domain explores the borders, both psychological and physical, between the person and other people and the surroundings. Demarcation refers to a normal feeling of an impermeable and intact border between me, and other people and the world. The experience of this border as weak is reflected in statements such as; "I do not use the bus. If someone comes too close to me, I am afraid my body will melt into their body". Transitivism refers to the experiences of diminished privacy of one's mental states or a loss of ego-boundaries, described as; "I am unsure of my thoughts - are they mine or are they others'?" There are five items in this domain, and there are links between this domain and Domain 2 (self-awareness and presence). Domain 4 was however established as separate because of the distinctive appearance and articulation of the phenomena.

Domain 5 - Existential reorientation

This domain refers to fundamental changes and reorientation in the metaphysical worldview and/or hierarchy of values and interests. This domain assesses disturbances in self-awareness related to existential questions. An essential part of this domain is the sense of *centrality* (Parnas, Moller, et al., 2005). Changes in existential orientation can be expressed as; "I feel I

have a special insight in how the world is linked together” or “I feel I can control other people, - everything depend on me”. This domain has eight items.

Methodological aspects of using the EASE interview is described in the Methods part of the thesis (paragraph 3.4.2). When using the EASE manual, we assess single items. However, it is necessary to have in mind that BSDs and its phenomena are highly overlapping and interwoven changes in subjectivity, and must be seen as an aspect of a Gestalt (Parnas & Handest, 2003; Parnas, Handest, Jansson, & Saebye, 2005; Sass & Parnas, 2003).

1.4 Remission and recovery in psychotic disorders.

1.4.1 Remission and recovery

Remission of clinical symptoms is a necessary step to full recovery, and full recovery is the optimal goal of any treatment. In 2005, the Remission of Schizophrenia Working Group (RSWG) proposed a consensus definition of remission based on international standardised criteria. The working group here defined remission as a stage where the patients had experienced an improvement in core signs and symptoms, to the extent that any remaining symptoms no longer interfered significantly with behaviour and were below the threshold that justified an initial diagnosis.) To meet these criteria, the patient must have a PANSS-score below 4 for both positive symptoms (item P1, P3, G9), disorganisation symptoms (P2, G5) and negative symptoms (N1, N4, and N6) (Andreasen et al., 2005). There is currently no consensus definition of recovery in schizophrenia. The term "full recovery" is often defined as meeting the both the RSWG remission criteria, in addition to the remission of affective symptoms and having regained normal functioning.

Based on concepts used in previous studies from our research organisation, restored functioning is defined as having an employment level equal to full-time work/ studies and social activities equivalent to at least weekly patient-initiated contact with family and/or friends (Hegelstad et al., 2012).

Since this study specially wanted to look at remission and recovery of psychosis, recovery is in this thesis defined as experiencing the combination of full remission of psychotic symptoms and restored functioning during the last 24 months before follow-up.

1.4.2 Prediction of course and outcome

Historically, schizophrenia and other related psychotic disorders have been seen as chronic disorders with a poor outcome and few possibilities of recovery. However, studies from the last five decades show that the course of schizophrenia is more heterogeneous than first assumed, and the outcome is less chronic than previously suggested (Ciompi, 1980; Harrison et al., 2001; Torgalsbøen & Rund, 2002).

Depending on the specific diagnosis, the length of the follow-up period and the criteria used to define recovery, the percentage of recovery in schizophrenia and in schizoaffective disorder vary between 10 and 25% (Austin et al., 2013; Jaaskelainen et al., 2013; Robinson, Woerner, McMeniman, Mendelowitz, & Bilder, 2004; Torgalsboen, Mohn, Czajkowski, & Rund, 2015). A large meta-analysis, using the RSWG criteria and including 35 studies and 9,642 first-episode psychosis patients (both schizophrenia and affective psychosis), showed that 38 % of the patients were in full recovery after a mean follow-up period of 7.3 years (Lally et al., 2017). There are, however, differences between rates of full recovery in schizophrenia spectrum disorders and bipolar disorder. In patients who were followed 2- 4 years after their first hospitalisation for mania, 43% were in full functional recovery (Tohen et al., 2003). However, studies are showing that only 16% of patients with bipolar disorders had periods of five years with both stable remissions of symptoms, and a stable good social and occupational performance (Angst, 2009). Reports of recovery rates of delusional disorders are infrequent. An exception is a follow-up study of 48 first-episode psychosis patients, diagnosed with delusional disorders (DSM-5), that reports 72% with full recovery after one year (Rowland et al., 2019). The study used recovery criteria based on PANSS and GAF scores (Bebbington et al., 2006).

It is difficult to predict the outcome of a psychotic disorder on an individual level, and several factors influence the outcome. Impaired cognitive functioning is shown to be a driver of occupational-, social- and economic dysfunction in patients with schizophrenia, and is thus an essential prognostic factor (Keefe, Harvey, Geyer, & Gross, 2012; Lepage, Bodnar, & Bowie, 2014). Studies also show that poor premorbid function is associated with low quality of life and negative symptoms (MacBeth & Gumley, 2008). A systematic review found that schizophrenia and other psychosis with onset in childhood or adolescence followed a worse course than in groups with later onset of symptoms (Clemmensen, Vernal, & Steinhausen, 2012). A long duration of untreated psychosis (DUP) indicate a poorer long-term prognosis

(Penttilä, Jaaskelainen, Hirvonen, Isohanni, & Miettunen, 2014), together with depression (Upthegrove et al., 2010), high level of negative symptoms at the onset of the illness as well as persistent negative symptoms (Austin et al., 2013) in addition to substance use (Weibell et al., 2017). Some studies also indicate poorer outcome in males than in females (Clemmensen et al., 2012; Tandon, Nasrallah, & Keshavan, 2009).

1.5 Health, salutogenesis and Sense of Coherence.

The World Health Organization (WHO) definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" has been widely criticised as an unachievable state, and for taking all of human life and its miseries, including politics, economic, world peace, as a health issue (Callahan, 2012). Still, the definition gives an essential signal that health is not only the absence of disease but a complex phenomenon that comprises many factors in life. Moreover, despite the WHO definition, there are also people with an obvious severe illness that still experience good health; how can this happen?

Aron Antonovsky (1923-1994), an Israeli American sociologist, coined the term "salutogenesis" based on a study of ageing women in Israel. He became aware of a group of women who had faced and survived the most punishing life-stress experiences, the Nazi concentrations camps, but still had positive emotional health. He questioned, "What gives good health?" (Antonovsky, 1979). The word *salutogenesis* comes from the Latin *salus* = health and the Greek *genesis* = origin. In salutogenic theory, the experience of health is seen on a continuum from good health (ease) to poor health (disease). Where a specific person is placed on this continuum depends on the individuals' inner and external resources to cope with internal and external stress (Antonovsky, 1993). In a salutogenic approach, the focus is on health and health-promoting activities, to achieve a good life (Eriksson & Lindström, 2006).

1.5.1 Sense of coherence

Antonovsky's theory of Sense of Coherence (SOC) has been suggested as a possible explanation of the phenomenon that people with obvious severe illnesses still experience good health. The SOC comprises three core components that are closely woven together but theoretically separate and contains:

- 1) Comprehensibility – to what extent one's internal and external environments throughout life is predictable, structured and explainable
- 2) Manageability –to what extent a person has the experience of available inner or external resources to meet the demands life brings
- 3) Meaningfulness – to what extent these demands, brought by life, are challenges, worthy of investment and engagement (Antonovsky, 1987).

The components of SOC can be more or less present during different phases of life. A person can experience life manageable, but not explainable or meaningful, or life can be meaningful but not predictable and manageable (Antonovsky, 1987). A strong SOC is a way of making sense of the world that facilitates successful coping with the many complex stressors that confront us in the course of living (Antonovsky, 1993).

SOC is not the same as health, but is strongly related to good health and especially good mental health, and is an essential basis for individual development and maintenance of health (Eriksson & Lindström, 2006). Both quantitative and qualitative studies support the notion that a strong SOC contributes to a high quality of life (Eriksson & Lindström, 2007).

1.5.2 General Resistant Resources

In a salutogenic orientation, the metaphor "River of Life" is often used. It takes into account that life (the river) is full of risks, illness, and disease. While the stream force you down the river in the direction of disease, some factors help you not being drawn downwards. These factors can be both internal and external resources which promote health. These are called General Resistant Resources (GRRs). GRRs are prerequisites for the development of the SOC (Antonovsky, 1979, 1987; Eriksson & Lindström, 2007; Lindström & Eriksson, 2010). Some external GRRs can be education, preventive programs, public health system, and available medicine and cures, or more interpersonal resources as positive social relationships.

Although SOC is not seen as a personality trait, it is closely related to personal key resources that increase the ability to master stress and tension such as self-esteem, optimism and perceived control (Hobfoll, 2002; Pallant & Lae, 2002). Lindstrom and Eriksson (2010) highlight four GRRs to be at one's disposal in order to facilitate the development of a strong SOC. These are meaningful activities, existential thoughts, contact with one's inner feelings, and social relations.

1.5.3 Sense of coherence and psychopathology

Earlier studies have found associations between SOC and psychopathology. One study including 136 patients with schizophrenia or schizoaffective disorder, found an association between low SOC and high level of negative symptoms (Witkowska-Łuć, 2018). Another study with 120 patients, also with schizophrenia or schizoaffective disorder, showed an association between low SOC and high levels of positive, negative and affective symptoms including anxiety, guilt feelings, tension and depressive mood (Bengtsson-Tops & Hansson, 2001). Another study with 48 patients with schizophrenia showed that high level of delusions correlates with a low level of SOC (Bergstein, Weizman, & Solomon, 2008). The last study also showed that higher SOC scores at the "acute delusional state" predicted better prognosis concerning resolving the delusions (Bergstein et al., 2008).

Antonovsky also raised the issue that some people had what he called a fake or rigid SOC. This concept includes people who always report high SOC irrespective of circumstances, not because of a positive attitude to life, but by refusing to acknowledge facts (Antonovsky, 1987).

An example illustrates the three components *comprehensibility*, *manageability* and *meaningfulness*, and their potential associations to aspects of BSDs:

John works at a factory. When he comes to his job, he knows his tasks for the day. He knows the people he works with, and the payment is predictable. His job is to load containers with the products that are produced at the factory. He has the skills and the devices he needs to do this safely and correctly. His job is manageable. He knows that the products he prepares for sending are medicines that are important for thousands of people. He feels his job is important. This makes the job meaningful. John's work gives him high SOC.

The case could, however, be formulated differently: John could have a job where his engagement was temporary. Never knowing where to work, whom he works with or how much he got paid, he could be unsure to what extent he had the right competence and knowledge to manage the job. Not knowing why he does the thing he does, the job appears meaningless. In this situation, John's work gives him a low SOC.

We can take this example further into a case where the job in itself is not the problem, but where John is struggling with BSDs with psychotic qualities. He wonders; Is the factory real? Are his colleagues real people? Do they exist when he is not seeing them? Is the job he is

asked to do only a construction to set him up – testing him? Are the products the factory produces real products, or are they just fake things that no one needs? In this case, it is the BSDs and the psychosis that make the work (and probably the world) incomprehensible, challenging to manage and meaningless. The disorder contributes to a low SOC.

1.6. The baseline study

In 2008-2009, the baseline part of the study was carried out in two Norwegian counties (Hedmark and Oppland), with a county-wide population of 375,000 people. The baseline study included all patients who entered their first adequate treatment for a broadly defined psychotic disorder including schizophrenia, schizophreniform disorder and schizoaffective disorder, bipolar psychosis (bipolar disorder I and NOS – all with psychotic symptoms), and other psychotic disorders usually classified outside of the (narrow) schizophrenia spectrum (delusional disorder and psychosis NOS). The baseline study also included patients enrolled in a closely related study on young patients with psychosis born in 1985/86 (Bratlien et al., 2013). Except for the strict definition of coming to their first treatment, they met the same inclusion and exclusions criteria as the rest of the group. Inclusion criteria were: Age between 18 and 65 years and $IQ > 70$. Patients with substance use disorders were included, but they had to demonstrate at least one month without substance use or show clear signs that the psychotic disorder had started before the onset of significant substance use. All potentially eligible patients at all treatment services in the two counties were screened, and those who met the inclusion criteria and agreed to participate were included. A total of 91 patients were included in the baseline study - 73 patients from the first treatment cohort and 18 patients from the birth cohort. Later, one of the participants was taken out of the study because a review of illness history and symptoms indicated that the person had not met the criteria for a psychotic disorder. There is almost no private mental health care in Norway and no private health insurances, so all citizens independent of socioeconomic background get access to the same health care services. This ensured that the 90 patients included represented close to an epidemiological sample.

Diagnoses at baseline were: 57 participants (63%) met the DSM-IV criteria for schizophrenia, schizophreniform- and schizoaffective disorder, 20 participants (22%) met the criteria for a bipolar I or bipolar NOS disorders (all with psychotic features) and 13 participants (14%) met the criteria of other psychotic disorders (delusional disorder or psychosis NOS). All participants gave consents to be contacted again for the follow-up.

The main aim of the baseline study was to contribute to more knowledge about basic self-disturbances (BSDs) in the early stage of psychosis. One of the aims was to explore the interrater reliability of the EASE. The study concluded that the EASE provides a reliable and internally consistent clinical tool (Moller, Haug, Raballo, Parnas, & Melle, 2011).

Another finding from the baseline study was that the level of BSDs at that point of time discriminated between schizophrenia and both bipolar and other psychoses, with a significantly higher level of BSDs in schizophrenia than in bipolar and other psychoses (Haug, Lien, et al., 2012). In patients with schizophrenia, there were associations between a high level of BSDs and suicidality mediated by depression (Haug, Melle, et al., 2012). There was also found a relationship between a high level of BSDs and impaired verbal memory in schizophrenia (Haug, Oie, et al., 2012). In patients with schizophrenia and psychotic bipolar disorder, there was found an association between a high level of BSDs and social dysfunction (Haug et al., 2014). There was a significant association between childhood trauma and high level of BSDs in women in the early phase of schizophrenia (Haug et al., 2015). In the same group of women, it was also found a significant association between depression and BSDs, and this association was mediated by self-esteem (Haug et al., 2016). There was also a strong association between high levels of BSDs and long DUP in patients referred to their first adequate treatment for schizophrenia (Haug et al., 2017) For a more detailed description of the baseline study see Haug and colleagues (Haug, Lien, et al., 2012).

2 Aims of the thesis

The main aims of the studies comprised by this thesis were to investigate the stability of BSDs as measured by EASE seven years after first treatment for a psychotic disorder and to investigate if the level of EASE at baseline was a possible predictor of diagnostic changes (at follow-up). We also aimed to investigate the association between BSDs at baseline and follow-up and outcome, in particular the relation to recovery and to SOC.

2.1 Study I

The main aims of study I were thus to investigate:

- 1) The stability and changes in BSDs, at total and domain level, and the stability in diagnoses in relation to BSDs
- 2) Whether baseline levels of BSDs predict diagnostic change
- 3) Whether changes in the level of BSDs predict diagnostic change.

The hypotheses were: (1) Because BSDs are core features of schizophrenia, they may show minor individual fluctuations but are relatively stable at the group level. Based on findings from high-risk studies, we also hypothesised that particularly Domains 1 and 2 would show a high degree of stability. (2) High levels of BSDs at start of treatment in patients with psychotic disorder outside of the schizophrenia spectrum predict diagnostic change into schizophrenia seven years later, (3) An increase in BSDs over time in patients with a diagnosis outside the schizophrenia spectrum is associated with diagnostic change into schizophrenia.

The results of study I is presented in paper 1.

2.2 Study II

The main aims of study II were to investigate:

- 1) The relationship between BSDs at baseline, and clinical outcome with a particular focus on recovery.
- 2) The relationship between change in BSDs from baseline to follow-up and clinical outcome with a particular focus on recovery.

The main hypothesis was that low levels of BSDs at baseline would be associated with recovery.

The results of study II is presented in paper 2.

2.3 Study III

The main aims of study III were to investigate

- 1) The relationship between BSDs and SOC
- 2) To what extent a putative association between SOC and BSDs are mediated by clinical characteristics, including clinical symptoms, functioning, and diagnosis.

The main hypothesis was that patients with a high level of BSDs would experience low SOC.

The results of study III is presented in paper 3.

3 Methods

3.1 Design

This thesis is based on a prospective longitudinal study; a seven-year follow up of a cohort of first treated psychosis patients from two Norwegian counties, as part of the "Thematically Organised Psychosis" (TOP) study. Two of the papers investigate the development from baseline to follow-up, and are prospective longitudinal studies. The third paper is based on data collected in the follow-up study and is thus a cross-sectional study. The study is a quantitative study using structured and semi-structured interviews.

3.2 The Follow-up study

3.2.1 The participants

The baseline study and its participants is described in paragraph 1.6. All participants in the baseline study gave verbal consent to be contacted in case of a follow-up study. In the follow-up study, the patients were all invited through a letter giving written information about the study and informing that the researcher would make contact by phone in a few days' time.

Of the 90 patients included at baseline, 56 patients (62%) agreed to participate in the follow-up study. Of the people who did not participate in the follow-up study all 34 were alive, we were not able to get in contact with 15 of them, and 19 did not want to. Because of ethical reasons, we did not ask those who refused to participate why they did so.

Based on the measures made in the study, there was only one significant difference in the baseline demographic and clinical characteristics between those who participated and those who did not participate in the follow-up. There were higher scores in the participate-group than in the non-participate group for AUDIT (Alcohol Use Disorder Identification Test) (Table1).

Table 1 Group statistics and comparisons of central clinical and demographic measures at baseline, between those who did not and those who did participate in the follow-up study.

Group Statistics			t-test for Equality of Means				
			t	df	p-value	95% CI of diff.	
						Lower	Upper
Male (%)	Non participants	57%					
	Participants	50%					
Age (mean/SD)	Non participants	24.77/6.95	-0.19	88	0.85	-3.46	2.85
	Participants	25.07/7.58					
DUP (mean/SD)	Non participants	225.73/428.92	0.47	83	0.64	-112.3	182.2
	Participants	190.77/254.24					
EASE total score (mean/SD)	Non participants	20.11/12.35	0.74	89	0.46	-3.24	7.04
	Participants	18.21/11.77					
GAF symptom (mean/SD)	Non participants	41.34/12.67	1.49	88	0.14	-1.28	8.95
	Participants	37.51/11.40					
GAF function (mean/SD)	Non participants	38.71/10.73	0.04	88	0.97	-4.15	4.31
	Participants	38.64/9.23					
PANSS total score (mean/SD)	Non participants	70.29/19.04	-0.05	88	0.96	-8.09	7.68
	Participants	70.49/17.90					
CDSS total score(mean/SD)	Non participants	7.88/6.23	-0.41	86	0.68	-3.12	2.04
	Participants	8.42/5.70					
YMRS total score (mean/SD)	Non participants	5.71/4.99	0.41	88	0.68	-1.64	2.48
	Participants	5.29/4.67					
AUDIT total score (mean/SD)	Non participants	6.09/5.84	-2.07	87	0.04	-6.71	-0.14
	Participants	9.51/8.46					
DUDIT total score (mean/SD)	Non participants	2.18/5.59	-0.13	87	0.90	-3.06	2.68
	Participants	2.36/7.17					

The median follow-up period was 2579 days/7.5 years (range: 2362 - 2973 days). Five of the 56 participants had a follow-up period of eight years or more. An independent samples t-test showed that there were no significant differences between participants with less than seven and a half year and more than seven and a half year follow-up period, for central measures

including the EASE, SFS and PANSS total score at baseline and follow-up, and the SOC-13 core at follow-up. The same was the case for the participants with more than eight years follow-up period compared to the rest of the group.

3.3.2 Treatment during the follow-up period

During the follow-up period, the patients received treatment as usual in their local health services. This treatment most often contained regularly appointments with a therapist, receiving mental support and medication. Four patients had received structured psycho-educative treatment – one in a multi-family group. Seventeen had received cognitive behaviour therapy (CBT). Of the 56 patients in the follow-up study, near 80% had regular contact with general practitioners or specialists in mental health professions, and 40% were in regular contact with municipal health personnel. At follow-up 17 (49%) of the participants in the schizophrenia group (N=35) were on antipsychotic medication, 18 (51%) were on antidepressant medications, and 6 (17%) used lithium or antiepileptic as mood stabilisation. In the group with bipolar disorder (N=13), the numbers were 2 (15%), 2 (15%) and 5 (39%) respectively. In the group with other psychosis (N=8) 2(25%) used antipsychotic medication, 4 (50%) used antidepressant medications. There was no use of lithium or antiepileptic medications in the last group.

3.4 Collection of data

At baseline, the diagnoses were determined by two researchers who were experienced psychiatrists, and at follow-up, SCID-I diagnoses were determined by trained clinical psychologists or medical doctors. The psychiatrist/psychiatric residents and psychologist who did the diagnostic interviews at follow-up received supervision from experienced and specially trained psychiatrists.

At follow-up, all the assessments, except for the diagnostic interviews, were conducted by the author of this thesis.

All assessments personnel completed training programs including theory lessons, training sessions and scoring of international gold standard interviews. The training was based on the University of California Los Angeles (UCLA) program (Ventura, Liberman, Green, Shaner,

& Mintz, 1998) as part of the training program in the NORMENT centre and had access to supervision from the centre.

The interviews were mainly taking place in the patients' home or at the local district psychiatric centre - as chosen by the participant. At baseline, several of the participants were students and were staying in the study counties only temporarily. At follow-up, some had moved back to their home cities, and several had moved to the capital, Oslo. The participants in the follow-up were basically recruited from the whole of Norway, with clustering of participants living in the original two counties and Oslo.

Upon completion of the assessment battery, all participants received monetary compensation of NOK 500 (approximately €44 or US\$48).

3.4.1 Clinical assessments

The data were collected using standardised clinical instruments, structured, semi-structured and self-report questionnaires.

At baseline, all patients were evaluated with an extensive clinical assessment battery, and they were re-evaluated with the same battery in the follow-up study seven years later. At both baseline and at follow-up, the diagnoses were based on the Structured Clinical Interview for DSM-IV Axis I disorders (SCID module I, chapter A-E) (First, Williams, Spitzer, & Gibbon, 1996). Because we wanted to compare the results from the baseline and follow-up parts with a minimum of methodological changes, we decided to continue to use the DSM-IV even if DSM-5 had become available in 2013.

Present symptom severity and functional status were measured with the Global Assessment of Functioning scale, split version - symptom (GAF-S) and, function (GAF-F) (Endicott, Spitzer, Fleiss, & Cohen, 1976; Pedersen, Hagtvet, & Karterud, 2007).

Structured Clinical Interview for Positive and Negative Syndrome Scale (SCI-PANSS) was used for assessing current psychopathology (Kay, Fiszbein, & Opler, 1987). SCI-PANSS is a semi-structured interview with an aim to reveal positive (p-score), negative (n-score) and general symptoms (g-scores) in patients with psychoses. In paper 1 and 2, we used the PANSS original three-factor model. During the work with paper 3, we saw that using a five-factor model could give us a more nuanced description. The Wallwork and Fortgang five-factor model (W/F) is the PANSS five-factor models that have demonstrated the best

statistical model fit in this patient group (Langeveld et al., 2013). W/F contains 20 of the original 30 items organised into positive, negative, disorganised, excitement and depressive symptoms (Wallwork, Fortgang, Hashimoto, Weinberger, & Dickinson, 2012).

Calgary Depression Scale for Schizophrenia (CDSS) was used to assess symptoms of depression (Addington, Addington, & Schissel, 1990). CDSS is the most widely used scale for assessing depression in schizophrenia and discriminate better between depression, negative and positive symptoms in patients with schizophrenia than other depression inventories (Addington, Shah, Liu, & Addington, 2014).

Social functioning was assessed by the comprehensive 79-items self-report Social Function Scale (SFS) (Birchwood, Smith, Cochrane, Wetton, & Copestake, 2018). This scale is shown to be reliable, valid and sensitive in measuring social functioning both in schizophrenia and in bipolar disorder (Hellvin et al., 2010).

Substance use was assessed with the use of the self-report questionnaires Alcohol Use Disorder Identification Test (AUDIT) (Saunders, Aasland, Babor, de la Fuente, & Grant, 1993), and Drug Use Disorder Identification Test (DUDIT). Both AUDIT and DUDIT are found to be reliable and valid clinical- and research tools (Dybek et al., 2006; Hildebrand, 2015)

Premorbid functioning was measured using the Premorbid Adjustment Scale (PAS). PAS is designed to evaluate the degree of achievement of development goals of a patient's life before the onset of schizophrenia (Cannon-Spoor, Potkin, & Wyatt, 1982). The scale is found to be both reliable and valid in use in persons with schizophrenia and schizoaffective disorder (Brill, Reichenberg, Weiser, & Rabinowitz, 2008; Krauss, Marwinski, Held, Rietschel, & Freyberger, 1998).

Rosenberg Self-esteem Scale (RSES) was used to measure self-esteem. RSES is a 10 item self-report questionnaire. RSES is validated and used in several studies with psychotic patients (Torrey, Mueser, McHugo, & Drake, 2000).

Childhood Trauma Questionnaire, short-form (CTQ) was used to assess childhood trauma. The short form of CTQ is a 28-item self-report inventory based on the original 70-item version and is a relatively short screening of experiences of maltreatment before the age of 18 (Bernstein et al., 2003). CTQ is found to be a valid and reliable measure of early trauma both

in schizophrenia (Kim, Bae, Han, Oh, & Macdonald, 2013) and in bipolar disorder (Shannon et al., 2016).

Duration of Untreated Psychosis (DUP) was defined as numbers of weeks before the onset of psychotic symptoms (defined as the first week with scores of four or more on the PANSS items P1, P3, P5, P6, and G9) until the start of first adequate treatment (Melle et al., 2004).

PAS, CTQ and DUP were only measured at baseline.

We also registered following data from the follow-up period: education and work experience, economy, living situation and independence in everyday life, received treatment and family history of psychiatric illnesses, the course of the disease (duration of psychosis, depression, and mania), and physical health.

3.4.2 Assessment of self-disturbances

BSDs were assessed with the Norwegian version of the Examination of Anomalous Self Experience (EASE) manual. Assessing EASE demands an in-depth knowledge about BSDs, and the author needed a certification before using the EASE manual in research. This included a three-day course with phenomenological educated and experienced EASE raters. The author also rated videotaped EASE interview, and there were calculated interrater reliability (IRR) between the author and two experienced psychiatrists and certificated EASE instructors, Elisabeth Haug and Paul Møller. The training IRR demonstrated an average Cohen's kappa of 0.71, which is considered to be good. The author did five EASE interviews before the start of the study under the supervision of an experienced rater. Almost all EASE interviews in the study were videotaped. An IRR between the author and Haug was calculated for the first seven interviews in the study, with an average Cohen's kappa of 0.78. The author also got supervision on occasions when this was requested. Haug did the supervision.

EASE is a semi-structured interview and contains 57 main items and several sub-items. The items represent five domains 1) Cognition and stream of consciousness 2) Self-awareness and presence 3) Bodily experiences 4) Demarcation and transitivity 5) Existential reorientation (Parnas, Møller, et al., 2005). These domains are described in paragraph 1.3.4.

The EASE domains are highly intercorrelated, and the internal consistency is good to excellent (Nordgaard & Parnas, 2014; Møller et al., 2011; Raballo & Parnas, 2012). This

underpins the notion that the results of EASE must be seen as one Gestalt and not as single items or phenomenon.

The items are scored using a 5-point scale (0-4), 0= absent; 1= questionably present; 2= definitely present, mild; 3= definitely present, moderate; 4= definitively present, severe. The scores were dichotomised into 0 (absent and questionably present) and 1 (definitely present, all severity levels), in line with earlier publications using the EASE manual. Item 2.13 (anxiety) were not taken into the analysis, because this item does not represent a self-disturbance per se, but serves to as a contrast to the item ontological anxiety (2.14) (Parnas, Moller, et al., 2005).

3.4.3 Assessment of Sense of Coherence (SOC)

Antonovsky's theory is originally operationalised through a 29 items questionnaire (SOC-29). A shorter version (SOC-13) based on 13 items chosen from the SOC-29 was later presented by Antonovsky (Antonovsky, 1987). Each question is linked to one of the core components in the SOC, comprehensibility, manageability, and meaningfulness (Antonovsky, 1987).

In the current study, the SOC was measured by the SOC 13 items questionnaire (Antonovsky, 1987, 1993) a version modified and used in a part of a multi-centre study of patients in acute psychiatric units in Norway (Gråwe, Hatling, & Ruud, 2006) and a recently completed multi-community research project carried out by Innlandet Hospital Trust (results not published). The modified version has the same questions as the original version, but instead of a Likert scale from 1 to 7, there are five alternatives of answers scaled from 1 to 5. This simplification was made for making the scale more straightforward to understand for patients in crisis and with severe psychiatric problems. The last six questions have predefined answers at 1, 3, and 5, with the possibility to use 2 and 4. The possible range of the SOC score is 13 to 65. High scores indicate positive (good) results. In line with several other studies using SOC questionnaires (Eriksson & Lindström, 2005), this study handles the results from SOC-13 as continual measures.

The Comprehensibility score is the total score of question 1, 2, 3, 10, and 13. Manageability is the total score of question 4, 5, 6, and 12, and Meaningfulness contains the scores from question 7, 8, 9, and 11.

Both the original and the modified version of The SOC-13 questionnaires are shown in the appendix to paper 3.

Table 2 Overview of measurements by papers in the follow-up study

Measurement	Paper 1	Paper 2	Paper 3
EASE (Baseline)	X	X	
EASE (Follow-up)	X	X	X
SCID-I (Baseline)	X	X	
SCID-I (Follow-up)	X	X	X
SOC-13 (Follow-up)			X
DUP	X	X	
GAF Function (Baseline)	X	X	
GAF Function (Follow-up)	X	X	X
GAF Symptoms (Baseline)	X	X	
GAF Symptoms (Follow-up)	X	X	X
PANSS Positive, negative, general and total score (Baseline)	X	X	
PANSS Positive , negative, general and total score (Follow-up)	X	X	X
PANSS Wallwork/Fortgang five-factor model (Follow-up)			X
CDSS (Baseline)	X	X	
CDSS (Follow-up)	X	X	
SFS (Baseline)		X	
SFS (Follow-up)		X	X
AUDIT (Baseline)		X	
AUDIT (Follow-up)		X	
DUDIT (Baseline)		X	
DUDIT (Follow-up)		X	
RSES (Baseline)		X	
RSES (Follow-up)		X	
PAS Childhood Social function, (Baseline)		X	
PAS Childhood Academic function (Baseline)		X	
CTQ-SF (Baseline)		X	

3.5 Statistical analyses

SPSS version 23.0 (SPSS inc., Chicago, IL, USA) was used to perform all statistical analyses. The variables were explored for normality, extreme outliers, and missing values. In general, the mean and standard deviation were reported for continuous variables and percentages for categorical variables. Most continuous/ordinal data had an approximately normal distribution, and here primarily mean and standard deviation are reported. The exceptions were DUP, AUDIT and DUDIT. Here median and range is reported. In addition, the EASE total score had normal distribution but several EASE domain scores had not. For the EASE total, both means with standard deviation and median with ranges are reported (based on context). Correlations between variables were explored by Spearman or Pearson correlation according to the type of data.

Group comparisons for dichotomous variables were made using chi-square statistics, while group comparisons for continuous variables were evaluated with independent sample t-test for normally distributed data and Mann-Whitney U test for data without normal distribution.

In paper 1, we used the Wilcoxon sign rank test to test the changes between baseline and follow-up for the dichotomised EASE scores. McNemar's test for equal frequencies was used for exploring changes in the frequency of EASE items from baseline to follow-up. The level of significance was set to $p \leq 0.05$, two-sided.

In paper 2 the association between recovery and BSDs at baseline, and at follow-up, controlling for potential confounding variables, was investigated using multiple logistic regression analysis. The level of significance was set to $p \leq 0.05$, two-sided.

In paper 3 we explored associations and diagnostic group differences for the two variables of interest (SOC and BSDs) in addition to eight clinical characteristics with a potential influence on the association between SOC and BSDs. Six of these were partly interdependent symptom measures (PANSS scores and GAF-S), and two were partly interdependent measures of function (SFS and GAF-F) that also were influenced by symptoms. Based on this interdependence, a full Bonferroni correction would be too restrictive, and the level of significance was set to $p \leq 0.01$, two-sided.

4 Results

At follow-up 35 (63%) out of 56 participants were diagnosed with a DSM-IV diagnosis of schizophrenia (n=25) or schizoaffective disorder (n=10). As also done in the baseline study, these participants were merged into one group consisting of *schizophrenia spectrum disorders* and labelled *schizophrenia* (paper 1 and 2) or *SZspect* (paper 3). Twenty-one (37%) were diagnosed with other psychotic disorders (Bipolar I Disorder (n=13, Psychotic disorder, NOS (n=5) and Delusional Disorder (n=3)). Since we found no significant differences at clinical measures important for this study, these three diagnostic groups were merged into one group labelled *non-schizophrenia* (paper 1 and 2) or *NonSZspect* (paper 3).

4.1 Study I

4.1.1 Stability of BSDs

The main aims of study I were to investigate:

- 1) The stability and changes in BSDs, at total and domain level, and the stability in diagnoses in relation to BSDs
- 2) Whether baseline levels of BSDs predict diagnostic change
- 3) Whether changes in the level of BSDs predict diagnostic change.

At baseline, the schizophrenia group had a statistically significant higher EASE total score (median 22; range 4-45) than the non-schizophrenia group (median 7; range 0-31). At follow-up, we still found a statistically significant higher EASE total score in the schizophrenia group (median 14; range 0-38) than the non-schizophrenia group (median 5; range 0-22). At the group level, the results showed a statistically significant reduction in EASE total score in the schizophrenia group (Wilcoxon signed Ranked Test, z -value = -3.81, $p < 0.001$). The correlation matrix (fig. 1 in paper 1) demonstrates increases, as well as decreases, in EASE total score at the individual level. There was statistically significant reductions in all EASE domains, but less reduction in domain 1 (Cognition and stream of consciousness) and domain 4 (Demarcation and transitivity) than in the others (Wilcoxon Signed Ranked Tests.)

Further investigation showed that in the schizophrenia group, 91% had items from domain 1 present at both baseline and follow-up. The stability found in domain 4 was, on the other hand, based on an absence of items at both measure points. Forty-five per cent of the

participants had no domain 4 scores, neither at baseline nor at follow-up (see supplementary table Paper 1). Based on this, we concluded that domain 1 was the most stable of the EASE domains.

In the non-schizophrenia group, the changes in EASE total score from baseline to follow-up were not statistically significant (z-value -0.66, $p < 0.512$). There were also no significant changes from baseline to follow-up in the separate EASE domains in this group.

4.1.2 Stability of diagnosis and relation to BSDs.

Of the 56 participants in the follow-up study, 35 had a baseline diagnosis of a schizophrenia spectrum disorder, and 21 were diagnosed with a psychotic disorder outside the schizophrenia spectrum.

At baseline, 80% of the schizophrenia group had an EASE total score of ≥ 15 . In the non-schizophrenia group, only around 20% (four participants) had an EASE total score of ≥ 15 (range 15-31) at baseline. We were particularly interested in these four participants since we hypothesised that high levels of BSDs at start of treatment in patients with psychotic disorder outside of the schizophrenia spectrum would predict diagnostic change into schizophrenia spectrum disorders over time. We also hypothesised that an increase in BSDs over time in patients with a diagnosis outside the schizophrenia spectrum would be associated with diagnostic change into a schizophrenia spectrum disorder.

After a review of diagnosis at follow-up based on a new SCID-I interview, we found minimal diagnostic changes within the main diagnostic groups (Schizophrenia spectrum disorders, Bipolar Disorder with psychotic features, and Other psychosis including Psychotic Disorder, NOS and Delusional Disorder) and no changes between the main diagnostic groups. This lack of change of diagnosis from baseline to follow-up made it impossible to explore to what extent level of BSDs at baseline, and changes in BSDs from baseline to follow-up, predicted diagnostic changes. However, the lack of change in the small group of non-schizophrenia patients with a high level of BSDs indicated that the effect on diagnostic change was limited. It is of note that the researcher responsible for the EASE interview at follow-up did not participate in the diagnostic process and was blind to diagnosis both at baseline and follow-up.

4.2 Study II

4.2.1 BSDs and the relation to recovery

The main aims of study II were to investigate:

- 1) The relationship between BSDs at baseline, and clinical outcome with a particular focus on recovery.
- 2) The relationship between change in BSDs from baseline to follow-up and clinical outcome with a particular focus on recovery.

The main hypothesis was that low levels of BSDs at baseline would be associated with recovery.

The criteria for symptomatic remission was based on a PANSS score of 3 or lower for selected symptoms (PANSS items P1, P2, P3, N1, N4, N6, G5 and G9). The participant had to be in stable symptomatic remission for the last 24 months, combined with regaining significant functioning in areas corresponding to work or school activities equal to full-time work and reports of social activities at least once weekly to meet the criteria for recovery.

At follow-up, 34 out of the 56 participants (60%) were in stable symptomatic remission. In the schizophrenia group, 15 out of 35 (43%) were in stable symptomatic remission, and in the non-schizophrenia group, 19 out of 21 (91%) were in stable symptomatic remission.

Nineteen of the total sample of 56 (34%) meet the criteria for recovery. The recovery rate in the schizophrenia group was 14% (5 out of 35), and in the non-schizophrenia group, the rate of recovery was 67% (14 out of 21). A total of 15 participants were in stable symptomatic remission but without regained function.

The participants who were in stable symptomatic remission had a significant lower EASE total score at both baseline and at follow-up than those who were not in remission. The group in remission had at baseline an EASE total score at median 14 (range 0-40), and the non-remission group had a median of 21 (2-45). At follow-up, the numbers were 7 (0-7) vs 19 (5-38) (Mann-Whitney U test, all p 's < 0.01). The same pattern was seen for the achievement of recovery. The baseline EASE total score in participants who met the criteria for recovery had a median of 7 (range 0-40). In comparison, the group that had not recovered had a median of 21 (range 2-45). At follow-up, the recovered group had an EASE total score median of 5 (range 0-18) while the group not in recovery had a median 14 (range 2-38). Mann-Whitney U

tests showed that the differences in EASE total score between the recovery group and the non-recovery group were statistically significant at both baseline and follow-up (both p 's < 0.01).

Participants in recovery were also more likely to have a diagnosis outside the schizophrenia spectrum, to have a better premorbid function and shorter DUP compared to those who did not achieve recovery. These characteristics were also associated with a lower baseline- and follow-up EASE total score. Since we could not rule out that these characteristics cofounded or mediated the association between EASE and recovery, we conducted a hierarchical multivariate binary logistic regression analysis with full recovery (yes vs no) as the dependent variable. EASE total score baseline, EASE total score change (EASE baseline minus EASE follow-up), premorbid academic function, premorbid social function, DUP, and diagnosis were entered as independent variables. The final step of this analysis showed that only EASE total score baseline and EASE change had statistically significant contributions to the chances of being in recovery. A reduction in EASE total score from baseline to follow-up was the strongest predictor of recovery at follow-up.

4.3 Study III

4.3.1 BSDs and the relation to Sense of Coherence (SOC).

The main aims of study III were to investigate:

- 1) The relationship between BSDs and SOC
- 2) To what extent a putative association between SOC and BSDs are mediated by clinical characteristics, including clinical symptoms, functioning, and diagnosis.

This study of the relationship between BSDs and SOC was designed as a cross-sectional study, and only data from the follow-up study were used to investigate this aim.

We first compared the level of SOC (measured with the SOC-13) in the schizophrenia group (in the published article referred to as schizophrenia spectrum group/SZspect) with the level in the non-schizophrenia group (in the article referred to as outside of the schizophrenia spectrum group/non-SZspect) but did not find any statistically significant differences between the two groups. On the other hand, we found statistically significant differences between the diagnostic groups for EASE total score ($p < 0.01$), GAF symptom ($p < 0.001$), GAF function ($p < 0.001$), PANSS Positive Score (Wallwork and Fortgang's five-factor model (W/F))

($p < 0.001$), PANSS Dissociative (W/F) ($p < 0.001$) and PANSS item G12 (Lack of judgement and insight) ($p = 0.009$). The schizophrenia group had higher EASE total score, higher PANSS scores and lower GAF scores than the non-schizophrenia group.

We found a significant negative correlation (Pearson's r) between SOC-13 and EASE total score. There was also a statistically significant negative correlation between several of the three SOC components (Comprehensibility, Manageability, and Meaning) and the EASE domain scores. However, the EASE domain 4 scores had only statistically significant correlations with the SOC component Manageability, while EASE domain 5 scores had only statistically significant correlations with the SOC components Meaningfulness, in addition to the SOC-13 total score. We found an especially strong correlation between all the three components of SOC and domain 2, Self-awareness and presence (all p 's < 0.002).

We also found a statistically significant correlation (Pearson's r) between high levels of SOC and high GAF- S and - GAF-F, between high levels of SOC and low PANSS W/F Positive, Depressive and Excitement factors, and between high levels of SOC and good social functioning as measured with the SFS (all p 's < 0.01).

To disentangle to what extent clinical characteristics influenced the association between SOC and BSDs as measured by the EASE, we conducted multiple linear regression analysis. In this model, SOC was the dependent variable, while EASE total score, GAF-Symptom, GAF-function and diagnosis (schizophrenia versus non-schizophrenia groups) were entered as independent variables. We also entered the PANSS item G12 (Lack of judgment and insight) as an independent variable into the model to control for lack of insight. The result of this regression model was, that the association between SOC and EASE appeared as independent of diagnostic categories, and not mediated by neither the level of PANSS nor the level of social functioning. The diagnosis did, however, contribute independently to the levels of SOC in the regression model, but to a smaller degree than the EASE total score.

5 Discussion

5.1 Summary of main findings

The main findings from the study are:

5.1.1 Study I

- 1) In schizophrenia, we found a statistically significant decrease in EASE total score from baseline to follow-up. In the non-schizophrenia group, we found a stable low level of the EASE total score.
- 2) There were no changes between diagnostic groups (Schizophrenia versus Bipolar disorder and other psychosis) from baseline to follow-up, also in non-schizophrenia participants with high EASE total scores at baseline.

5.1.2 Study II

- 3) EASE total score at baseline was a significant predictor for recovery, also when controlled for differences in premorbid adjustment and DUP, and this was not confounded by diagnosis.
- 4) Reduction in EASE total score during the follow-up period was the strongest predictor of recovery also when controlled for differences in premorbid adjustment and DUP, and this was not confounded by diagnosis.

5.1.3 Study III

- 5) There was a strong association between low EASE total score at follow-up and subjective experience of good health at follow-up as measured by SOC-13. The association between SOC and EASE was independent of other clinical symptomatology, functioning, insight and diagnosis.

5.2 Discussion of main findings

Being human is not static – we change continually. These changes take place across the lifespan – they can be caused by biological ageing, social interaction, education, economy, and even accidents or diseases.

When the baseline study started, in 2008/2009, most of the participants were in their early twenties. Many of them had experienced symptoms of their illness for a short period when they participated in the study. At follow-up seven years later, they all had experienced several changes in their life, some related to their disorder and some related to other developments in life. This study explores some of these changes, changes in BSDs, changes in symptomatology, social and occupational function, and changes in diagnosis. We here particularly wanted to explore to what extent the status at baseline and changes that were seen seven years later, with a particular focus on BSDs, were associated with recovery as measured by standardised criteria, and subjective experience of health at the time of this study.

5.2.1 Stability and changes in BSDs

In study I, one aim was to discover to what extent BSDs were stable over the longer term. We found that BSDs were not as stable as expected from background theories (Nordgaard, Nilsson, et al., 2017; Parnas, Raballo, et al., 2011; Raballo et al., 2011). This was particularly the case in the schizophrenia group, where there were significant reductions in BSDs from baseline to follow-up in all EASE domains. In the non-schizophrenia group, the level of BSDs was significantly lower than in the schizophrenia group at both baseline and follow-up, with no significant changes between baseline and follow-up. Since the level of BSDs was low already at baseline, there was limited room for further reductions, but at group level, they did also not experience any increases.

The EASE manual was initially designed as a lifetime measure, and all questions were to be asked with a lifetime perspective: "Do you ever have/feel/experienced..." This was the way the manual was used at baseline. When planning the follow-up, we realised that this approach limited our ability to register changes. The lifetime approach would also include all BSDs experiences at baseline, and the only change we could register would be an increase. At follow-up, we thus decided to use the EASE to assess BSDs for the last two years before

follow-up. The shorter period for registering BSDs at follow-up could be the underlying basis for the reduction in BSDs that was seen at follow-up. Since we did not investigate the two years before baseline specifically, we do not know the developmental patterns of BSDs before baseline and cannot compare the exact same time-periods.

The high level of BSDs at baseline can also be explained by the fact that the participants at this point of time experienced their first psychotic episode. This is a period characterised by anxiety, stress and emotional arousal. An increase of BSDs in this period would be in line with the theory that some BSDs are secondary to stress (Borda & Sass, 2015; Sass & Borda, 2015).

At follow-up, most of the participants were in a stable phase of the disorder with a lower symptom pressure than at baseline. Many of the participants (59%) were even in full symptomatic remission. The participants additionally had more knowledge about the disorder and were more familiar with both their symptoms and where they could get help from the treatment services. It is thus plausible that BSDs secondary to the stressful situation at baseline had remitted at follow-up. A decreased frequency of BSDs in advanced illness stages is also expected from the theoretical basis for the EASE-manual (Parnas, Moller, et al., 2005). The findings of a decrease in BSDs over time do not necessarily contradict the notion that primary BSDs, specific to schizophrenia, are stable phenomena.

We found EASE domain 1 (Cognition and stream of consciousness) to be the most stable. Domain 1 also had the highest score at both points of measure, even after adjusting domain scores for the number of items in the domains. Domain 1 and domain 2 (Self-awareness and presence) are found to be the first BSDs that appears in the prodromal phase of schizophrenia spectrum disorders and were also found to be the most predictive of transition to psychosis in a treated Ultra High-Risk group (Nelson et al., 2012). The stability found in domain 1, together with its role as a strong predictor of transition to psychosis in high-risk groups, may indicate that disturbances in domain 1 are in particular basic- or core phenomena to schizophrenia. They are thus less affected by general symptom levels and less responsive to treatment.

The EASE-manual measures 56 different phenomena of BSDs, and it is in this context essential to have in mind that BSDs, in this theoretical approach, is seen as parts of one

Gestalt (Raballo & Parnas, 2012). This means one has to examine the pattern of BSDs reported, and not merely the sum-scores of its parts. Even if the total score of the EASE is the same, it is not necessarily the same BSDs that are reported at both time points.

When we examined the reports of phenomena at the item level, we found that some items were only present at baseline, some items that only were present at follow-up and some items that were either stably present or absent at both time points (see article 1, Supplementary table 1). Among the twelve most frequently reported items, we found five items that did not change significantly from baseline to follow-up. These were: Thought block, hyperreflectivity, cenesthetic experiences, thought interference and loss of thought ipseity (see article 1, Supplementary table 4). In the Danish study referred to previously (Nordgaard, Nilsson, et al., 2017), six of the twelve most common item did not show any significant change; Thought pressure, ruminations - obsession, diminished initiative, perceptualization of inner thought, and disorders of short-term memory (with EASE item 2.13 anxiety excluded) This indicates that even if the EASE total scores or the EASE domain sum-scores are not significantly changed, the content of the disturbances experienced i.e. the item scores can to some extent change. This is in line with the concept of BSDs as representing a gestalt. The observed changes at several levels over time indicates that it can be of interest to evaluate BSDs several times both in research and clinical settings.

5.2.2 Diagnostic stability and the relation to BSDs

One of the original aims of the study was to explore the role of BSDs for diagnostic stability. The participants were recruited at their first treated psychosis, i.e. at a time where clinical syndromes might not be fully formed (Castro-Fornieles et al., 2011; Kim et al., 2011). We thus expected to see diagnostic changes, as shown in previous studies of first-episode psychosis (Haahr et al., 2008; Parnas et al., 2011). We hypothesised that those in the non-schizophrenia group that experienced high levels of BSDs at baseline had a higher risk of converting to a schizophrenia spectrum disorder over the follow-up period.

Contrary to expectations, we found that none of the study participants had changed diagnostic group – from non-schizophrenia to schizophrenia or vice versa - during the follow-up period. The only diagnostic changes were changes *within* the broader diagnostic groups. A possible explanation of the limited diagnostic change could be the long DUP (median 105 weeks, range 5-1041). The reason for the long DUP could be, that the current study was carried out in

a rural area with very long distances to specialised psychiatric health services and consequently practical problems for early access. Previous studies of diagnostic stability (Haahr et al., 2008; Parnas et al., 2011) were conducted in urban areas and reported considerably shorter DUPs than what we observed. It is thus possible that any changes of symptoms leading to diagnostic change from baseline seen in the early treated phases of psychosis in short-DUP studies could have already taken place inside the long DUP period in the current study, thus limiting further diagnostic change.

We hypothesised that high level of BSDs at baseline in the non-schizophrenia group could predict conversion to a schizophrenia spectrum disorder at follow-up. Since 80% of the schizophrenia group at baseline had an EASE total score at ≥ 15 (range 15-45), we set the cut-off for "high levels of BSDs" at an EASE total score ≥ 15 in the non-schizophrenia group. Only four participants in the non-schizophrenia group had an EASE total score of ≥ 15 (range 15 – 31). Because of the lack of changes in diagnostic groups from baseline to follow-up, we were not able to show any associations between the level of BSDs and stability of diagnosis. Even if the numbers are small, it is of note that none of the four non-schizophrenia participants with high BSDs changed their diagnosis to a schizophrenia spectrum diagnosis.

5.2.3 BSDs and recovery

At a group level, we found more BSDs at baseline than at follow-up, and it was of considerable interest to explore if the baseline level of BSDs and changes in BSDs were related to changes in outcome. We thus also wanted to investigate to what extent BSDs were related to the possibility of remission of psychotic symptoms and recovery, including restoration of normal functioning. Using the Andreasen "Remission in Schizophrenia Working Group" criteria (RSWG-criteria) as a basis for remission, with the added requirement of return to functioning for recovery, we found similar levels of remission and recovery in our study as in other studies (Lally et al., 2017). Our analyses showed a statistically significant association between low levels of BSDs at baseline and recovery at follow-up. There was also a strong association between the degree of reduction in BSDs from baseline to follow-up, and recovery. These associations were independent of premorbid academic and social function, current social function and, most notably, not mediated by diagnostic group.

These results point to the fact that BSDs, with the associated loss of- or weakened ownership of one's thoughts, feelings, sensation, body movements or personal history, has an important impact on the person's life. The consequences of BSDs are in many ways self-evident: It's difficult to interact and be engaged in others if you feel that you are not a part of a shared world, or if you do not experience yourself as a human being. You will have reduced capacity to work or study if your thoughts feel strange to you, or if you feel that you are not thinking your thoughts or performing your actions. A weak social understanding caused by BSDs can lead to minimal or restricted social interactions, which in turn can increase the level of poor social understanding in a negative spiral (Haug et al., 2014). Even phenomena that are linked to a person's inner life and hidden to others can thus affect relationships and engagements with the world (Nelson et al., 2009), and lead to a reduced capacity to study, work or maintain self-care. Other studies, including the baseline part of the current, have also shown associations between BSDs and clinical- or cognitive symptoms including self-esteem and depression (Haug et al., 2016), suicidality (Haug, Melle, et al., 2012), verbal memory (Haug, Oie, et al., 2012) and negative symptoms (Nordgaard, Nilsson, et al., 2017). We do not know the direction of all these associations, but the finding demonstrates the burden associated with BSDs.

According to the ipseity disturbance model (Nelson, Parnas, & Sass, 2014; Sass & Parnas, 2003), BSDs are seen as vulnerability factors and serves as precursors for the development of psychotic symptoms. Changes in the level of BSDs may thus lead to changes both in symptoms and in functioning. As shown in paper 1, BSDs have the potential for change, and as shown in paper 2, we found a significant association between recovery and a reduced level of BSDs at follow-up on top of lower levels of BSDs at baseline. This finding was not explained by diagnosis. Since BSDs are basic symptoms and occur before frank psychotic symptoms, it is plausible to think that it is the BSDs that are generating psychosis, and not that changes in symptoms that influence BSDs. This raises the possibility that interventions aimed at reducing BSDs could influence the outcome.

This study shows that most of the participants had less symptoms and better function seven years after their first treatment for a psychosis. We do not know to what extent BSDs were taken into the therapeutic interventions the participants were offered, but the fact that BSDs was assessed and given attention to early in their treatment could influence on the therapeutic content. Some factors that we know are important for recovery are; positive relationship to the therapist (Norcross & Lambert, 2011), support from family and other important persons

(McFarlane, Dixon, Lukens, & Lucksted, 2003), adequate medication (Lally & MacCabe, 2015), and employment (Evensen et al., 2017; Rinaldi et al., 2010). Such positive factors together with attention and dialog related to BSDs could have had an effect on the recovery process. Since this is not an intervention study, our follow-up data does not contain any information about treatment at this level of detail.

5.2.4 BSDs and sense of coherence

The concept of full recovery implies that the person does not experience severe symptomatology, and that social and occupational capacity is not affected by the disorder. However, the concept does not capture the person's subjective experience of health. In the third part of the study, we thus wanted to explore aspects of the subjective experience of health, despite levels of symptoms and functional loss. The concept of SOC offers an ability to assess to what extent the person experience life as comprehensive, predictable and meaningful. From a salutogenic point of view, a high SOC helps the person to experience health, while a low SOC pushes the person in the direction of experience of dis-ease. We found a robust association between the SOC-13 score and the EASE scores. This association was independent of clinical symptoms, functioning, insight and diagnostic categories.

Could this finding be explained by the SOC-13 and the EASE measuring the same phenomenon? There are some questions in SOC -13 and in the EASE that are quite similar at first view. However, while SOC-13 is a short self-report questionnaire, the EASE is an extensive manual where the interviewer tries to capture the core of an experience through a personal interview. The SOC-13 asks: "How often does it happen that you are surprised by the behaviour of people whom you thought you knew well?" In other words: How predictable is the world to you? The EASE instead asks for experiences where the person's thoughts, ideas, body or history feels strange, unfamiliar and unpredictable.

The SOC-13' questions are related to the person's trust in other people, trust in themselves and to how they manage life. These questions are closely linked to the psychological concepts of self-esteem and self-image. According to the theory of different levels of self (the basic/pre-reflective and the narrative level of self (Gallagher, 2000; Sass & Parnas, 2003; Ritsner & Gottesman, 2011; Zahavi, 2002; Zahavi 2005;) the concepts of self-esteem and self-image are placed in the higher and most complex level of the self - the narrative level of self. The EASE, on the other hand, is focused on disturbances at the pre-reflective and the

most basic level of self. Based on this, the SOC-13 and the EASE assess changes and disturbances at different levels of the self. We do not know the direction of the association between BSDs and SOC, but according to both Nelson et al. (2014) and Zahavi (2005) it is natural to think that changes in the more basic pre-reflective self will disturb the narrative level of the self. From this point of view, it is reasonable to hypothesise that high levels of BSDs may lead to a poor SOC.

Antonovsky describes persons with what he called *a false or rigid SOC*. He did not particularly focus people with a severe psychiatric illness in this context, but we know that for some patients with these disorders being sick or needing treatment it is difficult to accept (Mintz, Dobson, & Romney, 2003; Pousa et al., 2017). Lack of judgement and loss of insight could influence SOC-13 levels and impact on the association between SOC and BSDs. We thus statistically controlled for lack of insight and judgement, by entering the PANSS item G12 (lack of judgement and insight) into the regression model. This indicated that although some participants to some extent showed lack of judgement and insight as measured on the PANSS, this did not have a statistically significant influence on the association between BSDs and SOC.

In paper 1 (Stability in basic self-disturbance and diagnosis), we found the highest stability of BSDs in domain 1 (Cognition and stream of consciousness) and discussed whether the phenomena comprised by Domain 1 could be more stable, fundamental trait phenomena in schizophrenia than those comprised by other domains and with subsequent more limited response to treatments. It was, therefore, natural to assume that domain 1 would be more strongly associated with the subjective experience of health as measured by SOC-13.

However, we found an especially strong association between low SOC-13 and high levels in EASE domain 2 (Self-awareness and presence). A possible explanation of this finding could be that domain 2 explores areas such as a diminished sense of basic self, distorted first-person perspective and loss of common sense. If these basic feeling of being a person, of owning own experiences and making sense of the world is diminished, it is difficult to understand what happens both in your mind and in the external world. Disturbances in domain 2 can also give a feeling of not existing, or having a distance to other people and the world. Such experiences can induce existential loneliness with a significant influence of the experience of life as meaningful.

The correlational nature of the association between SOC and BSDs gives neither firm conclusion of the direction of the associations nor indications of causality. Even if it is reasonable to assume that BSDs affect SOC, it is also possible that SOC affects BSDs. Since SOC can be seen as related to the narrative level of the self, this could be more available to interventions than the more basic BSDs. This is in line with studies showing that SOC-focused therapy has positive results in patients with mental health problems, including psychotic symptoms (Langeland et al., 2006). However, no studies have been measuring BSDs in this context.

5.2.5 The role of BSDs in early psychosis

BSDs are seen as precursors of psychotic disorders, particularly schizophrenia (Nelson et al., 2012). Both schizophrenia spectrum disorders, delusional disorders and severe mood disorders share a propensity for psychotic symptoms. Even if the experience of psychosis can be described through first-person accounts and in literature, movies, painting and other types of art it is however difficult for others to fully understand psychotic phenomena and their associated suffering.

BSDs are phenomena which are not common in the general population. We often lack words to describe these phenomena, and they are thus not something those who experiencing them can easily talk about. This can also contribute to loneliness among patients with BSDs. A phenomenological approach may give us a better understanding (Sass & Parnas, 2003). Through assessments tools such as the BSABS (Gross et al., 1987) and the EASE-manual (Parnas, Moller, et al., 2005), evaluations of BSDs have been operationalised and a common language has been made available for communications between patients and therapists.

As a clinical psychiatric nurse, using the EASE-manual in interviews has given me an opportunity to achieve a common language with these patients; a possibility for increased communication and help to verbalise experiences of BSD phenomena. By verbalising the experiences, their experiences are partly moved from a pre-reflective level to a reflective/narrative level. This can help the patient improve self-understanding, and increase the experience of coherence in life.

There are however no current therapeutic approaches that are aimed specifically to reduce BSDs. Our findings indicate an association between the level of BSDs at start of treatment together with subsequent reduction in BSDs, and core areas of outcome such as recovery and subjective experience of health. If it is possible to develop interventions that reduce the levels of BSDs in the early phases of psychosis, this could potentially have important implications for outcome.

Also, by identifying and communicating the patients' experience of BSDs, we can also help the network around the patient; professionals, relatives, and friends, to better understand the inner struggle they are facing and explain some of their bizarre behaviour and delusions. Knowledge increases the possibility of empathy. To cite Søren Kierkegaard: "If one is truly to succeed in leading a person to a specific place, one must first and foremost take care to find him where he is and begin there. This is the secret in the entire art of helping" (Kierkegaard, Hong, & Hong, 1998 p 45).

5.3 Discussion of methodological issues

Specific methodological issues regarding the EASE and interpretation of study findings are discussed in the general discussion. The following discussion focuses on more general methodological considerations.

5.3.1 Sample representatively

The sample in this study is a cohort recruited from a naturalistic clinical setting. All treatment facilities in two neighbouring Norwegian counties were involved in the recruitment of participants to the baseline study. In Norway, the public Health system offers treatment to all individuals with a need for mental care. There are very few private mental health care units, so socioeconomically bias is not assumed to be an issue for the sample.

Of the 90 initial participants at the baseline study, 56 (62%) participated in the current follow-up. Other comparable follow-up studies have shown participation rates similar to the current study (Gardsjord et al., 2016 (10 year/68%), Nordgaard, Nilsson et al., 2017 (5 year/65%), Parnas et al., 2011 (5 year/64%)).

A thorough analysis of missing cases did not reveal any important differences between the group who participated in the follow-up study and the group that did not participate. This

includes a lack of statistically significant differences in essential clinical features, including the level of BSDs and diagnosis and we assume that the sample at follow-up is representative of the initial sample at baseline (See table 1 in paragraph 3.2.1).

It is difficult to recruit to follow-up studies, and participants do not always want to come in for interviews when it suits the time plan of a study. The median follow-up period was 2579 days/7.5 years (range: 2362 - 2973 days), i.e. with more than one year between the shortest and longest follow-up length. There were not found any statistically significant differences between those with a short or a long follow-up period.

5.3.2 Reliability and validity of main assessments.

This study is a quantitative study, using well-known instruments with established good psychometric properties. The phenomena evaluated are however based on the subjective experience of the study participants. The researcher asks the questions in the interviews, the questions are then interpreted by the participant and responded to, and the researcher then interprets the answer and quantified. This could lead to mis-interpretations and biased data. Good standards of training in the use of these assessments and testing of reliability between raters reduce these errors. Using structured and semi-structured interviews, we ensure that an agreed-upon minimum of data is gathered systematically. However, structured interviews may ignore important questions and information that is of importance to the participants.

The focus of this study is BSDs, which were assessed with the Norwegian interview guide to the EASE-manual (Parnas, Moller, et al., 2005). At baseline, BSDs were assessed by an experienced psychiatrist, and the tapes from the interviews were rated blindly to scorings by one of the original scale constructors. The inter-rater reliability (IRR) for the baseline EASE assessments was found to be very good (Moller, et al., 2011), and in line with other studies of the reliability of BSDs using the EASE (Nelson et al., 2012; Raballo & Parnas, 2012). In the follow-up study, BSDs were assessed by the author of this thesis, after comprehensive training in using EASE. The training included a three days introductory course, followed by supervision from two experienced psychiatrists and two certified EASE instructors. During training, videotaped EASE interviews were rated by the authors and the instructors. The training IRR demonstrated an average Cohen's kappa of 0.71, which is considered to be good.

The first seven EASE interviews were also rated separately by the author and the rater of the baseline interviews. The IRR testing showed Cohen's kappa of 0.78. The IRR of the EASE interviews thus appears good, with limited differences between the evaluator at baseline and follow-up.

The diagnostic evaluation both at baseline and follow-up was done by either psychiatrist, psychiatric residents or clinical psychologists using the SCID-I for DSM-IV. All interviewers were trained through the same training program used at the Semel Institute of the University of California Los Angeles (UCLA) including IRR tests (Ventura et al., 1998). The author of the thesis did not participate in the diagnostic interview to ensure blindness between the EASE evaluation and diagnostics. The author was responsible for the follow-up symptom evaluation, using the structured interview for the PANSS (SCI-PANS), after completing the NORMENT/ TOP training program which included theoretical background, scoring of training videotapes with included reliability check.

The sense of coherence was measured with the SOC-13 self-report questionnaire. SOC-13 has shown a high level of validity and reliability (Eriksson & Lindström, 2005), and internal consistency is found to be very good with a Cronbach's alpha ranging from 0.70 to 0.92 in 127 studies using SOC-13 (Antonovsky, 1993; Eriksson & Lindström, 2005). We used a modified version of SOC-13 previously used in sub-study of a multi-centre study of patients in acute psychiatric units in Norway. The strength of this version is the predefined answers and that all answers are asked the same direction. It makes the form easier to understand. The modified SOC-13 questionnaire with its predefined answers could however also give less nuanced data than the original form with a seven-point Likert scale.

Long-term memories tend to be reconstructed and reinterpreted to reflect the person's current situation. It can also be difficult to remember the timing of events or experiences if they are not linked to other events (Menard, 2002). Cognitive deficits, including impaired memory are often seen in patients with psychosis and give recall-bias (Brill et al., 2003). In this study, we asked for information about previous experiences of several phenomena and symptoms, and information about relations to other people, social activity and occupational capacity. This requires good access both short - and long-time memories. Except for the SCID-I interview, which assessed lifetime experience, the most extended period we explored was the last two

years. The possibility of recall bias for interview data must thus be taken into account despite good inter-rater reliability.

5.3.3 Strengths and limitations of the study

The patient sample was broadly recruited with few exclusions criteria and represent a comprehensive, near to epidemiological sample.

The follow-up period was seven and a half year and is to our knowledge the most extended follow-up study of BSDs using the EASE instrument at both time-points.

The person who conducted the assessments of BSDs at follow-up was blind to baseline data and the results of the diagnostic interviews at follow-up.

The study uses a strict and commonly used definition of stable symptomatic remission ("Remission in Schizophrenia Working Group" -criteria), with the addition of social and occupational function equal to a full-time job or studies the last two years to fulfil the criteria of recovery. The criterion of two-year stability ensure that recovery is stable.

Only fifty-six of the original 90 (62%) agreed to participate in the follow-up. This is a lower participation rate than initially aimed at, despite persistent attempts to re-recruit.

The low rate of diagnostic change made it impossible to study to what extent the level of BSDs in the early phase of a psychotic disorder was related to diagnostic changes at follow-up.

5.4 Implications and questions for further research

BSDs appears to have a negative association with peoples' mental health. The links we here found between BSDs, clinical symptoms and function on the one hand, and between BSDs and the person's experience of life as predictable, manageable and meaningful on the other, underlines the importance of these phenomena. Our finding of reductions in the level of

BSDs over time gives an optimistic view of the possible effects of an intervention aimed at BSDs. Since BSDs are considered as core features/symptoms of the disorder, it is an exciting thought that an intervention targeting these core symptoms could be especially effective. Yet, as far as we know there are no systematically intervention especially targeting BSDs and further research in this area is needed.

However, there may be several ways of helping the patients to manage and reduce the level of BSDs. Already established interventions as Cognitive Behavior Therapy and Psycho-Educative Interventions could potentially have an effect, but this is not systematically evaluated. Still, if the clinicians know the BSDs experienced by the patients, it will give valuable information about their inner world, and increase the possibility to understand their symptoms and their behaviour regardless of the type of interventions offered.

Larger studies could help investigate the role of BSDs for diagnostic change in the early phases of psychotic disorders. New longitudinal studies could also give valuable knowledge to the questions of primary and secondary BSDs, by including measures related to the experience of crisis and of other putative factors increasing risks of secondary BSDs.

5.5 Ethics

The study protocol was approved by the Regional Committee for Medical Research Ethics. All participants provided informed consent to participate at both the baseline and the follow-up study. The study has been conducted in full accordance with the World Medical Association's Declaration of Helsinki.

6 Conclusion

We found a statistically significant decrease in BSDs from baseline to follow-up in participants with a schizophrenia spectrum disorder. This indicates that BSDs weaken over time and that currently unknown individual characteristics may influence the progress of BSDs.

There were no changes in the initially low level of BSDs in the non-schizophrenia group. We also were unable to find any associations between levels of BSDs and diagnostic change, due to a high degree of diagnostic stability.

Low baseline levels of basic self-disturbances and further reductions over time independently predict recovery seven years later in a group of first-treated psychosis patients. These findings were not confounded by premorbid academic function, premorbid social function, DUP or diagnosis.

A statistically significant association between BSDs and SOC indicates that the presence and level of self-disturbances may influence the person's ability to experience life as comprehensive, manageable and meaningful. This association was not influenced by diagnostic, clinical symptoms or level of functioning. However, the cross-sectional nature of the study precludes conclusions regarding the direction of this association.

7 References

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8 Appendix

EASE Item Key List

Domain 1. Cognition and stream of consciousness

- 1.1 Thought interference
- 1.2 Loss of thought ipseity
- 1.3 Thought pressure
- 1.4 Thought block
 - 1.4.1 Subtype 1: blocking
 - 1.4.2 Subtype 2: fading
 - 1.4.3 Subtype 3: combination
- 1.5 Silent thought echo
- 1.6 Ruminations-obsessions
 - 1.6.1 Subtype 1: pure rumination
 - 1.6.2 Subtype 2: secondary rumination
 - 1.6.3 Subtype 3: true obsessions
 - 1.6.4 Subtype 4: pseudo-obsessions
 - 1.6.5 Subtype 5: rituals/compulsions
- 1.7 Perceptualization of inner speech or thought
 - 1.7.1 Subtype 1: internalized
 - 1.7.2 Subtype 2: equivalents
 - 1.7.3 Subtype 3: internal as first-rank symptom
 - 1.7.4 Subtype 4: external
- 1.8 Spatialization of experience
- 1.9 Ambivalence
- 1.10 Inability to discriminate modalities of intentionality
- 1.11 Disturbance of thought initiative/intentionality
- 1.12 Attentional disturbances
 - 1.12.1 Subtype 1: captivation by details
 - 1.12.2 Subtype 2: inability to split attention
- 1.13 Disorder of short-term memory
- 1.14 Disturbance of time experience
 - 1.14.1 Subtype 1: disturbance in subjective time
 - 1.14.2 Subtype 2: disturbance in the existential time (temporality)
- 1.15 Discontinuous awareness of own action
- 1.16 Discordance between expression and expressed
- 1.17 Disturbance of expressive language function

Domain 2. Self-awareness and presence

- 2.1 Diminished sense of basic self
 - 2.1.1 Subtype 1: early in life
 - 2.1.2 Subtype 2: from adolescence
- 2.2 Distorted first-person perspective
 - 2.2.1 Subtype 1: mineness/subjecthood
 - 2.2.2 Subtype 2: experiential distance
 - 2.2.3 Subtype 3: spatialization of self
- 2.3 Psychic depersonalization (self-alienation)
 - 2.3.1 Subtype 1: melancholiform depersonalization
 - 2.3.2 Subtype 2: unspecified depersonalization
- 2.4 Diminished presence
 - 2.4.1 Subtype 1: not being affected
 - 2.4.2 Subtype 2: distance to the world
 - 2.4.3 Subtype 3: as subtype 2 plus derealization
- 2.5 Derealization
 - 2.5.1 Subtype 1: fluid global derealization
 - 2.5.2 Subtype 2: intrusive derealization
- 2.6 Hyperreflectivity; increased reflectivity
- 2.7 I-split
 - 2.7.1 Subtype 1: I-split suspected
 - 2.7.2 Subtype 2: 'as if' experience
 - 2.7.3 Subtype 3: concrete spatialized experience
 - 2.7.4 Subtype 4: delusional elaboration
- 2.8 Dissociative depersonalization
 - 2.8.1 Subtype 1: 'as if' phenomenon
 - 2.8.2 Subtype 2: dissociative visual hallucination
- 2.9 Identity confusion
- 2.10 Sense of change in relation to chronological age
- 2.11 Sense of change in relation to gender
 - 2.11.1 Subtype 1: occasional fear of being homosexual
 - 2.11.2 Subtype 2: a feeling as if being of the opposite sex
- 2.12 Loss of common sense/perplexity/lack of natural evidence
- 2.13 Anxiety
 - 2.13.1 Subtype 1: panic attacks with autonomous symptoms
 - 2.13.2 Subtype 2: psychic-mental anxiety
 - 2.13.3 Subtype 3: phobic anxiety
 - 2.13.4 Subtype 4: social anxiety
 - 2.13.5 Subtype 5: diffuse, free-floating pervasive anxiety
 - 2.13.6 Subtype 6: paranoid anxiety

- 2.14 Ontological anxiety
- 2.15 Diminished transparency of consciousness
- 2.16 Diminished initiative
- 2.17 Hypohedonia
- 2.18 Diminished vitality
- 2.18.1 Subtype 1: state-like
- 2.18.2 Subtype 2: trait-like

Domain 3. Bodily experiences

- 3.1 Morphological change
 - 3.1.1 Subtype 1: sensation of change
 - 3.1.2 Subtype 2: perception of change
- 3.2 Mirror-related phenomena
 - 3.2.1 Subtype 1: search for change
 - 3.2.2 Subtype 2: perception of change
 - 3.2.3 Subtype 3: other phenomena
- 3.3 Somatic depersonalization (bodily estrangement)
- 3.4 Psychophysical misfit and psychophysical split
- 3.5 Bodily disintegration
- 3.6 Spatialization (objectification) of bodily experiences
- 3.7 Cenesthetic experiences
- 3.8 Motor disturbances
 - 3.8.1 Subtype 1: pseudo-movements of the body
 - 3.8.2 Subtype 2: motor interference
 - 3.8.3 Subtype 3: motor blocking
 - 3.8.4 Subtype 4: sense of motor paresis
 - 3.8.5 Subtype 5: desautomation of movement
- 3.9 Mimetic experience (Resonance between own movement and others' movements)

Domain 4. Demarcation/transitivism

- 4.1 Confusion with the other
- 4.2 Confusion with one's own specular image
- 4.3 Threatening bodily contact and feelings of fusion with another
 - 4.3.1 Subtype 1: feeling unpleasant, anxiety provoking
 - 4.3.2 Subtype 2: feeling of disappearance, annihilation
- 4.4 Passivity mood
- 4.5 Other transitive phenomena

Domain 5. Existential reorientation

- 5.1 Primary self-reference phenomena
- 5.2 Feeling of centrality
- 5.3 Feeling as if the subject's experiential field is the only extant reality
- 5.4 'As if' feelings of extraordinary creative power, extraordinary insight into hidden dimensions of reality, or extraordinary insight into own mind or the mind of others
- 5.5 'As if' feeling that the experienced world is not truly real, existing, as if it was only somehow apparent, illusory or deceptive
- 5.6 Magical ideas linked to the subject's way of experiencing
- 5.7 Existential or intellectual change
- 5.8 Solipsistic grandiosity

Table 1 (appendix)

The eight most stable EASE items among the 13 most frequent EASE items in the schizophrenia group by the studies of Nordgaard, Nilsson et al. (2017) and Svendsen et al. (2018), based on the results of McNemar 2-sided exact p of results from baseline and follow-up

Nordgaard, Nilsson et.al (2017)	McNemar 2-sid exact P	Svendsen et al. (2018)	McNemar 2-sid exact P
Ambivalence (item 1.9)	1	Cenesthetic experiences (item 3.7)	0.51
Primary self-reference (item 5.1)	1	Thought interference (item 1.1)	0.45
Perceptualization of inner thought (item 1.7)	0.58	Thought block (item 1.4)	0.45
Thought pressure (item 1.3)	0.34	Hyperreflectivity; increased reflectivity (item 2.6)	0.27
Diminished initiative (item 2.16)	0.27	Loss of thought ipseity (item 1.2)	0.17
Rumination –obsession (item 1.6)	0.13	Rumination – obsession (item 1.6)	0.04
Hypohedonia (item 2.17)	0.06	Perceptualization of inner thoughts (item 1.7)	0.04
Diminished sense of basic self (item 2.1)	0.01	Diminished initiative (item 2.16)	0.01
Item 2.13 (anxiety) are not taken into the table			

9 Papers 1- 3

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Stability in basic self-disturbances and diagnosis in a first treated psychosis: A seven year follow-up study

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ABSTRACT

Background: Basic self-disturbances (BSDs) are considered core features of schizophrenia spectrum disorders, and are present in the prodromal, early psychotic and chronic phases. Considerable levels of BSDs are also present at first treatment in some patients with psychotic disorders outside the schizophrenia spectrum. There is limited knowledge about the stability of self-disturbances over time.

Aim: To explore the stability of BSDs in a seven-year follow-up of first treatment patients, and the association between baseline levels and changes in BSDs and diagnostic changes at follow-up.

Method: Longitudinal study of 56 patients (35 schizophrenia and 21 non-schizophrenia) recruited at their first treatment for a psychotic disorder. BSDs were assessed using the Examination of Anomalous Self-Experience (EASE), while diagnostic categories, clinical symptom severity, and functioning were assessed with standard clinical instruments.

Results: The schizophrenia group had significantly lower levels of BSDs at follow-up compared to baseline. The EASE domain “Cognition and stream of consciousness” was the most stable. There were no diagnostic changes into or out of schizophrenia spectrum. Patients with schizophrenia had significantly higher levels of BSDs both at baseline and at follow up than patients with psychotic disorders outside the schizophrenia spectrum, who showed stable low levels.

Conclusion: We found a decrease and thus less stability in BSDs in schizophrenia than expected. This might indicate that BSDs tend to weaken over time, and that unknown individual characteristics may influence the development of BSDs. Diagnostic stability from baseline to follow-up may be due to long DUP before service entry.

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1. Introduction

Basic self-disturbances (BSDs) selectively aggregate in schizophrenia spectrum disorders and are thus considered to be core features of the schizophrenia spectrum (Haug et al., 2012a; Henriksen and Parnas, 2014; Nordgaard and Parnas, 2014; Sass and Parnas, 2003). BSDs are non-psychotic subtle disturbances of the person's spontaneous experience of him-/herself as a vital subject, naturally immersed in the

world. BSDs affect the person's fundamental level of consciousness, the sense of corporeality, stability of self-experience and ‘grip’ on the world (Parnas and Handest, 2003). Typical descriptions of experiences are statements like “It is almost as I am not thinking my own thoughts”, “I have lost something that seems natural for everybody – I have lost the manual for understanding life.”

BSDs are in this context not considered as sequelae of psychosis, but instead seen as representing fundamental and potentially generative layers of psychopathology (Nordgaard and Parnas, 2014).

Stimulated by two Scandinavian qualitative studies (Møller and Husby, 2000; Parnas et al., 1998), recent studies have confirmed high levels of BSDs in prodromal/Ultra High Risk (UHR) (Comparelli et al., 2016; Koren et al., 2016; Koren et al., 2013; Koren et al., 2017; Nelson et al., 2012; Parnas et al., 2011; Raballo et al., 2016), early psychotic (Haug et al., 2012b; Nordgaard and Parnas, 2014) and chronic phases

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of schizophrenia (Raballo et al., 2011). Additional findings of BSDs in a study of children at high risk for schizophrenia support the notion that BSDs are part of a core vulnerability for developing schizophrenia (Parnas et al., 2016). In an Ultra High Risk group, BSDs were primarily seen in the domains “Cognition and stream of consciousness” (Domain 1) and “Self-awareness and presence” (Domain 2). The presence of BSDs in “Cognition and stream of consciousness” were also found to be the most predictive of transition to full-threshold psychosis (Nelson et al., 2012). Studies assessing BSDs in bipolar I disorder (Haug et al., 2012b) and in severe depersonalization (Sass et al., 2013) found both lower levels and a narrower range of BSDs in these disorders than in schizophrenia. Recent additions to the concept of BSDs are theories suggesting that while some BSDs are fundamental and core to schizophrenia (i.e. primary BSDs), others may be more consequential, compensatory or an attempt at coping (e.g., as a response to traumatic environmental circumstances; secondary BSDs) (Borda and Sass, 2015; Sass et al., 2018; Sass and Borda, 2015).

In clinical practice, diagnoses are based on cross-sectionally- and historically reported symptoms. Since the clinical syndromes might not be fully formed at first treatment contact, diagnoses can change over time (Castro-Fornieles et al., 2011; Kim et al., 2011). This change may reflect the natural evolution of the disorder and/or new sources of information regarding the quality and quantity of initial symptoms (Schwartz et al., 2000). A study that examined diagnostic stability in first episode psychosis patients found that 11 out of 42 patients (26%) diagnosed with a mood disorder (major depression, bipolar I and II) with mood incongruent psychotic features in the first weeks of treatment had their diagnoses changed to schizophrenia or schizoaffective disorder over the next one to two years (Haahr et al., 2008). Another five-year follow-up study of first-admission patients found that high baseline levels of BSDs, as measured with a subset of the Bonn Scale for the Assessment of Basic Symptoms (BSABS), predicted subsequent development of schizophrenia spectrum disorders in those initially diagnosed outside of the spectrum. BSDs also predicted diagnostic stability in those within the spectrum (Parnas et al., 2011). That study is to our knowledge the only one until now to examine the association between BSDs and diagnostic stability and change.

Our research group have previously shown that BSDs aggregate in first-treatment patients with schizophrenia (Haug et al., 2012b). While clinical symptoms are unstable and diagnosis might change, BSDs are thought to be a more stable structural aspect of consciousness rather than fluctuating abnormal mental content (Nordgaard et al., 2017a). There are, however, very few empirical studies investigating to what extent BSDs are stable over time. A recent follow-up study of first admission patients with non-affective psychosis, schizotypal disorder and other mental illnesses, examined the temporal persistence of life-time BSDs (assessed with the BSABS expanded with additional items targeting self-disorders) and found increased levels of BSDs after five years (Nordgaard et al., 2017a). Another study from the same research group investigated the development of BSDs from baseline to five years follow-up in 48 patients with first admission schizophrenia, using the Examination of Anomalous Self-Experiences (EASE) at baseline and during the 18-month period prior to follow up (Nordgaard et al., 2017b). The study found the same level of BSDs at baseline and follow-up. Both studies only included patients within the schizophrenia spectrum and could thus not investigate diagnostic stability for other conditions.

The current study was a seven year follow-up of a first treatment psychosis group (including both schizophrenia spectrum and non-schizophrenia spectrum cases). The aims were to investigate:

- 1) The stability/change of BSDs, at total and domain level.
- 2) Whether *baseline* levels of BSDs predicted diagnostic change.
- 3) Whether *changes* in the levels of BSDs predicted diagnostic change.

Our hypotheses were: (1) Because BSDs are core features of schizophrenia, they may show minor individual fluctuations but are relatively

stable at the group level. Based on previous findings we hypothesized that particularly Domains 1 and 2 would show a high degree of stability. (2) High levels of BSDs at start of treatment in patients with psychotic disorder outside of the schizophrenia spectrum predict diagnostic change into schizophrenia seven years later, (3) An increase in BSDs over time in patients with a diagnosis outside the schizophrenia spectrum is associated with diagnostic change into schizophrenia.

2. Material and methods

2.1. Participants

The current study was a seven-year follow up of a cohort of first treatment psychosis patients from the Norwegian “Thematically Organized Psychosis” (TOP) study.

At baseline the study involved all treatment facilities in two neighboring Norwegian counties, with a county-wide population of 375,000 people. The study included all patients entering first adequate treatment for a broadly defined psychotic disorder including schizophrenia, schizophreniform disorder and schizoaffective disorder (hereafter referred to as “schizophrenia”), bipolar psychosis (bipolar disorder I and NOS – all with psychotic symptoms), and other psychotic disorders usually classified outside of the (narrow) schizophrenia spectrum (delusional disorder and psychosis NOS). Inclusion criteria were: Between 18 and 65 years of age and IQ > 70. Patients with concurrent substance use disorders were not excluded, but had to demonstrate at last one month without substance use or clear signs that the psychotic disorder had started before onset of significant substance use. All possible cases at all treatment facilities were screened, and all patients who met the inclusion criteria and agreed to participate were included. The study also included 13 patients enrolled in a closely related and partly overlapping cohort study of young psychosis patients born in 1985/86 (Bratlien et al., 2013). They met the same inclusion and exclusions criteria except the strict definition of first treatment.

Forty-nine from the early treatment group (32 schizophrenia, 9 bipolar, 8 OP) and seven patients from the birth cohort (3 schizophrenia, 4 bipolar) participated in the follow-up study. The 90 people originally included thus represented close to an epidemiological sample. Fifty seven individuals (63%) in the baseline study met the DSM-IV (Diagnostic and Statistical Manual of Mental Disorder, Fourth Edition) (First et al., 1996) criteria for schizophrenia, twenty (22%) for bipolar disorders and thirteen (14%) for other psychotic disorders. For more detailed description of the baseline study see Haug and colleagues (Haug et al., 2012b).

During the follow-up period, the patients received treatment as usual in their local health services. This treatment comprised regular supportive appointments with a therapist and psychopharmacological medication. A few also received psycho-educative sessions and/or cognitive behavioral therapy. Of the 90 patients included, 56 patients (62%) agreed to participate in the follow-up study: Forty-nine from the early treatment group (32 schizophrenia, 9 bipolar, 8 OP) and seven patients from the birth cohort (3 schizophrenia, 4 bipolar). All of the 34 patients who were not part of the follow-up were alive, however 15 had moved and were impossible to reach, and 19 did not want to participate. There were no significant differences in the baseline demographic and clinical characteristics between those who participated and who did not participate in the follow-up.

All participants provided informed consent to participate at both time-points. The study was approved by the Regional Committee for Medical Research Ethics and the Norwegian Data Inspectorate.

2.2. Assessments

All patients were evaluated with an extensive clinical assessment battery at baseline, and reevaluated with the same battery seven years later. Only the instruments relevant for this part of the study are presented here.

2.2.1. Assessment of self-disturbances at baseline and follow-up

At baseline, BSDs were assessed with the Examination of Anomalous Self Experience (EASE) manual (Parnas et al., 2005) by an experienced psychiatrist (EH). The inter-rater reliability (IRR) for the EASE assessments, including the baseline study, has been found to be very good (Moller et al., 2011; Nelson et al., 2012; Raballo and Parnas, 2012). At follow-up the EASE was assessed by a clinically experienced psychiatric nurse (IHS) after comprehensive EASE training with two experienced psychiatrists and certified EASE instructors (EH and PM). For training, videotaped EASE interviews were used and rated by IHS, EH and PM. The training IRR demonstrated an average Cohen's kappa of 0.71 which is considered to be good. IRR testing of the first seven follow-up EASE interviews (EH and IHS) showed Cohen's kappa of 0.78.

The EASE manual usually aims to capture life-time experiences of BSDs, but this can be adjusted according to the study aim. At baseline we registered only life-time experiences. Since we aimed to measure change in BSDs between baseline and follow-up, we rated BSDs that the patients had at the interview time or could recall as an experience over the last two years before follow-up, and used this information in the current analyses.

The EASE comprises 57 main items organized in five domains: (1) Cognition and stream of consciousness, (2) Self-awareness and presence, (3) Bodily experiences, (4) Demarcation/transitivity, and (5) Existential reorientation. BSDs are not considered to be discrete symptoms but highly overlapping and interconnected aspects of a gestalt. There are thus considerable overlap between single items and domains, and both items and domains are statistically highly inter-correlated (Nordgaard and Parnas, 2014; Raballo and Parnas, 2012). The items are scored using a 5-point Likert scale (0–4), 0 = absent; 1 = questionably present; 2 = definitely present, mild; 3 = definitely present, moderate; 4 = definitively present, severe. To be able to compare to previous publications these were dichotomized into 0 (for absent and questionably present) and 1 (for definitely present, all severity levels). Item 2.13 (anxiety) was not included in these analyses, neither at baseline nor at follow-up, because that item is not a BSD per se but serves to enrich the data and as a contrast to the next item, ontological anxiety (item 2.14) (Parnas et al., 2005). The EASE has demonstrated high internal consistency (Moller et al., 2011; Nordgaard and Parnas, 2014).

2.2.2. Clinical assessments at follow-up

Diagnoses at follow-up were ascertained by trained clinical psychologists or medical doctors using Structured Clinical Interview for DSM-IV Axis I disorders (SCID module I, chapter A–E) (First et al., 1996), with additional information from medical charts. Eight of the patients were not in treatment contact with the public health system and were thus without available updated charts. They were still diagnosed based on SCID and available information.

Present symptom severity and functional status were measured with the Global Assessment of Functioning scale, split version - symptom (GAF-S) and, function (GAF-F) (Endicott et al., 1976; Pedersen et al., 2007), the Structured Clinical Interview for Positive and Negative Syndrome Scale (SCI-PANSS) (Kay et al., 1987) and the Calgary Depression Scale (CDSS) (Addington et al., 1990).

All assessments except the diagnostic interviews were conducted by the first author (IHS), who was blind both to baseline and current diagnoses and to baseline BSDs assessments to avoid assessment bias.

2.3. Statistical analyses

SPSS version 23.0 (SPSS inc., Chicago, IL, USA) was used to perform all statistical analyses. Mean and standard deviation are reported for continuous variables and percentages for categorical variables. Correlations were assessed using Pearson r and Spearman's ρ . Since BSDs are considered to be a core feature of schizophrenia and not of other psychotic disorders, we a priori decided to combine patients with bipolar psychotic disorders and other psychotic disorders into one group, the “non-schizophrenia group”. There were no significant differences between the bipolar group and the other psychosis group (psychotic disorder, NOS and delusional disorder) in the EASE total score or any EASE domain scores neither at baseline or at follow-up. Group comparisons for dichotomous variables were done using chi-square statistics, while group comparisons for continuous variables were evaluated with independent sample t -test for normally distributed data and Mann-Whitney test for data without normal distribution. The EASE scores were significantly skewed and were analyzed using nonparametric tests. We used Wilcoxon sign rank test to test the changes between

Table 1
Clinical and demographic characteristic, correlations and changes.

	Baseline		Follow-up		Change over time
	Schizophrenia	Non-schizophrenia	Schizophrenia	Non-schizophrenia	
Total N	35	21	35	21	
Male N(%)	17/48.6	11/52.4	17/48.6	11/52.4	
DUP weeks (median/range)	105/5–1041	8/1–675	105/5–1041	8/1–675	
GAF-S (mean/SD)	33.0/7.9	45.1/12.2	51.2/15.4	67.1/14.5	F = 81.5* p < 0.001
GAF-F (mean/SD)	35.3/4.8	44.8/11.8	55.1/15.9	69.2/14.8	F = 121.9* p < 0.001
PANSS positive (mean/SD)	18.3/4.3	14.3/4.9	13.4/4.6	9.1/2.9	F = 52.7* p < 0.001
PANSS negative (mean/SD)	18.5/7.7	13.1/5.4	14.4/5.6	10.7/3.8	F = 11.3* p = 0.001
PANSS general (mean/SD)	40.1/8.3	33.9/9.4	27.9/6.4	22.8/5.5	F = 85.6* p < 0.001
CDSS (mean/SD)	9.7/5.8	6.1/7.0	4.8/4.6	3.6/4.0	F = 26.0* p < 0.001
Use of antipsychotics (one or more type) (N/%)	25/71	11/52	17/49 ^b	4/19	p = 0.001 [†]
Use of antidepressant (one or more type) (N/%)	12/34	7/33 ^a	18/51 ^c	6/29 ^e	p = 0.41 [†]
Use of mood stabilizations (Lithium or antiepileptic) (N/%)	5/14	5/24	6/17 ^d	5/24	p = 1.0 [†]

* Repeated measures ANOVA, within-subjects effects. Between-subjects effects (group differences) < 0.001 for all analyses, no interaction effects.

[†] Related-Samples McNemar Test.

^a Correlate significantly (Spearman's ρ) with PANSS negative ($p < 0.01$), PANSS general ($p < 0.05$) and CDSS ($p < 0.05$) at baseline.

^b Correlate significantly (Spearman's ρ) with PANSS negative ($p < 0.05$) at follow-up.

^c Correlate significantly (Spearman's ρ) with GAF-F ($p < 0.05$) and PANSS negative ($p < 0.01$) at follow-up.

^d Correlate significantly (Spearman's ρ) with CDSS ($p < 0.01$) at follow-up.

^e Correlate significantly (Spearman's ρ) with GAF-F ($p < 0.05$) at follow-up.

Table 2
Changes in EASE from baseline (BL) to follow-up (FU) (Wilcoxon Signed Ranked Test).

Diagnoses		Schizophrenia N = 35				Non-schizophrenia N = 21			
EASE		Median	Range	z-Value	p-Value	Median	Range	z-Value	p-Value
Total (56 items)	BL	22	4–45	−3.81	<0.001	7	0–31	−0.66	0.512
	FU	14	0–38			5	0–22		
Domain 1 (17 items)	BL	9	1–14	−2.64	0.008	3	0–9	−0.34	0.737
	FU	6	0–13			3	0–6		
Domain 2 (17 items) ^a	BL	7	1–14	−3.34	0.001	1	0–12	−0.21	0.832
	FU	3	0–14			2	0–11		
Domain 3 (9 items)	BL	2	1–8	−3.12	0.002	0	0–5	−0.75	0.454
	FU	1	0–6			0	0–5		
Domain 4 (5 items)	BL	1	0–4	−2.52	0.012	0	0–1	−0.63	0.527
	FU	0	0–4			0	0–2		
Domain 5 (8 items)	BL	2	0–7	−3.89	<0.001	0	0–4	−1.63	0.104
	FU	0	0–7			0	0–4		

^a (without EASE item 2.13).

baseline and follow-up for the dichotomized EASE scores. The level of significance was set to $p = 0.05$, two-sided.

3. Results

The median follow-up period was 2579 days/7.5 years (range: 2362–2973 days). Baseline and follow-up socio-demographic and clinical features for each diagnostic group are reported in Table 1. There were significant clinical improvements, i.e. increase in functioning and a decrease in symptoms over time, with a clear effect of diagnostic groups and no time x group interactions (Table 1). There was a statistically significant association between baseline total EASE scores and baseline clinical characteristics, ranging from -0.60 for GAF symptoms to 0.28 for PANSS negative symptoms and between follow-up total EASE score and follow-up clinical characteristics ranging from -0.72 for GAF symptoms to 0.32 for PANSS negative symptoms (for full correlational matrix see Supplementary Tables 2 and 3).

The significant differences in baseline EASE total score between diagnostic groups were reproduced also for the follow-up subsample: The baseline median score was 22 (range 4–45) for the schizophrenia group and 7 (range 0–31) for the non-schizophrenia group (Mann Whitney U test z-score -5.23 , $p < 0.01$). While 80% of the patients with schizophrenia had an EASE total score ≥ 15 at baseline, there was only four patients (19%) who had an EASE total score of ≥ 15 in the non-schizophrenia group. At follow-up the median score was 14 (range 0–38) for the schizophrenia group and five (range 0–22) for the non-schizophrenia group (Mann Whitney U test z-score -3.51 , $p < 0.01$). The significant differences between the two diagnostic groups in EASE total at follow-up were mainly based on differences in Domain 1 (Cognition and stream of consciousness), with lower differences, but still statistically significant, for Domains 2 (Self-awareness and presence) and 3 (Bodily experiences) and no differences for Domains 4 (Demarcation/transitivity), and 5 (Existential reorientation). However, Domain 1 scores were also the highest in the non-schizophrenia group (see Table 2).

Fig. 1 illustrates the correlation matrix of EASE domain scores at baseline and follow-up in the two diagnostic groups, and show increases as well as decreases in EASE scores for individual patients. A Wilcoxon Signed Rank Test confirmed significant reduction from baseline to follow-up in total EASE score in the schizophrenia group ($z = -3.81$, $p < 0.001$) but not in the non-schizophrenia group ($z = -0.66$, ns). The least changes were seen in domains 1 (Cognition and stream of consciousness) and 4 (Demarcation/transitivity) (Supplementary Table 1). Because these tests were based on the sum of reported items within each domain, it is not given that the same items were reported at both baseline and at follow-up (Supplementary Table 2). For patients in the non-schizophrenia group, there were no significant EASE changes over time, probably based in the very low scores with limited variation

at both time-points creating low statistical power and a ceiling effect for change.

There were limited diagnostic changes over the follow-up period within the diagnostic main groups, and no change between the diagnostic groups (Fig. 2). The four patients in the non-schizophrenia group with high baseline EASE total scores (>15 ; range 15–31) retained their baseline diagnosis at follow-up. Two of these four patients were diagnosed with bipolar disorder (baseline EASE total score 15 and 17) and two patients were diagnosed with psychotic disorder NOS (baseline EASE total score 15 and 31). At follow-up these four patients' EASE scores were reported as 10, 5, 5 and 22 respectively. A total of six (29%) non-schizophrenia patients also reported one or more new EASE items at follow-up that they did not report at baseline (see Supplementary Table 2). None of these however had high EASE total scores (i.e. ≥ 15).

4. Discussion

4.1. General discussion

As expected, we found significantly higher levels of BSDs in the schizophrenia compared to the non-schizophrenia group also at follow-up, particularly for Domain 1 (Cognition and stream of consciousness). We also hypothesized that BSDs would show limited individual changes and be relatively stable at the group level, but the results did not support this hypothesis: We found significantly lower level of reported BSDs for the last two years before follow-up for the schizophrenia group, with an all-over stability of low levels for the non-schizophrenia group.

At baseline the BSDs were based on reports of life-time experiences. However, if the same approach had been taken to rating SD at follow up (i.e., lifetime rating, including the baseline time point), only increases in SD could be detected and not decreases. In line with this, Nordgaard et al. who reported lifetime levels of BSDs at baseline and at follow-up indicated an increase in BSDs over time (Nordgaard et al., 2017a). In the next study from the same group they reported BSDs from the 18 month period prior to follow-up, and here found no changes in BSDs compared to baseline (Nordgaard et al., 2017b). We thus decided to restrict the follow-up to the two-years preceding the interview. During the interviews, patients with a decrease in reported BSDs confirmed having experienced BSDs previously. A common answer was, "When I was really sick, I felt that way, but I don't have this feeling now" followed by an example. Thus, the reduction does not appear to be based on recollection bias. However, we cannot know the exact level of BSDs during the two years prior to baseline. Based on the patient's reports of "when I was really sick" we however find it likely that levels were at their highest close to the start of first treatment (i.e. study baseline).

Fig. 1. Scatterplots of baseline versus follow-up scores for different EASE domains, to illustrate the development of SDs on the individual level.

Fig. 2. Diagnostic changes from baseline to follow-up.

We saw the least changes in Domain 1 (*Cognition and stream of consciousness*) and 4 (*Demarcation/transitivity*), controlled for the number of items comprised by the domains. In addition, Domain 1 scores were higher with significantly more items reported at both time points. This was in line with our hypothesis. Distinctive of the items in domain 1 is the experience of a disturbance in the flow of thoughts and in the ownership of one's own thoughts, i.e. the feeling of a gap between the self and the mental content. Domain 1 disturbances have previously been described as some of the first BSDs appearing in the prodromal phase and are also found to be the most predictive of transition to full-threshold psychosis in a treated Ultra High Risk group (Nelson et al., 2012). It is worth considering that there might be a link between Domain 1 as the strongest predictor of transition to psychosis in high risk groups, and for lack of therapeutic response.

We also hypothesized that high levels of BSDs at baseline and/or an increase in BSDs over time in patients with a non-schizophrenia group would predict diagnostic change to the schizophrenia group seven years later. However, we found a very high degree of diagnostic stability with no changes between the two diagnostic main groups during the follow-up period. Previous studies of diagnostic stability (Haahr et al., 2008; Parnas et al., 2011) were both conducted in urban areas, and particularly in the case of the Haahr study, the participants had very short durations of untreated psychosis (DUP). The current study was conducted in rural areas with considerable distances to the specialized psychiatric health services, and consequently with long DUPs. Since the

expected diagnostic change usually take place early in the first episode, in this case before the first treatment contact, the observed diagnostic stability could thus be related to sample characteristics. Based on the diagnostic stability we could neither confirm nor reject our hypotheses related to BSDs and diagnostic change. It is however noteworthy that the four patients in the non-schizophrenia group with high baseline levels of BSDs did not convert to schizophrenia, nor did the six patients in the non-schizophrenia group who reported an appearance of BSDs in new domains at follow-up.

While the main effect was a decrease of BSDs at the group level, some patients had stable levels, some experienced increases while others experienced decreases from baseline to follow-up. Since the two pre-existing studies of longitudinal development of BSDs report either an increase or stability in BSDs as main effects, the nuances in our findings might indicate that as yet unknown individual characteristics may influence the level or severity of BSDs which make them more susceptible to fluctuations than previously thought. At baseline the patients had experienced their first psychotic episode, which is usually associated with stress and emotional arousal, while at follow up most patients were in a more advanced and stable phase. This may explain some of the decreases in BSDs seen at follow-up in this study, as also indicated in the guidelines for the EASE interview (Parnas et al., 2005, p.239). As indicated by others, it is also possible that some BSDs fluctuate on top of stable trait disturbance while acute "episodes" of BSDs are triggered by or exacerbated as a response to traumatic environmental circumstances

(secondary BSDs) (Koren et al., 2017; Sass et al., 2018; Sass and Borda, 2015).

The patients' treatment units received general information about BSDs and, when the patient agreed, the clinician also received a report including information about BSDs for the particular patient at baseline. Receiving a report detailing aspects of BSDs may have influenced the content of treatment. At follow-up, a majority of the patients had regular contact with a specialist or a general practitioner, over a third was using anti-psychotic medication and nearly 30% used medication for mood-disorders. To what extent treatment directly or indirectly influences fluctuations in BSDs is not known at this stage. Our results however suggest that this should be a focus for future studies.

4.2. Strengths and limitation of the study

4.2.1. Strengths

The patient sample was broadly recruited with few exclusions criteria and represents a comprehensive, near to epidemiological sample. The follow-up period was seven and a half year and is to our knowledge the longest follow-up study of BSDs using the EASE instrument at both baseline and follow-up.

4.2.2. Limitations

There was some attrition of the original sample, but without signs that attrition was biased. After standard training, the IRR testing of the follow-up EASE assessments comprised the first seven (12.5%) out of 56 interviews. We used a standard life-time measure of BSDs at baseline but chose to measure over the last two years at follow-up. We do not know if the life-time report is fully representative of the level of BSDs in the two-year period preceding baseline.

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.schres.2018.07.011>.

Contributions

EH, MØ, PM and IM planned the original study, while EH, MØ, IM, BN and IS planned the follow-up study. IS and EH conducted the follow-up, whereas IS made the follow-up interviews, the statistical analyses and made the first draft of the paper. All authors have made contributions to interpretations and content.

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Conflict of interests

The authors report no conflicts of interest.

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Paper 1 Supplementary material

Supplementary Table 1 Frequency of patients reporting EASE items by domains

	EASE Domain		d1	d2	d3	d4	d5
Schizophrenia N=35	No items at both baseline and follow-up	N/%	0/0	0/0	7/20	19/54	9/26
	Items at baseline but not at follow-up	N/%	2/6	8/23	15/43	10/29	16/46
	Items at follow-up but not at baseline	N/%	1/3	0/0	2/6	2/6	2/6
	Items at both baseline and follow-up	N/%	32/91	27/77	11/31	4/11	8/23
Non-Schizophrenia N=21	No items at both baseline and follow-up	N/%	1/5	8/38	15/71	18/90	16/76
	Items at baseline but not at follow-up	N/%	3/14	2/10	3/14	0/0	3/14
	Items at follow-up but not at baseline	N/%	2/10	6/29	1/5	2/10	1/5
	Items at both baseline and follow-up	N/%	15/71	5/24	2/10	0/0	1/5

d1 – EASE Domain 1 (17 items), Cognition and stream of consciousness

d2 – EASE Domain 2 (17 items (without item 2.13)), Self-awareness and presence

d3 – EASE Domain 3 (9 items), Bodily experiences

d4 – EASE Domain 4 (5 items), Demarcation/transitivity

d5 – EASE Domain 5 (8 items), Existential reorientation

Supplementary Table 2 Correlation (Spearman's rho) between EASE total score at baseline, domains and clinical measures at baseline

Baseline		GAF-S	GAF-F	PANSS positive	PANSS negative	PANSS general	CDSS
All diagnosis N=56	EASE Total Score	-0.60**	-0.48**	0.38**	0.28*	0.38**	0.44**
	Domain 1	-0.52**	-0.40**	0.33*	0.24	0.34**	0.40**
	Domain 2	-0.60**	-0.47**	0.42**	0.28*	0.37**	0.38**
	Domain 3	-0.56**	-0.46**	0.31*	0.22	0.30*	0.40**
	Domain 4	-0.43**	-0.46**	0.10	0.24	0.24	0.49**
	Domain 5	-0.46**	-0.33*	0.30*	0.21	0.31*	0.41**
Schizophrenia N=35	EASE Total Score	-0.40*	-0.04	0.12	-0.26	0.12	0.43*
	Domain 1	-0.32	-0.01	0.21	-0.23	0.15	0.31
	Domain 2	-0.35*	-0.07	0.10	-0.24	0.04	0.34*
	Domain 3	-0.35*	-0.03	0.02	-0.23	0.02	0.46**
	Domain 4	-0.24	-0.21	-0.17	-0.06	0.05	0.49**
	Domain 5	-0.16	0.09	0.01	-0.18	0.07	0.23
Non- schizophrenia N=21	EASE Total Score	-0.34	-0.35	0.31	0.45*	0.49*	0.33
	Domain 1	-0.01	-0.09	-0.08	0.37	0.23	0.29
	Domain 2	-0.48*	-0.35	0.47*	0.53*	0.52*	0.16
	Domain 3	-0.48*	-0.50*	0.40	0.38	0.42	0.10
	Domain 4	-0.02	-0.27	0.04	0.44*	0.37	0.20
	Domain 5	-0.30	-0.33	0.33	0.48*	0.35	0.42

** Correlation is significant at the 0.01 level (2-tailed)

* Correlation is significant at the 0.05 level (2-tailed).

Supplementary table 3 Correlation (Spearman's rho) between EASE total score, domains and clinical measures at follow-up

Follow-up		GAF-S	GAF-F	PANSS positive	PANSS negative	PANSS general	CDSS
All diagnosis N=56	EASE Total Score	-0.73**	-0.53**	0.70**	0.38**	0.70**	0.60**
	Domain 1	-0.67**	-0.45**	0.66**	0.36**	0.59**	0.49**
	Domain 2	-0.61**	-0.48**	0.55**	0.37**	0.59**	0.62**
	Domain 3	-0.57**	-0.43**	0.48**	0.13	0.56**	0.39**
	Domain 4	-0.53**	-0.30*	0.53**	0.11	0.52**	0.42**
	Domain 5	-0.33*	-0.28*	0.41**	0.06	0.35**	0.30*
Schizophrenia N=35	EASE Total Score	-0.64**	-0.31	0.69**	0.20	0.58**	0.53**
	Domain 1	-0.51**	-0.14	0.64**	0.24	0.49**	0.52**
	Domain 2	-0.48**	-0.30	0.46**	0.24	0.41*	0.51**
	Domain 3	-0.54**	-0.28	0.53**	-0.09	0.53**	0.33*
	Domain 4	-0.60**	-0.24	0.54**	-0.06	0.51**	0.47**
	Domain 5	-0.25	-0.19	0.39*	-0.11	0.33	0.21
Non- schizophrenia N=21	EASE Total Score	-0.61**	-0.55*	0.48*	0.21	0.67**	0.66**
	Domain 1	-0.48*	-0.47*	0.36	0.07	0.49*	0.36
	Domain 2	-0.62**	-0.48*	0.41	0.32	0.61**	0.75**
	Domain 3	-0.42	-0.45*	0.05	0.19	0.36	0.43
	Domain 4	-0.08	-0.12	0.35	-0.12	0.39	0.25
	Domain 5	-0.28	-0.28	0.22	0.16	0.21	0.38

** Correlation is significant at the 0.01 level (2-tailed)

* Correlation is significant at the 0.05 level (2-tailed)

Supplementary table 4 The twelve most frequent EASE items in the Schizophrenia group, with McNemar's test for equal frequencies

EASE item	Frequency (%)		McNemar2- sid exact <i>P</i>
	at baseline	follow-up	
Rumination – obsession (item 1.6)	91	69	0.04*
Perceptualization of inner speech or thought (item 1.7)	86	63	0.04*
Diminished intitative (item 2.16)	77	48	0.01*
Primary self-reference phenomena (item 5.1)	74	26	<0.01**
Thought block (item 1.4)	71	60	0.45
Hyperreflectivity; increased reflectivity (item 2.6)	71	57	0.27
Cenesthetic experiences (item 3.7)	71	63	0.51
Thought interference (item 1.1)	67	57	0.45
Inability to discriminate modalities of intentionality (item 1.10)	66	37	0.01*
Diminished sense of basic self (item 2.1)	66	29	<0.01**
Distorted first person perspective (item 2.2)	66	23	<0.01**
Loss of thought ipseity (item 1.2)	63	43	0.17

** Significant at a 99% confidence interval * Significant at a 95% confidence interval

Note: Frequency are based on percentage of patients reporting EASE-item at baseline and at follow-up

Supplementary Table 5 The twelve most frequent EASE items in the non-schizophrenia group, with McNemar's test for equal frequencies

EASE item	Frequency (%) at baseline	Frequency (%) at follow- up	McNemar2- sid exact <i>P</i>
Rumination – obsession (item 1.6)	67	62	1
Inability to discriminate modalities of intentionality (item 1.10)	48	09	0.02*
Ambivalence (item 1.9)	38	38	1
Hyperreflectivity; increased reflectivity (item 2.6)	33	38	1
Disorder of short-term memory (Item 1.13)	33	33	1
Hypohedonia (item 2.17)	33	24	0.73
Cenesthetic experiences (item 3.7)	33	29	1
Disturbance of expressive language function (item 1.17)	29	43	0.58
Diminished initiative (item 2.16)	29	43	0.51
Thought block (item 1.4)	29	09	0.29
Thought interference (item 1.1)	24	14	0.69
Primary self-reference phenomena (item 5.1)	25	05	0.22
Attentional disturbance (item 1.12)	19	24	1

* Significant at a 95% confidence interval

Note: Frequency are based on number of patients reporting the EASE-item at baseline and at follow-up

Basic self-disturbances independently predict recovery in psychotic disorders: A seven year follow-up study

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ABSTRACT

Background: Recovery is the ultimate goal of psychosis treatment. Basic self-disturbances (BSDs) are non-psychotic phenomena associated with clinical outcome, present in prodromal, psychotic and residual phases of psychotic disorders.

Aim: To investigate the relationship between BSDs and recovery seven years after first treatment in patients with psychotic disorders.

Method: Prospective longitudinal study of 56 patients recruited during first adequate treatment for schizophrenia (n = 35) and other psychotic disorders (n = 21) (psychotic bipolar disorder, delusional disorder, psychotic disorder NOS). At baseline and follow-up BSDs were assessed using the Examination of Anomalous Self-Experience (EASE) manual, while standard clinical instruments were used to ascertain diagnosis, clinical symptom severity, and functioning. Recovery was defined as absence of psychotic symptoms and regaining of functioning that persisted the last two years before follow-up.

Results: At follow up, 34% achieved recovery (5 (14%) with schizophrenia and 14 (67%) with other psychoses at baseline). Recovery was predicted by an absence of a schizophrenia diagnosis, low baseline level of BSDs and further reductions in BSDs from baseline to follow-up. Change in BSDs was the strongest predictor, also after adjusting for premorbid adjustment and duration of untreated psychosis, and was not confounded by diagnosis.

Conclusion: Low baseline levels of basic self-disturbances and further reductions over time independently predict recovery seven years later in first treated psychosis patients.

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1. Introduction

Full recovery is the optimal goal of any psychiatric treatment. In psychotic disorders, the term “full recovery” has been defined as stable remission of positive, negative and affective symptoms (Andreasen “Remission in Schizophrenia Working Group” (RSWG) criteria), in the context of regained normal functioning (Andreasen

et al., 2005). The rates of recovery in studies of first episode schizophrenia spectrum disorder vary between 10 and 25% of participants, depending on the specific diagnoses included in the study, the length of the follow-up period and the criteria used to define recovery (Austin et al., 2013; Jaaskelainen et al., 2013; Robinson et al., 2004; Torgalsboen et al., 2015). A recent meta-analysis, including 35 studies with a total of 9642 first episode psychosis patients (schizophrenia and affective psychosis), found that 38% were in full recovery after a mean follow-up period of 7.3 years (Lally et al., 2017). In a study of patients with bipolar disorder followed from their first hospitalization for mania, 43% were found to be in full functional recovery at 2–4 years follow-up (Tohen et al., 2003). However, Angst et al. (2009) found that only 16% of patients with bipolar disorder experienced full recovery throughout a five-year

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period (Angst, 2009). The outcome of first episode psychosis is both heterogeneous and difficult to predict on the individual level (Fusar-Poli et al., 2014). Known predictors of poor outcome are poor premorbid adjustment (MacBeth and Gumley, 2008), low age at onset of symptoms (Clemmensen et al., 2012), long duration of untreated psychosis (DUP) (Penttilä et al., 2014), depression (Upthegrove et al., 2010), persistent negative symptoms and substance use (Weibull et al., 2017). Some studies also indicate that males have poorer outcome than females (Tandon et al., 2009).

Basic self-disturbances (BSDs) have been established as core features of schizophrenia spectrum disorders (Parnas et al., 2005a; Parnas and Henriksen, 2014). The theory of BSDs is based on Continental phenomenology and psychiatry (Sass and Parnas, 2003) and overlaps with and can be seen as an evolution from the concept of Basic Symptoms (Gross et al., 1998; Klosterkötter et al., 1996; Parnas and Handest, 2003; Schultze-Lutter, 2009). BSDs are characterized by *diminished sense of self-presence* (existing as a vital subject of awareness or agent of actions), *hyperreflexivity* (exaggerated self-consciousness and heightened awareness of normally tacit or implicit aspects of experience), and disturbed 'grip' on the cognitive and/or perceptual field (Sass et al., 2018; Sass and Parnas, 2003). They also have profound implications for interpersonal functioning (Parnas and Handest, 2003). Empirical studies indicate that these phenomena are clearly present before the appearance of frank psychotic symptoms (Moller and Husby, 2000; Parnas et al., 1998) and in high-risk individuals (Davidsen, 2009). Furthermore, studies indicate that the presence of BSDs increases the risk of conversion to psychosis in high-risk groups (Nelson et al., 2012; Parnas et al., 2011). BSDs are present in all stages of psychotic disorders, including in first-episode (Haug et al., 2012a; Nordgaard and Parnas, 2014) and in chronic patients (Raballo et al., 2011). An addition to the BSDs concept, is the view that while some phenomena are fundamental to schizophrenia ("primary BSDs"), others may be particular responses to traumatic environments and could be seen as defensive-compensatory ("secondary BSDs") (Borda and Sass, 2015; Sass et al., 2018; Sass and Borda, 2015).

The presence and degree of BSDs differentiate between schizophrenia spectrum- and affective psychotic disorders (Haug et al., 2012a; Nelson et al., 2013; Nordgaard and Parnas, 2014; Raballo and Parnas, 2012). In the current study sample, we found that BSDs were present at start of first treatment (Haug et al., 2012a) and that this baseline level was significantly associated with long duration of untreated psychosis (DUP) (Haug et al., 2017), low self-esteem, high levels of depression and suicidal behavior (Haug et al., 2016), reduced social functioning (Haug et al., 2014), impaired verbal memory (Haug et al., 2012c), and presence of childhood trauma (in females) (Haug et al., 2015).

A recent study indicates an association between high level of BSDs in the early phase of illness and poor long-term outcome in the form of more negative symptoms five years later (Nordgaard et al., 2017; Raballo and Preti, 2018). We have recently reported a modest reduction in BSDs in patients with schizophrenia seven years after first treatment (Svendsen et al., 2018). The aim of the current study was to investigate the relationship between BSDs at baseline, change in BSDs over time, and clinical outcome in the seven-year follow-up study, with a specific focus on recovery. Our hypothesis thus is that low levels of BSDs at baseline would be associated with recovery.

2. Materials and method

2.1. Participants

The present study is a part of the Norwegian "Thematically Organized Psychosis" (TOP) study and is a seven year follow up of first-treatment psychosis patients (Haug et al., 2012a). At baseline, participants were recruited from two Norwegian counties with a combined population of 375,000. All patients between 18 and

65 years receiving their first treatment for schizophrenia, schizophreniform disorder and schizoaffective disorder (henceforth: "Schizophrenia"), psychotic bipolar disorder I and NOS, delusional disorder and psychosis NOS (henceforth: "other psychosis"). Exclusion criteria were substance-induced psychosis and having an IQ < 70. Ninety patients were included at baseline, 57 (63%) with schizophrenia and 33 (37%) with other psychosis. In the seven years between baseline and follow-up, patients were offered and mostly received treatment as usual in the local services, including regular appointments with a doctor, psychiatrist, psychologist or a social worker providing mental health support, in addition to medications (antipsychotics and/or mood stabilizers). Twenty patients (36%) also received psychoeducation and/or cognitive behavioral therapy. A total of 56 patients (62% of the baseline cohort) participated in the seven year follow-up. All 90 previous participants were still alive, but 15 (16%) had changed residence and were impossible to reach, and 19 (21%) declined participation. The baseline demographic and clinical characteristics between those who not participated and those who did participate in the follow-up, demonstrate no significant difference. At both time-points, all participants gave informed, voluntary, written consent to participate. Regional Committee for Medical Research Ethics and the Norwegian Data Inspectorate approved the study.

2.2. Assessments

The same clinical assessment battery was used at baseline and at follow up. Only the instruments relevant for this report are presented.

2.2.1. Assessment of basic self-disturbances at baseline and follow-up

BSDs were assessed with the Examination of Anomalous Self Experience (EASE) manual (Parnas et al., 2005b). The interrater reliability (IRR) for EASE assessments has been found to be very good (Moller et al., 2011; Nelson et al., 2012; Raballo and Parnas, 2012). At baseline, the interviews were done by an experienced psychiatrist (EH). A clinically experienced psychiatric nurse (IHS) assessed the EASE at follow-up. She was trained by two certified EASE instructors (EH and PM). Videotaped EASE interviews were used for pre-study training. The interviews were rated by IHS, EH, and PM, and IRR showed an average Cohen's kappa of 0.71 which is considered to be good. The first seven EASE interviews at follow-up (EH and IHS) were also IRR tested and showed a Cohen's kappa of 0.78.

The EASE is grouped into 5 domains: (1) Cognition and stream of consciousness, (2) Self-awareness and presence, (3) Bodily experiences, (4) Demarcation/transitivity, and (5) Existential reorientation. These five domains comprise 57 main items BSDs are not considered to be single and independent phenomena but highly overlapping and interwoven aspects of a gestalt (Nordgaard and Parnas, 2014; Raballo and Parnas, 2012). The items are scored using a 5-point scale (0–4), 0 = absent; 1 = questionably present; 2 = definitely present, mild; 3 = definitely present, moderate; 4 = definitely present, severe. As described in previous publications, the scores were dichotomized into 0 (absent and questionably present) and 1 (definitely present, all severity levels). Item 2.13 (anxiety) does not represent a self-disturbance per se, but serves as a contrast to the item ontological anxiety (Parnas et al., 2005b), and item 2.13. was not included in the analyses at baseline and follow-up. At baseline, we registered life-time experience of BSDs, but at follow-up we registered the presence of BSDs during the previous two years to be able to examine change over time (Svendsen et al., 2018).

2.2.2. Other assessments at baseline and follow-up

At baseline, duration of untreated psychosis (DUP) was ascertained, and Premorbid Adjustment Scale (PAS) was applied (Canon-Spoor et al., 1982). At baseline and follow-up, diagnoses were ascertained using the Structured Clinical Interview for DSM-IV Axis I disorders (SCID module I, chapter A-E) (First et al., 1996). In

addition to personal interviews, information from medical charts was used to aid the assessments. Eight participants had no updated charts available at follow-up because they had no treatment contact with the public health system. At baseline, two experienced psychiatrists determined diagnoses using the SCID-I. At follow-up, SCID-I diagnoses were determined by independent, trained medical doctors or clinical psychologists blind to EASE scores.

To measure present symptom severity, The Global Assessment Functioning scale, split version (GAF–S), (Endicott et al., 1976; Pedersen et al., 2007), the Structured Clinical Interview for Positive and Negative Syndrome Scale (SCI-PANSS) (Kay et al., 1987), and Calgary Depression Scale for Schizophrenia (CDSS) (Addington et al., 1990) were used. Social functioning was assessed using the Social Function Scale (SFS) (Birchwood et al., 2018), and substance use was assessed with the use of the self-report questionnaires Alcohol Use Disorder Identification Test (AUDIT) (Saunders et al., 1993) and the Drug Use Disorder Identification Test (DUDIT) (Beriman et al., 2005). Information about childhood trauma was collected using the Norwegian version of the Childhood Trauma Questionnaire, short form (CTQ-SF) (Bernstein et al., 2003) and self-esteem at baseline was measured using the Rosenberg Self-Esteem Scale (RSES) (Rosenberg, 1989).

The first author (IHS) conducted all of the assessments at follow-up, except the diagnostic interviews, in order to attempt to maintain blindness to information from the diagnostic interviews concerning both baseline and current diagnoses. She was also blind to information about baseline BSDs.

2.2.3. Remission and recovery

Remission of symptoms and regaining functioning are both necessary for recovery. We used Andreasen's "Remission in Schizophrenia Working Group" (RSWG) criteria (Andreasen et al., 2005). To meet these criteria, the patient must have a PANSS score of 3 or lower for both positive symptoms (item P1, P3, G9), for disorganization symptoms (P2, G5), and for negative symptoms (N1, N4, N6). Since all participants had a psychotic disorder at baseline we only focused on remission of psychotic symptoms, not affective symptoms. Regained function was defined as having an employment level equal to full-time work or studies and social activities equivalent to at least weekly patient-initiated contact with family and/or friends, in line with a definition previously used in the TIPS study (Ten Velden Hegelstad et al., 2013). In this paper, recovery is defined as experiencing the combination of full remission of psychotic symptoms and regained functioning over the last 24 months before follow-up.

2.3. Statistical analyses

All statistical procedures were conducted using the SPSS version 23.0 (SPSS Inc., Chicago, IL, USA). All continuous/ordinal data had an approximately normal distribution with mean and standard deviation reported. The exceptions were DUP, AUDIT and DUDIT, and here median and range is reported. For categorical variables percentages are reported. Group comparisons for normally distributed data were evaluated with parametric tests, group comparisons for skewed data were evaluated with non-parametric tests and group comparisons for dichotomous variables were evaluated with chi-square tests. Several potential predictors of poor outcome, including premorbid functioning, DUP, childhood trauma, depression and self-esteem were associated with the level of BSDs (EASE score) at baseline. The association between recovery and BSDs at baseline, controlling for potential confounding- or mediating variables, was investigated using multiple logistic regression analysis correcting for diagnosis. Childhood trauma, self-esteem and depression were however not differentially distributed across the recovery-based groups, and

were not included in the final analyses. Also, since the assessment of recovery at follow-up was directly based on current symptoms and functioning at follow-up, with the presence of a high correlation between baseline- and follow-up levels for all clinical measures (GAF–F, GAF–S, PANSS, CDSS, and SFS), these were not entered in the multivariate analysis. Because DUP had a markedly skewed distribution, it was transformed to its natural logarithm which were used in the multivariate analyses (LnDUP - since no participants had a DUP of 0 weeks). Since only one hypothesis – that there was an association between BSDs and recovery – was tested, the alpha level was set to 0.05, two-sided.

3. Results

3.1. General outcome

The follow-up period had a median length of 2579 days (7.1 years) (range: 2362–2973 days; 6.5–8.1 years). At follow-up 35 out of 56 (63%) participants had a DSM-IV diagnosis of schizophrenia and 21 (37%) other psychotic disorders (bipolar disorder with psychotic features, delusional disorder or psychosis NOS). Diagnostic changes from baseline to follow-up were limited (See Svendsen et al. (2018) for details). At follow-up, and across diagnostic groups, a total of 33 (59%) were in stable symptomatic remission, and 19 (34%) met the criteria for recovery. Demographic and clinical data at baseline for recovered vs. non-recovered participants are shown in Table 1. Clinical data at follow-up for recovered vs. non-recovered participants are shown in Table 2.

There were statistically significant associations between baseline and follow-up levels of EASE, GAF–F, GAF–S, PANSS (all components), CDSS, SFS, AUDIT, and DUDIT with significant improvements in all parameters except drug use (Table 3).

Fig. 1 (scatterplot) show the distribution of EASE total score at baseline and changes in EASE total score at follow-up, sorted by recovered and not recovered.

3.2. Basic self-disturbances, remission, and recovery

As reported previously (Svendsen et al., 2018), there was a significant association between total EASE scores at baseline and follow-up ($r = 0.54$ $p < 0.01$) with a modest but significant reduction over the follow-up period ($t = -4.01$, $p < 0.01$).

Participants in stable symptomatic remission (15 out of 35 [43%] with schizophrenia and 19 out of 21 [91%] with other psychoses) had significant lower EASE total scores than those not in symptomatic remission, at both baseline and at follow-up (baseline median EASE total score (sympt. remission) 14 (0–40) vs (sympt. non-remission) 24 (7–45); follow-up median EASE total score 7 (0–7) vs 19 (5–38)) (Mann-Whitney U test, all p 's < 0.01).

The participants who met the criteria for recovery (5 [14%] schizophrenia and 14 [67%] other psychoses) also had significantly lower EASE total scores than those who did not (baseline median of EASE total score (recovery) 7 (0–40) vs. (non-recovery) 21 (2–45) – and follow-up median of EASE total score 5 (0–18) vs 14 (2–38)) (both p 's < 0.01 Mann-Whitney U test).

However, recovered participants were more likely to have a diagnosis outside of the schizophrenia spectrum, better premorbid functioning and shorter DUP than those who had not achieved recovery. These characteristics were also significantly associated with lower baseline- and follow-up EASE total scores, and we could initially not rule out that they confounded or mediated the association between EASE total score and recovery. We thus conducted a hierarchical multivariate binary logistic regression analysis with "Recovered" (yes vs no) as the dependent variable. Since baseline and follow-up levels of EASE total score were highly correlated, we could not enter both EASE total score at baseline and at follow-up

Table 1

Demographic and clinical characteristics at baseline, shown for the total sample, and separately for those recovered versus not recovered at follow-up.

	Baseline (N = 56)	Not recovered follow-up (n = 37)	Recovered follow-up (n = 19)	t-test/ Chi-Square Analysis/ Mann Whitney U for recovered vs not recovered participants (baseline data)	
				t/X ² /U	P
Male (N/%)	28/50	20/54	8/42	X ² = 0.31	0.57
Age (mean/median/SD)	25.2/22/7.5	25.3/23/7.4	24.5/22/8.0	U = 309	0.46
DUP ^a in weeks (median/range)	86/1–1041	105/1–1041	9/1–675	U = 169.5	<0.01
EASE ^b total (mean/SD)	17.2/11.7	19.2/10.9	10.1/12.5	t = 2.49	=0.02
GAF-S ^c (mean/SD)	37.6/11.3	34.2/8.25	44.2/13.6	t = -2.96	<0.01
GAF-F ^d (mean/SD)	38.9/9.3	35.7/5.7	45/11.8	t = 3.21	<0.01
PANSS ^e positive component (mean/SD)	16.9/4.9	18.3/4.4	13.9/4.6	t = -2.96	<0.01
PANSS ^e negative component (mean/SD)	16.6/7.4	17.7/8.1	14.2/5.2	t = 1.74	0.09
PANSS ^e general component (mean/SD)	37.8/9.2	40.3/8.3	32.8/8.9	t = 3.14	<0.01
SFS ^f total score (mean/SD)	103.2/8.4	101.7/7.5	106.7/9.7	t = 2.07	0.04
CDSS ^g (mean/SD)	8.4/5.7	9/5.6	7.2/5.6	t = 1.16	0.25
AUDIT ^h (median/range)	7/0–38	7/0–38	8/1–19	U = 340.5	0.85
DUDIT ⁱ (median/range)	0/0–44	0/0–44	0/0–20	U = 321	0.46
PAS ^j -social function, childhood (median/range)	1/0–6	1.5/0–5	0.5/0–3.5	U = 216	<0.01
PAS ^j -academic function, childhood (median/range)	1.25/0–5	1.5/0–6	0/0–6	U = 203.5	<0.01
RSES ^k (mean/SD)	21.9/6.9	20.8/5.4	24.2/9	t = -1.45	0.16
CTQ-SF ^l (median/range)	41/25–117	41/25–117	41/27–54	U = 221.0	0.54

P-values in bold are statistically significant.

^a DUP; Duration of Untreated Psychosis.^b EASE; Examination of Anomalous Self-Experiences.^c GAF-S; Global Assessment Functioning Scale split version – Symptom.^d GAF-F; Global Assessment Functioning Scale split version – Function.^e PANSS; Positive and Negative Syndrome Scale.^f SFS; Social Function Scale.^g CDSS; Calgary Depression Scale for Schizophrenia.^h AUDIT; Alcohol Use Identification test.ⁱ DUDIT; Drug Use Disorder Identification Test.^j PAS; Premorbid Adjustment Scale.^k RSES; Rosenberg Self-esteem Scale.^l CTQ-SF; Childhood Trauma Questionnaire – Short Form.

into the equation. Instead we used the change in the EASE total score from baseline until follow-up as an expression of the EASE total score at follow up (Fig. 1). EASE total score baseline and EASE

change were entered into the regression as separate variables. At the final step, only EASE total score at baseline and change in EASE total score had statistically significant contributions (Table 4).

Table 2

Clinical characteristics at follow-up, shown for the total sample, and separately for those recovered versus not recovered at follow-up.

	Follow-up (N = 56)	Not recovered follow-up (n = 37)	Recovered follow-up (n = 19)	T-test/ Chi-Square Analysis/ Mann Whitney U for recovered vs not recovered participants (follow-up data)	
				t/X ² /U	P
EASE ^a total (mean/SD)	11.7/8.9	14.5/8.7	5.0/5.1	t = 3.60	<0.01
GAF-S ^b (mean/SD)	57.2/16.8	48.2/10.8	74.6/12.0	t = -8.33	<0.01
GAF-F ^c (mean/SD)	60.4/16.9	51.5/11.9	77.7/10.3	t = -8.18	<0.01
PANSS ^d positive component (mean/SD)	11.8/4.3	13.6/4.4	8.2/2	t = 5.06	<0.01
PANSS ^d negative component (mean/SD)	13/5.3	15.2/5.1	8.8/2.3	t = 6.37	<0.01
PANSS ^d general component (mean/SD)	25.8/6.3	28.7/5.5	20.7/4.8	t = 5.33	<0.01
SFS ^e total score (mean/SD)	108.3/10.5	103.2/7.8	117.6/8.2	t = -6.33	<0.01
CDSS ^f total score (mean/SD)	4.3/4.3	5.3/4.1	2.4/3.7	t = 2.45	0.02
RSES ^g	21.9/6.9	21.5/5.9	23.2/9.8	t = -0.73	0.47
AUDIT ^h (median/range)	5/0–28	5/0–28	3/0–15	U = 169	0.06
DUDIT ⁱ (median/range)	0/0–42	0/0–42	0/0–4	U = 237	0.52

P-values in bold are statistically significant.

^a EASE; Examination of Anomalous Self-Experiences.^b GAF-S; Global Assessment Functioning Scale split version – Symptom.^c GAF-F; Global Assessment Functioning Scale split version – Function.^d PANSS; Positive and Negative Syndrome Scale.^e SFS; Social Function Scale.^f CDSS; Calgary Depression Scale for Schizophrenia.^g RSES; Rosenberg Self-esteem Scale.^h AUDIT; Alcohol Use Identification test.ⁱ DUDIT; Drug Use Disorder Identification Test.

Table 3Bivariate correlation, paired samples *t*-test, and Wilcoxon signed rank test between baseline and follow-up scores.

	Correlations		Paired samples <i>t</i> -test					t-value	<i>P</i> -value
			Paired differences						
			Mean	SD	Std. Err. Mean	99% CI			
	<i>r</i> -value	<i>P</i> -value				Lower	Upper		
EASE total score	0.541	<0.01	−5.50	10.20	1.36	9.14	1.86	4.04	<0.01
GAF function	0.509	<0.01	21.52	14.55	1.94	16.33	26.71	11.07	<0.01
GAF symptom	0.400	<0.01	19.61	16.09	2.15	13.87	25.34	9.12	<0.01
PANSS positive	0.440	<0.01	−5.04	5.00	0.67	6.82	3.25	7.53	<0.01
PANSS negative	0.426	<0.01	−3.50	7.02	0.94	6.00	1.00	3.73	<0.01
PANSS general	0.344	<0.01	−11.79	9.22	1.23	15.07	8.50	9.57	<0.01
CDSS total score	0.447	<0.01	−4.04	5.39	0.72	5.96	2.11	5.60	<0.01
SFS total score	0.500	<0.01	4.37	9.62	1.35	0.76	7.97	3.24	<0.01
RSES score	0.455	<0.01	−4.02	6.75	0.96	−5.96	−2.08	−4.17	<0.01

	Rho	<i>P</i> -value	Median	Min	Max	Wilcoxon signed rank test	<i>P</i> -value
AUDIT total score ^a	0.607	<0.01	−1.00	−17.0	11.0		=0.01
DUDIT total score ^a	0.447	=0.01	0.00	−5.0	23.0		0.92

^a Nonparametric tests are used for AUDIT and DUDIT because of a skew distribution.

4. Discussion

4.1. General discussion

Consistent with recent reviews, as many as one third of all participants in the present study achieved recovery at follow-up (Lally et al., 2017). We found that a lower EASE total score at baseline and reduction of EASE total score from baseline to follow-up increased the chance of recovery seven years later, also after adjustment for other characteristics previously found to influence the outcome (diagnosis, DUP, premorbid functioning). These characteristics had statistically significant bivariate associations with recovery in the current study but had less explanatory power than the EASE level when entered together in multi-variate analyses. Most notably, the findings were not confounded by diagnosis.

The considerable impact of high levels of BSDs on mental state and functioning is in many ways self-evident. The weakening or loss of ownership of one's own thoughts, feelings, sensations, body,

movements, or personal history will influence life markedly. Even though these phenomena pertain to the person's inner world and are not visible to others, they regularly lead to compromised engagement with the outer world (Nelson et al., 2009), reduced capacity to interact with other people, to work, to study or to maintain self-care. This is in line with studies showing associations between BSDs and self-esteem, depression (Haug et al., 2016), suicidality (Haug et al., 2012b; Skodlar and Parnas, 2010), social function (Haug et al., 2014), verbal memory (Haug et al., 2012c), and negative symptoms (Nordgaard et al., 2018). According to the ipseity disturbance model (Nelson et al., 2014; Sass and Parnas, 2003) BSDs serve as precursors or vulnerability factor for developing psychotic symptoms, also indicating that changes in the level of BSDs may lead to changes in symptomatology and functioning.

Based on the notion that BSDs are core features in schizophrenia, it has been presumed that they are reasonably stable over time. Although there is considerable support for this view (Nordgaard et al., 2017; Nordgaard et al., 2018), a previous report has

Fig. 1. Scatterplot of EASE total score at baseline by change in EASE total score over the follow up period.

Table 4

Hierarchical logistic regression analysis with recovery as the dependent variable and EASE total score at baseline, EASE total score change, DUP, premorbid academic function, premorbid social function and diagnosis as independent variables.

Dependent variable: Recovery	B	P	95% CI
EASE total score at baseline	−0.31	<0.01	0.62 to 0.87
EASE total score change	−0.26	<0.01	0.65 to 0.90

Dependent variable: Recovery	B	P	95% CI
EASE total score at baseline	−0.32	<0.01	0.60–0.87
EASE total score change	−0.28	<0.01	0.63–0.90
Premorbid academic function	−0.49	0.23	0.26–1.13
Premorbid social function	−0.41	0.12	0.39–1.12

Dependent variable: Recovery	B	P	95% CI
EASE total score at baseline	−0.29	<0.01	0.61–0.91
EASE total score change	−0.29	<0.01	0.62–0.91
Premorbid academic function	−0.47	0.25	0.28–1.40
Premorbid social function	−0.42	0.13	0.38–1.14
LnDUP	−0.63	0.27	0.17–1.65

Dependent variable: Recovery ^a	B	P	95% CI
EASE total score at baseline	−0.20	0.03	0.67–0.98
EASE total score change	−0.26	<0.01	0.60–0.92
Premorbid academic function	−0.55	0.21	0.25–1.36
Premorbid social function	−0.43	0.14	0.37–1.15
LnDUP	−0.48	0.45	0.18–2.12
Diagnosis	2.32	0.06	0.87–118.8

^a Model Nagelkerke R square: 0.67.

shown a modest but statistically significant reduction in BSDs from baseline to follow-up (Svendsen et al., 2018). This support the need to further explore the potential for a changeable and treatment-responsive aspect of some BSDs. Recent ideas suggest that certain BSD phenomena can be triggered by or are reactive to stressors (Sass et al., 2018; Sass and Borda, 2015), and may thus be considered more ‘secondary’, while other phenomena are more foundational or ‘primary’. This might imply that at least some BSDs could remit with the removal of the stressor, or through treatment efforts specifically targeting the relevant BSDs. In the current study, therapists received a report from the baseline EASE interview. Most participants had long-term treatment contact, and the therapists’ knowledge of the presence and type of specific BSD features could possibly have directed the focus of psychosocial interventions. Our follow-up data does however not contain any qualitative information about treatment at this level of detail. Further research is required to study interventions specifically targeting BSDs.

4.2. Strengths and limitation of the study

4.2.1. Strengths

The study had few exclusion criteria, so the sample was broadly recruited through the Norwegian national public mental health system. There are almost no private mental health care in Norway, and the sample thus represents a comprehensive, near-to epidemiological sample of first treated psychosis. To our knowledge, this study has the longest follow-up period of studies using EASE. The study also had a fairly high follow-up rate (62%). The person who conducted the assessments of BSDs at follow-up was blind to baseline data and to the results of the diagnostic interviews at follow-up. The results of this study is found also after adjusting for diagnostic categories.

4.2.2. Limitations

Remission and recovery are both parts of a continuum. While there is a consensus about a cut-off for the term “recovery”, the experience of recovery is also a uniquely personal process and

participants that did not meet these criteria could still have a functional and meaningful life. The definition of recovery was based on psychotic symptoms. Since this definition does not include affective symptoms, we cannot rule out that some in the recovery group experienced depression or elevated mood at follow up. A total of 38% of the patients from the baseline study did not participate in the follow-up study; however, there was no indication that the attrition was biased. The sample size is low, increasing the risk for type II errors and for overestimating the effect sizes of positive findings. Finally, we are highlighting the findings relating to BSDs since they are seen as more basic and stable traits compared to clinical symptoms, but any conclusions regarding causality should be drawn with caution.

4.2.3. Conclusion

Low baseline level of basic self-disturbances in first treated psychotic disorders, and further reduction over time, independently predicted recovery seven years later. These findings strongly support the clinical value of including BSDs as core measures in the routine assessment of psychotic disorders.

Contributions

EH, MØ, PM and IM planned the original study, while EH, MØ, IM, BN and IHS planned the follow-up study. IHS and EH conducted the follow-up. IHS conducted the follow-up interviews, the statistical analyses and wrote the first draft of the paper. All authors made contributions to interpretations and content.

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Declaration of competing interest

The authors report no conflicts of interest.

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RESEARCH ARTICLE

Basic self-disturbances are associated with Sense of Coherence in patients with psychotic disorders

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Abstract

Background

The *Sense of Coherence* (SOC) theory gives a possible explanation of how people can experience subjective good health despite severe illness. Basic self-disturbances (BSDs) are subtle non-psychotic disturbances that may destabilize the person's sense of self, identity, corporeality, and the overall 'grip' of the world.

Aim

Our objective was to investigate associations between BSDs and SOC in patients with psychotic disorders.

Design

This is a cross-sectional study of 56 patients diagnosed with psychotic disorders inside and outside the schizophrenia spectrum (35 schizophrenia, 13 bipolar, and eight other psychoses). SOC was measured using Antonovsky's 13-item SOC questionnaire, and BSDs were assessed using the Examination of Anomalous Self-Experience (EASE) manual. Diagnosis, symptoms, and social and occupational performance were assessed using standardized clinical instruments.

Results

We found a statistically significant correlation ($r = -0.64$, $p < 0.001$) between high levels of BSDs and low levels of SOC. This association was not influenced by diagnostics, clinical symptoms or level of functioning in follow-up multivariate analyses.

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Conclusion

A statistically significant association between BSDs and SOC indicates that the presence and level of self-disturbances may influence the person's ability to experience life as comprehensive, manageable and meaningful. However, the cross-sectional nature of the study precludes conclusions regarding the direction of this association.

Introduction

The personal experience of health is complex and dynamic and relies on physical, social and mental factors [1]. According to the salutogenesis theory, an approach focusing on factors that support health and wellbeing, the experience of health is on a continuum from good health to poor health dependent on the individual's internal and external coping resources [2]. Aron Antonovsky's "Sense of Coherence (SOC)" theory is used to explain the apparent contradiction that people with severe illnesses report a subjective experience of good health.

According to this theory, the SOC comprises three theoretically separable but closely interwoven core components that include:

- 1) Comprehensibility: Refers to the extent to which a person perceives internal and external stimuli as rationally understandable and as information that is orderly, coherent, clear, structured rather than noise.
- 2) Manageability: Refers to the degree to which a person feels that there are resources at his/her disposal that can be used to meet the requirements of the stimuli that bombards him/her.
- 3) Meaningfulness: Refers to the extent to which a person feels that life has emotional meaning, that at least some of the problems faced in life are worth commitment and dedication, and are seen as challenges rather than as burdens [3].

These three core components can vary over time. A person can experience life as manageable but not explainable or meaningful, and later on as meaningful but not predictable and manageable [4]. A high SOC indicates the ability to make sense of the world, in a way that facilitates successful coping with the countless and complex stressors we confront throughout life [2].

Longitudinal studies of healthy teenagers [5], students [6] and unselected general population samples [7] show that a person's SOC is relatively stable throughout life. A 13-year follow-up study of 552 individuals followed from childhood to adulthood, found that SOC tended to increase with age and was most stable in those with a high SOC at study baseline [8]. While SOC is not seen as a personality trait, it is closely related to other personal resources such as self-esteem [9, 10].

Both quantitative and qualitative studies support the notion that a high SOC contributes to a high subjective quality of life [11]. Good health, and in particular, good mental health is also related to a high SOC. The original SOC theory takes the possibility of people refusing to acknowledge facts into account; i.e. the possibility of having a "false" SOC [3]. Loss of insight, especially the lack of awareness of positive- and cognitive symptoms, is common in patients with schizophrenia [12, 13]. Loss of insight could thus influence the association between SOC and mental health in schizophrenia. However, a study of 136 patients with schizophrenia or schizoaffective disorder, showed a statistically significant association between a low SOC and a high level of negative symptoms [14]. Another study of 120 patients with schizophrenia and schizoaffective disorder, showed a statistically significant association between low SOC and

high levels of positive, negative and affective symptoms including anxiety, guilt feelings, tension and depressive mood [15].

Contemporary phenomenology distinguishes between the *core- or basic self and the narrative self* [16, 17]. The *basic self* is a pre-reflective level of selfhood. The basic self refers to the first-person quality of a person's experiences and is entirely implicit in—and inseparable from—the act of experiencing in itself, i.e. all subjective experience implies a self who is having the experience [18]. The concept of a basic self derives from the given fact that there is an implicit "ownership" of experience and in other words comprises the tacit awareness that "this is my experience". As the term indicate, the basic self is the foundation upon which other aspects of the self, such as the narrative self, are based. The narrative self exists on a reflective and articulated level. The narrative self is the experience of the self as having particular characteristics, personality traits, values and history [19].

Basic self-disturbances are disturbances in the basic, pre-reflective self [19]. BSDs affect a person's ability to have an adequate interpretation of his/her inner feelings and thoughts and diminish the feeling of ownership of one's body, movements and personal history. BSDs will thus likely affect how a person experiences his/her existence as comprehensive, manageable and meaningful, i.e. influence the person's SOC.

Both SOC and BSDs are closely linked to the clinical severity of mental illness [20–28], more knowledge about the relationship between SOC and BSDs give us insight into the challenges experienced by people with schizophrenia and other psychotic disorders. We here aim to investigate the relationship between BSDs and SOC in patients with psychotic disorders. To our knowledge, this is the first study that focuses directly this potential relationship. Our main hypothesis, as outlined above, is that patients with high level of BSDs will experience low SOC. Since high levels of BSDs are associated with high levels of symptoms and high levels of symptoms potentially associated with low SOC, we also investigate to what extent a putative association between BSDs and SOC is mediated by clinical severity, including the severity of symptoms of psychosis and functional loss.

Material and method

Sample

The current study is based on a seven-year follow-up of a cohort of first-treatment patients recruited in the period 2008–2009, in a sub-study of the Norwegian "Thematically Organized Psychosis" (TOP) study. The original inclusion criteria were: 1) Entering the first treatment for a broadly defined psychotic disorder a) schizophrenia, schizophreniform disorder or schizoaffective disorder ("SZspect") or b) psychotic bipolar disorder PBD I, II and NOS or delusional disorder and psychosis NOS ("non-SZspect"). 2) Age between 18 and 65 years and 3) IQ > 70. Ninety patients met the criteria at baseline, for details see Haug et al. [29]. All participants were able and willing to consent. Ability to consent was determined in the following way: The patients were referred to the study by their treating clinician, who made the first evaluation of their ability to participate. The consent form was presented in both written and oral form to the patient by the interviewer, and questions regarding the study was discussed to make sure that the participant understood its content. Finally, the results of the symptom interviews, in particular the levels of psychotic symptoms, insight and disorganization were taken into account. Of the initial 90 patients recruited at baseline, 56 (62%) provided informed consent to participate in the follow-up study. All 34 patients who did not participate were alive; 19 did not want to participate, and we were unable to contact another 15 despite several attempts. The study was approved by the Regional Committee for Medical Research Ethics, South-East Norway.

Assessments

All participants were evaluated with an extensive clinical assessment. Only the instruments relevant to this part of the study are presented below.

Assessment of Sense of Coherence (SOC). SOC was measured with the SOC-13, a self-report questionnaire comprising thirteen questions. Each question links to one of the core components of the SOC (i.e. comprehensibility, manageability, and meaningfulness) [4]. Studies of the psychometric properties of the SOC-13 scale have shown high levels of validity and reliability [30], and internal consistency is found to be very good with Cronbach's alphas ranging from 0.70 to 0.92 in the 127 studies using SOC-13 [2, 31].

In the current study, we used a version of SOC-13 modified to make it easier to understand for patients with severe psychiatric problems and previously used in a study of patients in acute psychiatric units in Norway [32]. The modified questionnaire asks the same questions as the original version but includes predefined answers on 1–5 scale instead of the original 1–7 Likert scale. The possible range of the SOC-13 score is thus 13 to 65, with high scores indicating good SOC.

Assessment of basic self disturbances. BSDs were assessed with the *Examination of Anomalous Self Experience* (EASE) manual [30] by the first author (IHS). IHS was trained in the use of EASE by EH (a certified EASE instructor) and PM (one of the original EASE authors). The inter-rater reliability (IRR) for the EASE assessments in the study was good [33–35].

The EASE manual is usually employed to capture the lifetime experience of BSDs, but the time range can be adjusted to the aim of the study [33]. Since one of the original study aims was to assess changes in BSD over time, we here measured BSDs experienced over the last two years before follow-up.

The EASE has 57 main items divided into five domains: (1) Cognition and stream of consciousness, (2) Self-awareness and presence, (3) Bodily experiences, (4) Demarcation/transitivism, and (5) Existential reorientation. BSDs is not conceptualized as discrete symptoms but as interconnected and highly overlapping aspects of a coherent Gestalt. Both items and domains are statistically highly inter-correlated because of overlap between single items and domains [23,28]. The items are scored using a 5-point scale (0–4), 0 = absent; 1 = questionably present; 2 = definitely present, mild; 3 = definitely present, moderate; 4 = definitely present, severe. The items were dichotomized into 0 (for absent or questionably present) and 1 (for definitely present comprising all severity levels) for the current analyses. Item 2.13 (anxiety) was not included in the analyses since this item is not a BSD per se [36] but primarily served as a contrast to the subsequent EASE-item (2.14), ontological anxiety [33].

Diagnostics and symptom evaluation. Diagnoses were ascertained by trained clinical psychologists or medical doctors using the Structured Clinical Interview for DSM-IV Axis I disorders (SCID module I, chapter A-E) [36]. An independent samples t-test showed no differences between the bipolar and other psychosis for the SOC score, the EASE total score or any EASE domain scores. These two participant groups were merged into one group, representing psychotic disorders outside of the schizophrenia spectrum (non-SZspect) for the statistical analyses.

Current symptom severity was measured with the Global Assessment Functioning Scale, Symptoms (GAF-S) [37, 38] and the Positive and Negative Syndrome in Schizophrenia Scale [39]. We used the Structured Clinical Interview for PANSS (SCI-PANSS) and report Wall-work's five-factor model constituting positive, negative, disorganized, excitement and depressive symptoms [40]. PANSS item G12 (Lack of judgment and insight) was used as a measure of lack of clinical insight. Social functioning was assessed by the Global Assessment

Functioning scale, Function (GAF-F) [37, 38] and the Social Function Scale (SFS). The SFS covers the area of social contacts, independent living and vocational activities, with a high level of internal consistency for the scales and subscales [41–43]. The first author (IHS) conducted all assessments except the diagnostic interviews.

Statistical analyses. All analyses were done using SPSS version 23.0 (SPSS Inc., Chicago, IL, USA). In addition to investigate the primary research question of an association between EASE and SOC, we did follow up analyses exploring associations between their subdomains (five in EASE and three in SOC). The p value was thus preset to $p < 0.01$ to adjust for multiple testing. Means and standard deviations are reported for continuous variables and percentages for categorical variables. We used bivariate correlations (Pearson's r) to evaluate associations. Finally, a multiple linear regression analysis was used to assess the influence of clinical symptoms on the association between SOC and BSDs. The effect of potential confounders we evaluated through their bivariate associations with SOC and EASE). Based on a total $N = 56$ we restricted the number of independent variables to 5–6. Due to the high degree of association between different measures of symptoms, and between different measures of functioning, we chose to represent the two areas by the GAF-S and GAF-F scores, respectively. Substituting these with PANSS or SFS scores did not change the main results. Violations of assumptions of normality, homoscedasticity, linearity and multicollinearity were investigated for the final model.

Results

Clinical and demographic data are shown in Table 1. The correlation matrix indicates a statistically significant correlation ($p < 0.01$) between SOC and all clinical measures except PANSS NEG and PANSS DIS (Table 2). There were statistically significant differences ($p < 0.01$) in the EASE total score, GAF S, GAF F, PANSS POS and PANSS DIS between the two diagnostic groups, but no differences in the SOC-13 total score in bivariate analyses (Table 3).

There was a statistically significant (negative) correlation between the SOC-13 total score and the EASE total score ($r = -0.54/p < 0.001$) (Table 4). The follow-up analyses indicated statistically significant negative correlations between the main parts of the EASE domain scores and the SOC components, with the highest r 's for the associations between SOC and EASE domain 2, Self-awareness and presence (Table 4, in bold).

We then investigated if clinical characteristics mediated the association between SOC and BSDs (EASE total score) (Table 5).

The results of the regression analysis showed a statistically significant association between SOC and BSDs, in the direction that high levels of BSDs contributed to low levels of SOC. The analysis also indicated that the association between SOC and BSDs was independent of

Table 1. Clinical and demographic data.

	N	
Male (N/%)	56	28/50
Age (mean/median/SD)	56	32.2/29/7.4
Sense of Coherence (SOC) total score (mean/SD)	55	41.2/10.6
Examination of Anomalous Self-Experiences * (EASE) total score (mean/SD)	56	11.7/8.9
Global Assessment Functioning Scale split version–Symptom (GAF-S) (mean/SD)	56	57.2/16.8
Global Assessment Functioning Scale split version–Function (GAF-F) (mean/SD)	56	60.4/16.9
Positive and Negative Syndrome Scale (PANSS) total score (mean/SD)	56	50.7/13.5
Social Functioning Scale (SFS) (mean/SD)	53	107.6/10.4

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Table 2. Correlation between SOC-13, EASE, clinical measures.

	EASE total score	GAF symptom	GAF function	PANSS POS	PANSS NEG	PANSS DEP	PANSS EXC	PANSS DIS	SFS total
SOC 13 total score	-0.544* p<0.001 N55	-0.516* p<0.001 N55	-0.407 p = 0.002 N55	-0.362 P = 0.007 N55	-0.175 p = 0.201 N55	-0.632* p<0.001 N55	-0.393 p = 0.003 N55	-0.037 p = 0.790 N55	0.483 p<0.001 N53
EASE total score		-0.671* p<0.001 N56	-0.425 p = 0.001 N56	0.633* p<0.001 N56**	0.227 p = 0.092 N56	0.662* p<0.001 N56	0.481* p<0.001 N56	.453* p<0.001 N56	-0.468* p<0.001 N54
GAF symptom			-0.791* p<0.001 N56	-0.694* p<0.001 N56	-0.545* p<0.001 N56	-0.644* p<0.001 N56**	-0.419 p = 0.001 N56	-.567* p<0.001 N56	-0.708* p<0.001 N54
GAF function				-0.491* p<0.001 N56	-0.622* p<0.001 N56	-0.425 p = 0.001 N56	-0.370 p = 0.005 N56	-.459* p<0.001 N56	-0.734* p<0.001 N54
PANSS POS					0.245 p = 0.069 N56	0.486* p<0.001 N56	0.491* p<0.001 N56	.529* p<0.001 N56	-0.447 p = 0.001 N54
PANSS NEG						0.229 p = 0.090 N56	0.09 p = 0.510 N56	.449 p = 0.001 N56	-0.695* p<0.001 N54
PANSS DEP							0.422 p = 0.001 N56	0.159 p = 0.243 N56	-0.490* p<0.001 N54
PANSS EXC								0.290 p = 0.030 N56	-0.228 p = 0.097 N54
PANSS DIS									-0.369 p = 0.006 N54

* Correlation is significant at the < 0.001 level (2-tailed).

SOC, Sense of coherence; EASE, Examination of Anomalous Self-experience; GAF, *Global Assessment Functioning Scale*; PANSS, Positive and Negative Symptom Scale; POS, Positive; NEG, Negative; DEP, Depressive; EXC, Excitatory; DIS, Dissociative; SFS, Social Functioning Scale

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diagnostic group, and not mediated by levels of clinical symptoms or dysfunction. The level of clinical insight did not confound the analyses.

Table 3. Independent samples t-test between the diagnostic groups (SZspect and non-SZspect).

		N	Mean	SD	t	p-value
SOC total score	Szspect	34	40,9	10,47	-0,35	0,725
	Non-SZspect	21	41,9	11,08		
EASE total score	Szspect	35	14,7	9,14	3,57	0.001
	Non-SZspect	21	6,8	5,78		
GAF symptom	Szspect	35	51,2	15,35	-3,84	<0.001
	Non-SZspect	21	67,1	14,54		
GAF function	Szspect	35	55,1	15,94	-3,31	0.002
	Non-SZspect	21	69,2	14,82		
SFS total score	Szspect	33	105,6	10,65	-2,44	0,018
	Non-SZspect	21	112,4	8,90		
PANSS POS	Szspect	35	8,1	3,65	4,62	<0.001
	Non-SZspect	21	4,9	1,62		
PANSS NEG	Szspect	35	12,4	4,72	2,47	0,017
	Non-SZspect	21	9,4	3,68		
PANSS DEP	Szspect	35	7,9	2,80	1,62	0,110
	Non-SZspect	21	6,5	3,25		
PANSS EXC	Szspect	35	4,9	1,25	1,59	0,117
	Non-SZspect	21	4,4	0,81		
PANSS DIS	Szspect	35	5,4	2,37	4,93	<0.001
	Non-SZspect	21	3,3	0,58		

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Table 4. Correlations (Pearson's *r*) between SOC-13 and EASE scores.

	EASE Total Score <i>r</i> /p-value	Domain 1 <i>r</i> /p-value	Domain 2 <i>r</i> /p-value	Domain 3 <i>r</i> /p-value	Domain 4 <i>r</i> /p-value	Domain 5 <i>r</i> /p-value
SOC components						
Comprehensibility	-0.51' <0.001	-0.40/0.003	-0.55/<0.001	-0.42/0.002	-0.30/0.025	-0.32/0.019
Manageability	-0.45/0.001	-0.36/0.004	-0.41/0.002	-0.32/0.018	-0.40/0.003	-0.26/0.06
Meaningfulness	-0.46/<0.001	-0.28/0.04	-0.54/<0.001	-0.35/0.009	-0.19/0.16	-0.35/0.009
SOC-13 Total Score	-0.54/<0.001	-0.41/0.002	-0.55/0.001	-0.42/0.002	-0.33/0.014	-0.36/0.007

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Discussion

In line with our hypothesis, we found a statically significant association between SOC and BSDs, in the direction that patients with high levels of BSDs had low levels of SOC. The association was strongest for EASE domain 2: Self-awareness and presence. As expected, we also found associations between SOC, BSDs and clinical characteristics. However, the association between SOC and BSDs was not mediated by clinical symptoms, dysfunction, level of insight or diagnostic group.

BSDs comprises a disordered experience of thoughts, feelings, and sensations with consequential fundamental loneliness, despite access to relationships with others [26, 44, 45]. This counteracts trust in- and access to the person's own and others' resources and abilities, that are needed to handle difficult situations. The experience of loss of common sense makes everyday life appear as complicated and unnatural. Even trivial tasks have to be thought through in a deliberate and careful (rather than an automatic and intuitive) fashion [19, 46, 47], creating uncertainty around the performance of actions others take for granted. The experience that life is coherent, consistent and predictable is thus influenced in a negative way. BSDs also comprise a diminished first-person perspective, disrupting awareness of own actions and reducing the ability to be touched, moved or motivated by other people, events or situations [48]. This impaired awareness may weaken the experience of personal involvement in own life and the experience of life as meaningful.

In particular EASE domain 2 (i.e. self-awareness and presence) comprises changes in the experience of a normally tacit and pre-reflective self-presence. The items included in this domain are thus associated with diminished potentials for activity and pleasure, diminished

Table 5. Multiple linear regression models with SOC-13 total score as dependent variable.

	Beta	t	p-value	95.0% CI		Collinearity Statistics	
				Lower	Upper	Tolerance	VIF
Model 1							
(Constant)		24.3	< 0.001	44.76	52.803		
EASE total score	-0.544	-4.72	< 0.001	-0.93	-0.375	1.000	1.000
Model 2							
(Constant)		5.70	< 0.001	34.54	72.12		
GAF-F	0.177	0.82	0.42	-0.16	0.39	0.24	4.19
GAF-S	0.079	0.43	0.67	-0.19	0.29	0.32	3.11
Insight	-0.223	-1.75	0.09	-6.73	0.46	0.69	1.46
Diagnoses	-0.344	-2.81	0.006	-12.79	-2.11	0.74	1.35
EASE total score	-0.498	-3.32	0.002	-0.96	-0.24	0.50	2.01

CI indicates Confidence Interval; EASE, Examination of Anomalous Self-experience; GAF- F Global Assessment Functioning scale, Symptom; GAF-S, Global Assessment Functioning scale, Function; Insight, PANSS item G12 (Lack of judgement and insight); Diagnoses, SZspect vs. Non-SZspect

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engagement in the world and experiences of alienation [33]. The SOC concept includes predictability, manageability and meaningfulness. It is difficult to experience life as predictable in the context of experiencing the world as unnatural and strange, to experience life as manageable in the context of actively monitoring inner life and external reality and to experience meaningfulness in the context of severe estrangement.

Significant associations between two apparently different concepts can be based on overlapping criteria. There are, however, major differences in the way BSDs and SOC are assessed. The EASE manual is a comprehensive, in-depth interview made to elicit information about BSDs as complex, and often unexpressed, experiences or phenomena. The interviewer explores these phenomena together with the patient beyond the immediate answer to the question. The use of a particular word or metaphor is examined to grasp the patient's interpretation of the underlying phenomenon that can be literal, concrete or outside of the usual understanding of a concept [33]. The SOC-13, on the other hand, is a short self-report questionnaire assessing the person's global experience of comprehensibility, manageability and meaningfulness [4]. The self-report form precludes any further exploration of the answers, and mainly captures the person's immediate response to the question. There are questions in the SOC-13 and EASE-interview that appear closely related at first glance. SOC: "How often do you have the feeling that you are in an unfamiliar situation and do not know what to do?" EASE: "Have you ever experienced that you no longer understand natural things in life, that it is difficult to understand situations, people and objects?" The follow-up clarifications in the EASE interview, however, counteract the use of overlapping criteria.

The findings also support the notion that BSDs and SOC relate to different types of self-awareness: While BSDs are associated with the basic level of the self, SOC is associated with the narrative level. This assumption is the basis for interpreting BSDs as independent contributors to poor SOC, in patients with psychosis. The results of the multiple linear regression analyses also indicate that the association between BSDs and SOC is not confounded or mediated by clinical symptoms or social dysfunction. However, the correlational nature of this study precludes firm conclusions regarding the direction of the associations, or causality. SOC theory is used to explain the apparent contradiction that people with severe illnesses have a subjective experience of good health. In this study, there was a negative association between the level of symptomatology and the level of SOC. It is also of interest that lack of clinical insight contributed to a lower SOC, and did not influence the association between BSDs and SOC. Also, while some participants reported both high symptom levels and high SOC, this discrepancy was not explained by a lack of insight.

Experience of health is linked to personal history and influenced by access to resources and the impact of illness. Both BSDs and SOC captures subjective experiences and needs to be specifically explored by clinicians wanting to understand the subjective world of their patients. By taking a salutogenic position, the clinician and the patient can explore how different challenges in life, including the presence of BSDs, impact the experience of health and coherence. This exploration can serve as the basis for identifying resources and initiating interventions that strengthen the patient's experience of health.

Strengths of this study include: That the sample was broadly recruited from the Norwegian national health service offering public mental health care to all individuals with mental illness with few exclusion criteria. The participants represent a comprehensive, near to epidemiological sample.

Limitations include: While the current SOC-13 form is thought to be easier to use for patients with mental disorders, the use of the original form with a seven-point Likert scale could potentially give richer data through a wider range of scores. In addition, the study has

no explicit measure of the subjective experience of health, which could have strengthened the study.

Conclusion

This study is the first to demonstrate a statistically significant association between BSDs and SOC. The association is particularly high between SOC and the EASE domain 2, self-awareness and presence. The association is not influenced by diagnostic category, clinical symptoms and social dysfunction. Further research exploring this relationship, including the direction of the association, potential indications of causality and implications for treatment is needed.

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Paper 3 Supplementary material

Sense of Coherence 13 item questionnaire (SOC-13)

Modified version used in this study

1	How often does it happen that you are surprised by the behaviour of people whom you thought you knew well?				
	1. Very often	2. Often	3. Sometimes	4. Seldom	5. Very seldom
2	How often do you have the feeling that you are in an unfamiliar situation and don't know what to do?				
	1. Very often	2. Often	3. Sometimes	4. Seldom	5. Very seldom
3	How often do you have conflicting thought and feelings?				
	1. Very often	2. Often	3. Sometimes	4. Seldom	5. Very seldom
4	How often do you have the feeling that you're being treated unfairly?				
	1. Very often	2. Often	3. Sometimes	4. Seldom	5. Very seldom
5	Many people sometimes feel like sad sacks (loser) in certain situation. How often did you feel this way in the past?				
	1. Very often	2. Often	3. Sometimes	4. Seldom	5. Very seldom
6	How often does it happen that people whom you counted on disappointed you?				
	1. Very often	2. Often	3. Sometimes	4. Seldom	5. Very seldom
7	How often do you have the feeling that there's little meaning in the things you do in your daily life?				
	1. Very often	2. Often	3. Sometimes	4. Seldom	5. Very seldom
8	Until now; have your life had a clear goal and purpose?				
	1. No	2.	3. Hard to tell	4.	5. Yes
9	Are the things you do in your everyday life a source of deep pleasure and satisfaction?				
	1. No	2.	3. Hard to tell	4.	5. Yes
10	Does it happen that you have feelings inside you would rather not feel?				
	1. Very often	2.	3. Sometimes	4.	5. Very seldom
11	How often do you have the feeling that you don't really care about what goes on around you?				
	1. Very often	2.	3. Sometimes	4.	5. Very seldom
12	How often do you have feelings that you're not sure you can keep under control?				
	1. Very often	2.	3. Sometimes	4.	5. Very seldom
13	When something happened, have you generally found that:				
	1. You overestimated or underestimated its importance	2.	3. Neither nor	4.	5. You saw things in the right proportion

Sense of Coherence 13 item questionnaire (SOC-13)

Original version

Question 1, 2, 3, 7, 10 shall be reversed.

1.	Do you have feeling that you don't really care about what goes on around you?						
	1.	2.	3.	4.	5.	6.	7.
	Very seldom					Very often	
2.	Has it happened in the past that you were surprised by the behavior of people whom you thought you knew well?						
	1.	2.	3.	4.	5.	6.	7.
	Never happened					Always happened	
3.	Has it happened that people whom you counted on disappoint you?						
	1.	2.	3.	4.	5.	6.	7.
	Never happened					Always happened	
4.	Until now your life had:						
	1.	2.	3.	4.	5.	6.	7.
	No clear goals or purpose at all (1)				Very clear goals and purpose (7)		
5.	Do you have the feeling that you're being treated unfairly?						
	1.	2.	3.	4.	5.	6.	7.
	Very often					Very seldom or never	
6.	Do you have the feeling that you are in an unfamiliar situation and don't know what to do?						
	1.	2.	3.	4.	5.	6.	7.
	Very often					Very seldom or never	
7.	Doing the thing you do every day is:						
	1.	2.	3.	4.	5.	6.	7.

	A source of deep pleasure and satisfaction (1)	A source of pain and boredom (7)
8.	Do you have mixed –up feelings and ideas?	
	1.	2. 3. 4. 5. 6. 7.
	Very often Very seldom or never	
9.	Does it happened that you have feelings inside you would rather not feel?	
	1.	2. 3. 4. 5. 6. 7.
	Very often Very seldom or never	
10.	Many people – even those with strong character – sometimes feel like sad sacks (loser) in certain situations. How often have you felt this way in the past?	
	1.	2. 3. 4. 5. 6. 7.
	Never Very often	
11.	When something happened, have you generally found that	
	1.	2. 3. 4. 5. 6. 7.
	You always over – or under-estimate its importance (1)	You saw thing in right proportion (7)
12.	How often do you have the feeling that there's little meaning in the things you do in your daily life?	
	1.	2. 3. 4. 5. 6. 7.
	Very often Very seldom or never	
13.	How often do you have feelings that you're not sure you can keep under control?	
	1.	2. 3. 4. 5. 6. 7.
	Very often Very seldom	

Errata

Page	Line	Original text	Type of correction	Corrected text
1	3	They have an onset...	Cor	They often have an onset...
12	1	...the EASE manual to assess...	Cor	...the EASE manual (Parnas, Moller et al., 2005) to assess...
14	21	...meeting the both he RSWG	Cor	...meeting both the RSWG...
28	27	transivitism	Cor	Transitivism