Comprehensive Psychiatry 95 (2019) 152134

Contents lists available at ScienceDirect

Comprehensive Psychiatry

journal homepage: www.elsevier.com/locate/comppsych

Perceived and experienced stigma in first-episode psychosis: A 1-year follow-up study

Carmen Simonsen[a,b,*], Sofie R. Aminoff[a,b], Anja Vaskinn[a], Elizabeth A. Barrett[a,b], Ann Faerden[a], Torill Ueland[a,c], Ole A. Andreassen[a], Kristin Lie Romm[a,b], Ingrid Melle[a]

[a] NORMENT, Division of Mental Health and Addiction, Oslo University Hospital and Institute of Clinical Medicine, University of Oslo, Norway
[b] Early Intervention in Psychosis Advisory Unit for South East Norway, Division of Mental Health and Addiction, Oslo University Hospital, Norway
[c] Department of Psychology, University of Oslo, Norway

ARTICLE INFO

Keywords:
Perceived stigma
Experienced stigma
First-Episode psychosis
Life satisfaction
Symptomatology

ABSTRACT

Objectives: Perceived/experienced stigma and its relationship with clinical outcome were investigated across the first year of treatment in a large sample with first-episode psychosis (FEP).
Methods: FEP participants (n = 112) in the TOP study were investigated at baseline and 1-year follow-up. Perceived/experienced stigma was measured with items from the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0), assessing problems because of barriers and hindrances, and living with dignity because of attitudes and actions of others. Clinical outcome included: symptoms, global functioning, self-rated disability and self-rated life satisfaction.
Results: In the total sample, 46% perceived/experienced stigma at baseline, which decreased significantly to 32% at 1-year follow-up. Perceived/experienced stigma was present in 1/5 at both time-points (Sustained stigma), in 2/5 at only one time-point (Transient stigma), and in 2/5 it was not present at either time-point (No stigma). Compared to the No stigma group, the Sustained stigma group had significantly higher levels of positive, excited and depressive symptoms and self-rated disability, as well as lower levels of global functioning and life satisfaction at 1 year follow-up, while the Transient stigma group only had poorer functioning and higher self-rated disability. Yet the outcome variables improved across the first year of treatment in all three stigma groups.
Conclusion: Perceived/experienced stigma was common in FEP, yet the rate decreased across the first year of treatment. Although there was some clinical improvement across the first year of treatment irrespective of stigma, stigma was related to poorer clinical outcome in a bidirectional manner. This suggests that perceived/experienced stigma is an important target in the early stages of treatment.

1. Introduction

In recent years there has been an increase in awareness about and research into the scope and consequences of stigma towards mental illness in general and psychotic disorders in particular. Research has found that stigma leads to reduced help-seeking, longer pathways to care, longer duration of untreated psychosis (DUP), and poorer outcome in first-episode psychosis (FEP) [1–3]. Stigma has been conceptualised in different ways [4]. A common terminological distinction in psychosis research is that of *public* and *personal* stigma [5,6]. *Public stigma* involves the general population's negative *attitudes* (prejudice) and negative *behaviour* (discrimination) towards people with mental illness [7], which is believed to result from lack of *knowledge* (ignorance or misinformation) [8]. *Personal stigma* involves people with mental illness perceiving, experiencing, and internalising public stigma [5,6]. *Perceived (or anticipated) stigma* refers to the beliefs and expectations that people with mental illness have about the general populations' stigmatising attitudes toward themselves. *Experienced (or received) stigma* refers to their actual encounter with stigmatising attitudes and behaviour from the general population. This can lead to *internalised stigma (or self-stigma),* which refers to people with mental

* Corresponding author: Carmen Simonsen, Early Intervention In Psychosis Advisory Unit for South East Norway, Oslo University Hospital, Gaustad sykehus, Sognsvannsveien 21, Oslo, Norway.
E-mail addresses: c.e.simonsen@medisin.uio.no (C. Simonsen), s.r.aminoff@medisin.uio.no (S.R. Aminoff), anja.vaskinn@medisin.uio.no (A. Vaskinn), elanba@ous-hf.no (E.A. Barrett), ann.faerden@medisin.uio.no (A. Faerden), torill.ueland@psykologi.uio.no (T. Ueland), o.a.andreassen@medisin.uio.no (O.A. Andreassen), k.l.romm@medisin.uio.no (K.L. Romm), Ingrid.melle@medisin.uio.no (I. Melle).

https://doi.org/10.1016/j.comppsych.2019.152134

illness internalising the general populations' stereotypic or stigmatising views. As this conceptualisation and terminology has been commonly used in psychosis research [5,6] it will be used in this paper, with a focus on perceived and experienced stigma.

Research on personal stigma in psychotic disorders varies in terms of methodology. Firstly, the measurement scales differ amongst the studies by either: a) being self-rated or clinician-rated; b) measuring only perceived, experienced or internalised stigma or all three; or c) assessing the *severity or frequency* of stigma or *problems because* of stigma; either across different life areas or in general. Secondly, the study samples vary in terms of diagnostic inclusion criteria involving schizophrenia only, schizophrenia spectrum disorders or psychotic disorders more broadly. This may be significant as stigma may be more severe in schizophrenia than in the other psychotic disorders. Thirdly, previous studies are cross-sectional in design, with an absence of longitudinal studies. Thus we know little about how personal stigma develops over the illness course or affects long-term outcome.

A systematic review of studies on personal stigma in schizophrenia spectrum disorders found that it is common, with 64.5% perceiving stigma, 55.9% actually experiencing stigma, and around 50% internalising stigmatising views [5]. Two more recent European studies measuring frequency of perceived and experienced stigma in first-episode psychosis (FEP) samples in their first year of treatment, report somewhat lower rates of experienced stigma ranging from 6%–43% [9,10]. This suggests that experienced stigma may increase with duration of illness [10]. However, a recent study from Singapore found that over 70% of a FEP sample experienced stigma one year after index presentation [11]. Although the ratings of stigma were based on the participants' retrospective experience the last 12 months, they did not measure stigma at both baseline and 1-year follow-up, thus preventing investigation of development across the first year of treatment. Thus the rate of perceived and experienced stigma across the early illness course requires further research in a longitudinal study.

The systematic review of studies on personal stigma also investigated its' correlates and consequences [5]. They found that both frequency and severity of perceived and experienced stigma were related to more positive psychotic and depressive symptoms, general psychopathology, and poorer functioning, and that it predicted depression, social anxiety and outcome measures such as social functioning and quality of life. These findings are supported in several more recent cross-sectional studies from England [12–14], and in the FEP study from Singapore [11]. Moreover, perceived and experienced stigma was also related to lower personal recovery [12–14]. However, the relationship between perceived and experienced stigma and clinical outcome including more general wellbeing (such as life satisfaction) across the early illness course remains to be investigated in a longitudinal study. As symptoms and functioning improve across the first year of treatment in FEP [15] the potential impact of stigma on early clinical improvement is also of interest.

The above studies use measures capturing the *frequency and severity* of perceived and experienced stigma. However, one of the studies included in the systematic review, conducted in a Turkish sample with schizophrenia, used two items from the WHODAS 2.0 to measure perceived/experienced stigma [16]. This measure assesses the *degree of problems because of:* "barriers or hindrances in the world around you" and "living with dignity because of attitudes and actions of others", thus capturing the negative consequences of stigma. For both items respondents could refer to either problems because of their own *beliefs* about the general populations stigmatising attitudes and actions, or problems because of an *actual encounter* with stigma, thus the items have been argued to measure both perceived and experienced stigma [5]. The authors found that 45% had at least moderate problems because of perceiving/experiencing stigma, and that the participants with perceived/experienced stigma had more severe psychotic, depressive and anxiety symptoms, and were more disabled than those without.

A better understanding of how rate of perceived/experienced stigma develops across the illness course in psychotic disorders, and how it relates to clinical outcome or clinical improvement, requires investigation. This is particularly important during the first years of treatment considering the significance of early intervention and negative consequences from being labelled with a psychotic disorder [17]. This calls for large-scale studies with longitudinal designs and representative FEP samples including the schizophrenia spectrum. Using a measure that captures the self-rated *degree of problems* because of perceived/experienced stigma and not merely the *frequency and severity*, may contribute to the research field.

The aims of the present study are therefore:

1 Determine rate and development of perceived/experienced stigma in FEP across the first year of treatment.
2 Investigate the relationship between perceived/experienced stigma and clinical outcome (symptomatology, global functioning, self-rated disability, self-rated life satisfaction) in FEP across the first year of treatment.

2. Methods

The current study is part of a larger planned follow-up study and it represents an additional follow-up analysis (specifically focusing on perceived/experienced stigma) involving a cohort included in a previously published paper on disability [18]. Preliminary analysis of a subset of the findings that are included in the current paper has been published previously in a poster presented at the 11th Early Intervention in Mental Health Conference (IEPA) in Boston, October 2018 [19].

2.1. Participants

The participants are thoroughly described in our previous paper [18]. However, it should be mentioned here that they were recruited from in-patient and out-patient psychiatric units across the major hospitals in Oslo between 2003 and 2014. FEP was defined as recruitment into the study within 52 weeks after the onset of adequate treatment for a psychotic disorder (i.e. hospitalisation in psychiatric wards treating psychosis or adequate dosage of antipsychotic medication for over 12 weeks or until remission). All participants were selected based on their 1-year follow-up diagnosis (Diagnostic and Statistical Manual of Mental disorders-IV (DSM-IV) (American Psychiatric Association, 1994) within the *broad schizophrenia spectrum,* which consists of "schizophrenia spectrum disorders" (schizophrenia, schizophreniform disorder, schizoaffective disorder) and "other psychosis" (delusional disorder, brief psychotic disorder and psychosis NOS). But because major depressive disorder (MDD) with psychotic symptoms meeting the A-criterion for schizophrenia can develop into diagnoses from the broad schizophrenia spectrum over time, our retention rate calculations from baseline to 1-year follow-up included participants with MDD at baseline. The retention rate is presented in a flow chart in Fig. 1. and a complete description (including exclusion because of missing data) is presented in our previous paper [18]. However, in the current study an additional 3 participants were excluded because of missing stigma variables in WHODAS 2.0, resulting in a final sample of 112 participants. As in our previous paper there was no attrition bias in this study. There was no significant demographic or clinical differences at baseline between the participants

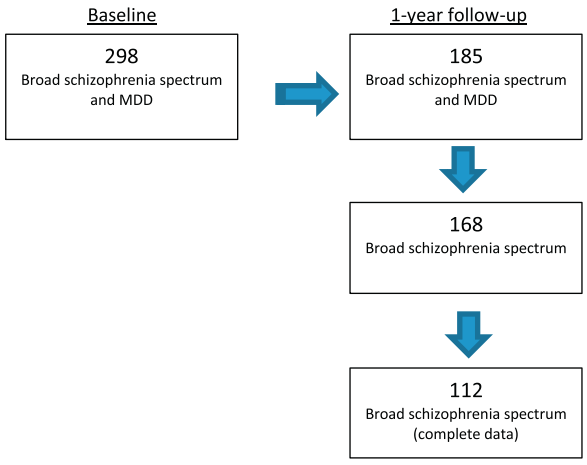

Fig. 1. Flow-chart—Attrition rate.

that completed reassessment at 1-year follow-up (completers) and those that did not (drop-outs); or between the broad schizophrenia spectrum participants reassessed at 1-year follow-up with missing WHODAS 2.0 data and those in the final sample.

Participants were excluded if they had an age outside the range of 18–65 years, hospitalised head injury, neurological disorder, unstable or uncontrolled medical condition that interferes with brain function, or IQ below 70. All participants gave written informed consent after complete description of the study and data was obtained according to the regulations of our institutions. The study was approved by the Regional Committee for Medical Research Ethics and the Norwegian Data Inspectorate.

2.2. Clinical assessment

Trained investigators (clinical psychologists and medical doctors) carried out the clinical assessment. The Structured Clinical Interview for DSM-IV Axis I disorders (SCID-I) [20] was used for diagnosis, with a satisfactory diagnostic reliability (overall agreement for DSM-IV diagnostic categories with an overall Kappa score 0.77 (95% CI: 0.60-0.949)). At baseline duration of untreated psychosis (DUP) was established based on the number of weeks from psychosis onset until start of treatment considered adequate. Psychosis was defined based on the Positive and Negative Syndrome Scale (PANSS) [21], involving a score equal to or above 4 for more than a week on either of the positive items; P1, P3, P5, P6 and G9 [22]. Alcohol Use Disorder Identification Test (AUDIT) [23] and Drug Use Disorder Identification Test (DUDIT) [24] was used to measure substance use at baseline and 1-year follow-up.

2.3. Clinical symptoms

Wallwork's PANSS – five factor model, consisting of a subset of items constituting positive, negative, disorganised, excited and depressive symptoms [25], was used to measure symptoms at baseline and 1-year follow-up because it has been found to be suitable for FEP populations [26].

2.4. Functioning

The Premorbid Adjustment Scale (PAS) [27] was used at baseline to measure social and academic premorbid functioning. For both domains we had a childhood score and developed a "change" score based on the difference between the childhood score and the latest available score [28].

The clinician-rated Global Assessment of Functioning scale Split version - function subscale (GAF-F), focusing on overall degree of social and occupational functioning [29], was used to measure Global functioning at baseline and 1-year follow-up. The GAF-F is rated from 1 to 100 with "1″ representing the hypothetically lowest possible functioning and "100″ representing the hypothetically best possible functioning.

2.5. Self-rated disability

The WHODAS 2.0 was used to measure self-rated disability at baseline and 1-year follow-up. This self-rating scale is reported reliable and valid to use across different populations of mental and physical disorders [30], including psychotic disorders [31]. The scale is described in our previous paper [18]. However, it should be mentioned here that it was developed to cover the domains in the International Classification of Functioning, Disability and Health (ICF), which recognizes that disability is a result of the interaction between health conditions and contextual factors. It consists of 36 statements falling into six domains (*1. Understanding and communicating, 2. Getting around, 3. Self-care, 4. Getting along with people, 5. Life activities, and 6. Participation in society).* The statements are rated in terms of how much of a problem this has been during the last 30 days (1 = none, 2 = mild, 3 = moderate, 4 = severe, 5 = extreme). In the current paper a total score was used as a measure of disability, excluding the two items used to measure perceived/experienced stigma, as well as the four items concerning work due to missing data.

2.6. Self-rated life satisfaction

The generic "Satisfaction with life in general" item in the Lehman's quality of life Interview, brief version [32,33] was used to measure life satisfaction at baseline and 1-year follow-up. Life satisfaction in general is rated from 1 to 7, with 1 representing very satisfied with life, and 7 representing very unsatisfied with life. Because this single item has been found to correlate highly with the 5 factors in the subjective quality of life sub-scale [32], it was used in the current study.

2.7. Perceived and experienced stigma

Perceived and experienced stigma was measured with two items in the WHODAS 2.0: 1) "*How much of a problem did you have because of barriers or hindrances in the world around you?*" and 2) "*How much of a problem did you have living with dignity because of attitudes and actions of others?*" In line with the systematic review [5], we argue that this can measure both perceived and experienced stigma. The two statements *both* measure perceived and/or experienced stigma, rather than one statement measuring perceived stigma and the other experienced stigma. The statements were rated on a 5 point Likert-type scale (1 = none, 2 = mild, 3 = moderate, 4 = severe, 5 = extreme) based on the last 30 days. In order to study stigma categorically, and in line with a previous study [16], participants with scores of 3 (moderate problems) or more for either of the two stigma items were considered to perceive/experience stigma, while participants with scores of 2 or below for both of the two stigma items were considered to not perceive/experience stigma. Moreover, the participants were classified into three stigma groups based on sustainability of stigma; 1. *Sustained stigma* included participants with perceived/experienced stigma at both time-points (baseline and 1-year follow-up); 2. *Transient stigma* included participants with perceived/experienced stigma at only one time-point (either baseline or 1-year follow-up); and 3. *No stigma* included participants without perceived/experienced stigma at either time-

point. In order to study stigma continuously, a stigma summary score was derived by averaging the two independent stigma items.

2.8. Statistical analysis

The statistical package for Social Sciences (IBM SPSS Statistics 22) was used. Analyses were two-tailed with the significance level set to 0.05. Parametric analyses were used, but because the two experienced stigma items and the stigma summary score had skewed distributions non-parametric analyses were conducted when experienced stigma was used as a continuous variable. Premorbid, demographic and clinical data for the total sample at baseline and 1-year follow-up is presented in Table 1. *Paired samples T-tests* revealed significant improvement on all clinical outcome scores apart from negative and disorganised symptoms.

The rate and development of perceived/experienced stigma in FEP across the first year of treatment was investigated by calculating rate of perceived/experienced stigma for the total sample at baseline and at 1-year follow-up. Firstly, the potential change in rate of perceived/experienced stigma from baseline to 1-year follow-up was investigated for the total sample with the *McNemar test*. Secondly, the development of the stigma summary score from baseline to 1-year follow-up was investigated for the total sample with the *Wilcoxon Signed Ranks Test*. Three groups varying in sustainability of stigma were classified (1. Sustained stigma; 2. Transient stigma; and 3. No stigma).

The relationship between perceived/experienced stigma and clinical outcome in FEP across the first year of treatment was investigated by comparing the three stigma groups on symptomatology, global functioning, self-rated disability and self-rated life satisfaction at 1-year follow-up and baseline with *One-way ANOVAs*. Comparisons between the three stigma groups on premorbid and demographic variables were also carried out by using *One-way ANOVAs* and *Chi-squared Test*. Because of skewed distribution, DUP was log-tranformed (DUPln + 1). In order to control for the potential premorbid and demographic differences between the three groups that might explain the differences in clinical outcome, follow-up analysis using an *Analysis of Covariance (ANCOVA)* was carried out.

The relationship between perceived/experienced stigma and clinical improvement across the first year of treatment was also investigated. Comparisons between the three stigma groups (between-subjects) in development of symptoms, global functioning, self-rated disability and life satisfaction from baseline to 1-year follow-up (within-subjects) were carried out using *Mixed between-within repeated measures ANOVAs.*

3. Results

At 1-year follow-up the diagnostic distribution in the total sample was schizophrenia = 63.4%, schizoaffective disorder = 4.5%, schizofreniform = 9.8% and other psychosis = 22.3%.

3.1. Rate and development of perceived/experienced stigma across the first year of treatment

Firstly, in the total sample the rate of perceived/experienced stigma significantly decreased from 46% at baseline to 32% at 1 year follow-up (*McNemar test:* $p = 0.029$), thus there is a reduction in number of participants with perceived/experienced stigma. Secondly, in the total sample the stigma summary score improved significantly from baseline to 1-year follow-up (*Wilcoxon Signed Ranks Test*: Z = -2.970, p = 0.003), suggesting a reduction in perceived/experienced stigma on an individual level. Thirdly, 20.5% perceived/experienced stigma at both time-points (Sustained stigma); 36.6% perceived/experienced stigma at only one time-point (Transient stigma) (11.6% at 1-year follow-up only and 25% at baseline only); while 42.9% did not perceive/experience stigma at either time-point (No stigma).

3.2. Relationship between perceived/experienced stigma and clinical outcome across the first year of treatment

Firstly, as presented in Table 2., the *One-way ANOVAs* comparing symptoms, global functioning, self-rated disability and self-rated life satisfaction at 1-year follow-up revealed that the *Sustained stigma group* had significantly higher levels of positive, excited and depressive symptoms and self-rated disability, as well as lower levels of global functioning and life satisfaction compared to the *No stigma group*. The *Sustained stigma group* also had significantly higher levels of positive and depressive symptoms, self-rated disability and lower life satisfaction compared to the *Transient stigma group,* which only differed from the *No stigma group* by having significantly lower global functioning and higher disability. As presented in Table 2, *Chi-squared comparison* revealed that there was no difference in diagnostic distribution at 1-year follow-up between the three stigma groups.

The same clinical differences between the stigma groups that were found at 1–year follow-up were also found at baseline. Thus already at baseline, compared to the no-stigma group, the sustained stigma group had higher levels of positive ($F = 3.71$, $p = 0.028$), excited ($F = 4.36$, $p = 0.015$), and depressive symptoms ($F = 3.47$, $p = 0.035$), and disability ($F = 27.71$, $p = 0.000$), and lower levels of global functioning ($F = 5.15$, $p = 0.007$) and life satisfaction ($F = 4.19$, $p = 0.018$).

One-way ANOVA and *Chi-squared* comparisons between the three stigma groups on premorbid and demographic variables identified that the *Sustained stigma group* and the *Transient stigma group* had significantly lower IQ compared to the *No stigma group* ($F = 4.95$, $p = 0.009$). Moreover, the *Sustained stigma group* also had lower education than the *No stigma group*, with the *Transient stigma group* positioned in the middle and not significantly different from either of the two other groups ($F = 3.22$, $p = 0.044$). Finally, *the Sustained stigma group* had significantly longer DUP than both the *Transient stigma group* and the *No stigma group* ($F = 7.90$, $p = 0.001$). There was no difference between the three groups in age ($F = 1.55$, $p = 0.217$), gender distribution ($F = 1.18$, $p = 0.553$), rate of ethnic minority background ($F = 2.07$, $p = 0.355$), premorbid functioning ($F = 3.69$, $p = 0.692$), or alcohol use/abuse ($F = 1.11$, $p = 0.332$) or drug use/abuse ($F = 0.18$, $p = 0.835$). Follow-up analyses using *ANCOVA* revealed that when controlling for level of IQ, years of education and length of DUP, all the differences in clinical outcome at 1-year follow-up found between the three stigma groups remained significant. Thus for positive symptoms ($F = 3.00$, $p = 0.025$), excited symptoms ($F = 3.66$, $p = 0.029$), depressed symptoms ($F = 7.76$, $p = 0.001$), global functioning ($F = 3.96$, $p = 0.022$), disability ($F = 21.59$, $p < 0.000$) and life satisfaction ($F = 3.84$, $p = 0.025$). This suggests that the difference in IQ, education and DUP between the three stigma groups cannot explain the differences in clinical outcome at 1-year follow-up.

Secondly, as presented in Table 3., *Mixed between-within repeated measure ANOVAs* investigated the potential impact of perceiving/experiencing stigma on the development of symptoms, global functioning, self-rated disability and life satisfaction from baseline to 1-year follow-up. There were no significant interaction effects between *stigma groups* (1/2/3) and *time* (baseline/1-year), apart from for positive symptoms where the *Transient stigma group* had a greater improvement in positive symptoms. This indicates that in general the degree of improvement in clinical outcome (symptoms, global functioning, self-rated disability and life satisfaction) did not differ between the groups. However, across positive symptoms, excited symptoms, depressive symptoms, global functioning, self-rated disability and self-rated life satisfaction there

Table 1
Premorbid, demographic and clinical characteristics at baseline and 1-year follow-up in the total sample (Paired samples t-test).

	Baseline(n = 112)	1 year follow-up(n = 112)	Paired samples t-test	
	Mean (SD)	Mean (SD)	t	P
Demographics				
Gender *n* (% males)	73 (65.2)			
Age (years)	26.2 (6.8)			
Education (years)	12.1 (2.0)[e]			
IQ (WASI)	101.8 (14.2)			
Minority background n(%)	39 (31.2)			
Premorbid function[a] *median (range)*				
PAS-social functioning childhood	2.0 (0–6)			
PAS-social functioning change	0.75 (−3.5–5)			
PAS-academic functioning childhood	2 (0–6)			
PAS-academic functioning change	0.5 (−2.5–4)			
DUP[b] *median (range)*	48 (1–1300)			
Substance use				
AUDIT -alcohol use *median (range)*	7.6 (7.3)	7.5 (6.9)		
DUDIT -drug use *median (range)*	6.5 (10.0)	4.3 (7.9)		
Clinical symptoms[c] *mean (SD)*				
PANSS – positive symptoms	10.7 (3.9)	8.6 (4.1)	5.554	**<.001**
PANSS – negative symptoms	12.5 (5.6)	11.8 (5.5)	1.428	.156
PANSS – disorganised symptoms	5.6 (2.2)	5.4 (2.3)	.992	.323
PANSS – excited symptoms	6.1 (2.1)	3.8 (1.2)	10.762	**<.001**
PANSS – depressive symptoms	8.8 (3.1)	7.2 (3.0)	5.055	**<.001**
Global functioning				
GAF-F	44.4 (13.1)	52.5 (15.2)	−6.453	**<.001**
Self-rated disability[d]				
Summary score *median (range)*	36.9 (5.4–126.0)	26.1 (0–104.3)	5.559	**<.001**
Life satisfaction				
Life satisfaction in general	4.46 (1.50)	3.6 (1.4)	5.211	**<.001**

Bold = < 0.05.
[a] PAS script; social functioning n = 90, academic functioning n = 89.
[b] Duration of untreated psychosis.
[c] PANSS five factor model by Wallwork (2012).
[d] WHODAS 2.0. summary score (domains 1–5).

Table 2
Clinical outcome variables at 1-year follow-up across the three stigma groups (One-way ANOVA).

	1. Sustained stigma group (n = 23)	2. Transient stigma group (n = 41)	3. No stigma group (n = 48)	ANOVA/Chi-squared		
	Mean (SD)	Mean (SD)	Mean (SD)	F	P	Post hoc
Clinical symptoms[a] *mean (SD)*						
PANSS -positive factor	10.9 (4.3)	8.3 (3.4)	7.6 (4.2)	5.45	**.006**	1>2,3
PANSS -negative factor	10.7 (4.6)	12.4 (5.1)	11.9 (6.2)	0.71	.49	
PANSS -disorganized factor	5.9 (2.4)	5.5 (1.8)	5.1 (2.5)	0.96	.385	
PANSS -excited factor	4.3 (1.3)	3.8 (1.2)	3.5 (0.8)	3.76	**.029**	1>3
PANSS -depressive factor	9.8 (2.4)	6.7 (2.5)	6.4 (3.0)	12.9	.000	1>2,3
Global functioning						
GAF-F	44.9 (11.3)	49.7 (11.3)	58.6 (15.6)	8.47	.000	1,2<3
Self-rated disability *mean (SD)*						
WHODAS 2.0 summary score	56.9 (24.0)	31.7 (19.1)	18.3 (12.6)	35.6	.001	1>2,3 | 2>3
Life Satisfaction *mean (SD)*						
Life satisfaction in general	4.5 (1.6)	3.4 (1.1)	3.2 (1.2)	7.5	**.001**	1>2,3
Diagnostic % distribution				3.095	.797	
Schizophrenia	65.2	68.3	58.3			
Schizophreniform	0.0	4.9	6.3			
Schizoaffective	13.0	9.8	8.3			
Other psychosis	21.7	17.1	27.1			

Bold = < 0.05.
[a] PANSS five factor model by Wallwork (2012).

were significant main effects' for both *time* and *stigma groups*. This indicates that all the dependent variables (clinical outcome) apart from negative and disorganised symptoms, improved from baseline to 1-year follow-up in all three groups. The main between-subjects effect for *stigma groups* corroborate the significant group differences in clinical outcome variables from the above *One-way ANOVA* presented in Table 2. Moreover, the main within-subjects effects for *time* corroborate the findings from the above paired samples *t*-test presented in Table 1. In sum, this implies that although the Sustained stigma group had poorer clinical outcome at 1-year follow-up, clinical outcome variables improved across the first year of treatment irrespective of perceived/experienced stigma.

4. Discussion

The main findings are that perceived/experienced stigma is common the first year of treatment in FEP, although the proportion with stigma decreases significantly from 46% at start of treatment

Table 3
Impact of perceiving/experiencing stigma[a] on the development of clinical outcome variables from baseline to 1-year follow-up (Mixed between-within repeated measures ANOVA).

	Group x Time Interaction				Time Main effect				Group Main effect		
	Wilkes' Lambda	F	p	Partial eta squared	Wilkes' Lambda	F	p	Partial eta squared	F	p	Partial eta squared
Clinical symptoms[a]											
PANSS -positive	.932	3.97	**.022**	.068	.824	23.31	**<.001**	.176	4.80	**.010**	.081
PANSS -negative	.998	0.11	.900	.002	.981	2.16	.145	.019	0.61	.547	.011
PANSS -disorganized	.995	0.29	.749	.005	.992	0.91	.342	.008	1.29	.190	.030
PANSS -excited	.983	0.96	.386	.017	.490	113.27	**<.001**	.510	6.74	**.002**	.110
PANSS -depressive	.967	1.88	.157	.033	.856	18.33	**<.001**	.144	10.10	**<.001**	.156
Global functioning											
GAF-F	.960	2.26	.109	.040	.779	30.91	**<.001**	.221	8.56	**<.001**	.136
Self-rated disability											
Summary score	.996	0.19	.829	.004	.798	27.13	**<.001**	.202	40.18	**<.001**	.429
Life Satisfaction											
- in general	.995	0.24	.788	.005	.810	22.98	**<.001**	.190	8.46	**<.001**	.147

Bold = < 0.05.
[a] three stigma groups.

to 32% one year later. Perceived/experienced stigma was present in 1/5 at both time-points (Sustained stigma), in 2/5 at only one time-point (Transient stigma), and in 2/5 not at either time-point (No stigma). Compared to the No stigma group, the Sustained stigma group had poorer clinical outcome in terms of symptoms, functioning, disability and life satisfaction, while the Transient stigma group only had poorer functioning and disability. The Sustained stigma group also had poorer clinical outcome than the Transient stigma group on most measures, suggesting that sustainability of stigma across the first year of treatment is related to clinical outcome. Fortunately, clinical outcome improved across the first year of treatment in all three stigma groups, thus irrespective of perceived/experienced stigma. To the best of our knowledge, this is the first study to investigate self-rated *problems because of* perceived/experienced stigma across the first year of treatment in a large FEP sample with high degree of representativity. The findings show the importance of addressing stigma in early clinical work.

4.1. Rate and development of stigma

The main contribution of the first set of findings in the present study is the longitudinal design allowing us to study the rate and development of stigma across the early illness course in FEP. The present study is the first to find that the rate of perceived/experienced stigma depends on the stage of the illness by decreasing from ½ - 1/3 over the first year of treatment, as well as the average level of stigma decreasing in the same time-span. Thus the present findings do not support the suggestion that experienced stigma increases with duration of illness [10]. In the only previous FEP 1-year follow-up study experienced stigma was only measured at follow-up, thus preventing investigation of development across the first year of treatment [11]. Moreover, the present study is the first to investigate *sustainability of stigma* across the first year of treatment finding that 1/5 perceived/experienced stigma at both baseline and 1-year follow-up, 2/5 only at one time-point only and 2/5 not at all.

The present rates of perceived/experience stigma in FEP, decreasing from 46% to 32% across the first year of treatment, are somewhat lower than what was found in the systematic review (55% perceived stigma and 64% experienced stigma) [5], and in the recent FEP study from Singapore (71% at 1-year follow-up) [11]. The variance in rate of stigma across these studies could be explained by type of stigma scale and how they are used. Several of the studies in the systematic review as well as the FEP study from Singapore used the Discrimination and Stigma Scale (DISC), measuring the *frequency* of experienced and perceived stigma. While the present and previous study [16], using WHODAS 2.0 measuring *problems because of* stigma, found similar rates of 46% (32%) and 45%, respectively. This implies that perceived/experienced stigma is not only *frequent*, but also *leads to problems* for people with FEP. In line with the previous study using WHODAS 2.0 [16,] the present study defined perceived/experienced stigma as a score of "moderate problems" on one of the two WHODAS 2.0 items. If the definition had included "mild problems" with stigma, the total rate of stigma would have been higher, possibly more comparable to the 71% found at 1-year follow-up in the FEP study from Singapore [11].

The variance in rate of stigma across the above previous studies and the present study could also be explained by differences related to study samples. However, diagnostic inclusion criteria do not seem to explain these differences. Firstly, within the present study the three stigma groups have a similar diagnostic distribution, suggesting that sustained stigma is no more common in schizophrenia than in the other schizophrenia spectrum disorders. Secondly, amongst previous studies the proportion with perceived/experienced stigma was not highest in the studies restricted to samples with schizophrenia diagnosis only [10,16], but was in fact highest in the recent FEP study from Singapore including psychotic disorders more broadly, thus including affective psychosis [11]. Despite a large-scale international study reporting that the proportion of stigma was fairly even across 27 different countries [34], the higher rate of experienced stigma in the study from Singapore may be explained by cultural differences, thus by experienced stigma being higher in Asian compared to European countries.

4.2. Relationship between stigma and clinical outcome

The main contribution of the second set of findings in the present study is the longitudinal design allowing us to study the relationship between stigma and clinical outcome across the early illness course in FEP. It is the first study to find that *sustainability* of perceived/experienced stigma the first year of treatment is related to poorer clinical outcome at 1-year follow-up. This suggests that perceiving/experiencing stigma over time is related to poorer clinical outcome than experiencing it at one time-point only. Fortunately, clinical improvement from baseline to 1-year follow-up was present in all three stigma groups, although less so in the sustained stigma group. This suggests that recovery in the early stages of treatment takes place even in the presence of sustained stigma.

However, the sustainability of perceived/experienced stigma the first year of treatment was also related to more severe clinical symptoms and disability and poorer functioning and life-satisfaction already at baseline. This illustrates the bidirectional quality of these findings, because it could on the one hand reflect that sustained perceived/experienced stigma leads to an increase in symptoms and fall in functioning, but on the other hand that people with severe symptoms and poor functioning may be subjected to more negative responses from others and thereby experience more stigma over time. Thus the present findings may reflect that the relationship between perceived/experienced stigma and symptoms and poor functioning is bidirectional and as such represents a vicious circle.

The relationship between perceived/experienced stigma and poor clinical outcome is also in line with previous findings with only minor differences in the type of clinical outcome that was measured [5,11–14,16]. This suggests that the relationship between stigma and clinical outcome does not depend on type of stigma scale. Similar relationships were found in the present and the previous study using WHODAS 2.0 [16], and the previous research which included the DISC, the Stigma Scale [35], the clinician-rated Semi-structured Interview Measure of Stigma (SIMS) [36]. This implies that clinical outcome is related to self-rated *problems because of* perceived/experienced stigma, as well as self-rated and clinician-rated *frequency and severity* of perceived and experienced stigma.

The relationship between stigma and clinical outcome is also similar across study samples, thus across diagnostic inclusion criteria and across different countries and cultural differences. To our knowledge the present study is the first Scandinavian study to investigate the relationship between stigma and clinical outcome in schizophrenia spectrum disorders. As the proportion with ethnic minority background did not differ between the three stigma groups in the present study, this cannot explain their differences in clinical outcome. Finally, the present findings suggest that the relationship between stigma and clinical outcome is not explained by longer DUP, lower IQ, or shorter education in the stigmatised groups.

In previous studies the symptoms related to perceived and experienced stigma included psychotic, depressive, anxiety and general psychopathology. Because the present study used the five factor model of the PANSS it was also possible to investigate excited symptoms, which turned out to also be related to stigma. More importantly the present study is the first FEP study on perceived/experienced stigma to include life satisfaction in addition to illness signs, thus to also include potential consequences for general wellbeing. Not surprisingly, the findings suggest that problems due to perceived/experienced stigma relate to lower life satisfaction in people with FEP.

Among the limitations to the present study, the measurement of stigma is limited to two items from a scale not originally designed to measure stigma, nor specifically people with psychotic disorders. The items measure perceived/experienced stigma in general rather than across different life areas, and they capture both the participants' *beliefs* about the general populations stigmatising attitudes and actions (perceived stigma), as well as their *actual encounter* with stigma (experienced stigma) [5]. Yet as we are unaware of what the participants had in mind we are unable to measure perceived and experienced stigma separately. Despite perceived and experienced stigma being considered separate constructs [6], they are closely related with a similar prevalence, which justifies investigating them as a joint construct.

These findings have several clinical implications. Firstly, they suggest that as perceived and experienced stigma are common in the first year of treatment and they are related to poorer clinical outcome that they are important targets in the early stages of treatment. In recent years, research into how personal stigma, and especially internalised stigma, can be reduced by treatment is increasing, with CBT for stigma showing promising results [37]. Secondly, the present findings suggest that perceived/experienced stigma decreases during the first year of treatment and that early clinical recovery occurs despite the perception and experience of stigma. This is good news which should be conveyed to patients with FEP in order to bring about hope for recovery and improved wellbeing despite the subjective experience of stigma. This is regarded particularly important considering the close relationship between stigma, hope and recovery [38].

5. Conclusion

Although the rate of perceived/experienced stigma decreases across the first year of treatment, it is common in FEP. Moreover, despite some clinical improvement occurring across the first year of treatment irrespective of stigma, perceived/experienced stigma is related to poorer clinical outcome, including poorer self-rated life satisfaction, in a bidirectional manner. This suggests that in order to increase wellbeing, perceived/experienced stigma is an important target in the early stages of treatment. Future research should investigate how personal stigma and its' correlates and consequences in psychotic disorders develop across the illness course more long-term.

Declaration of conflict

OAA received speaker's honorarium from Lundbeck. All other authors reported nothing to declare.

Acknowledgements

The authors are very grateful to the study participants for their time and effort devoted to participation.

Funding

This work was supported by grants from the South-Eastern Norway Regional Health Authority (#2006258, #2015-088), the Research Council of Norway(#217776) through its Centre of Excellence funding scheme (#223273), and the KG Jebsen Foundation (#SKGJ_MED_008). The funding sources had no involvement in the study design, data collection, analysis and interpretation of data, in the writing of the manuscript or in the decision to submit the paper for publication.

References

[1] Clement S, Graham T, Maggioni F, Lacko S, Bezborodovs N, et al. What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. Psychol Med 2015;45(1):11–27.
[2] Gronholm PC, Thornicroft G, Laurens KR, Evans-Lacko S. Mental health-related stigma and pathways to care for people at risk of psychotic disorders or experiencing first-episode psychosis: a systematic review. Psychol Med 2017;47(11):1867–79.
[3] Perkins DO, Gu H, Boteva K, Lieberman JA. Relationship between duration of untreated psychosis and outcome in first-episode schizophrenia: a critical review and meta-analysis. Am J Psychiatry 2005;162(10):1785–804.
[4] Pescosolido BA, Martin JK. The stigma complex. Annu Rev Sociol 2015;41:87–116.
[5] Gerlinger G, Hauser M, De Hert M, Lacluyse K, Wampers M, Correll CU. Personal stigma in schizophrenia spectrum disorders: a systematic review of prevalence rates, correlates, impact and interventions. World Psychiatry 2013;12(2):155–64.
[6] Brohan E, Slade M, Clement S, Thornicroft G. Experiences of mental illness stigma, prejudice and discrimination: a review of measures. BMC Health Serv Res 2010;10:80.
[7] Corrigan PW, Watson AC. Understanding the impact of stigma on people with mental illness. World Psychiatry 2002;1(1):16–20.
[8] Thornicroft G, Rose D, Kassam A, Sartorius N. Stigma: ignorance, prejudice or discrimination? Br J Psychiatry 2007;190:192–3.

[9] Lasalvia A, Zoppei S, Bonetto C, Tosato S, Zanatta G, Cristofalo D, et al. The role of experienced and anticipated discrimination in the lives of people with first-episode psychosis. Psychiatr Serv 2014;65(8):1034–40.
[10] Corker EA, Beldie A, Brain C, Jakovljevic M, Jarema Karamustafalioglu MO, et al. Experience of stigma and discrimination reported by people experiencing the first episode of schizophrenia and those with a first episode of depression: the FEDORA project. Int J Soc Psychiatry 2015;61(5):438–45.
[11] Kinson RM, Hon C, Lee H, Abdin EB, Verma S. Stigma and discrimination in individuals with first episode psychosis; one year after first contact with psychiatric services. Psychiatry Res 2018;270:298–305.
[12] Wood L, Irons C. Experienced stigma and its impacts in psychosis: the role of social rank and external shame. Psychol Psychother 2017;90(3):419–31.
[13] Wood L, Byrne R, Burke E, Enache G, Morrison AP. The impact of stigma on emotional distress and recovery from psychosis: the mediatory role of internalised shame and self-esteem. Psychiatry Res 2017;255:94–100.
[14] Vass V, Morrison AP, Law H, Dudley J, Taylor P, Bennett KM, et al. How stigma impacts on people with psychosis: the mediating effect of self-esteem and hopelessness on subjective recovery and psychotic experiences. Psychiatry Res 2015;230(2):487–95.
[15] Simonsen C, Faerden A, Romm KL, Berg AO, Bjella T, Sundet K, et al. Early clinical recovery in first-episode psychosis: symptomatic remission and its correlates at 1-year follow-up. Psychiatry Res 2017;254:118–25.
[16] Ertugrul A, Ulug B. Perception of stigma among patients with schizophrenia. Soc Psychiatry Psychiatr Epidemiol 2004;39(1):73–7.
[17] Correll CU, Galling B, Pawar A, Krivko A, Bonetto C, Ruggeri M, et al. Comparison of early intervention services vs treatment as usual for early-phase psychosis: a systematic review, meta-analysis, and meta-regression. JAMA Psychiatry 2018;75(6):555–65.
[18] Simonsen C, Faerden A, Ueland T, Vaskinn A, Bjella T, Andreassen O, et al. Self-rated disability in first treated episode of psychosis: a 1-year follow-up study. Compr Psychiatry 2018;85:48–54.
[19] Simonsen C. Poster: experienced stigma in first-episode psychosis: a 1-year follow-up study. Early Interv Psychiatry 2018;12(Suppl 1). October.
[20] First M, Spitzer R, Gibbon M, Williams JBW. Structured clinical interview for DSM-IV Axis I disorders: patient edition (SCID-P), version 2. New York: New York State Psychiatric Institute, Biometrics Research; 1995.
[21] Kay SR, Fiszbein A, Opler LA. The positive and negative syndrome scale (PANSS) for schizophrenia. Schizophr Bull 1987;13(2):261–76.
[22] Larsen TK, Johannessen JO, Opjordsmoen S. First-episode schizophrenia with long duration of untreated psychosis. Pathways to care. Br J Psychiatry Suppl 1998;172(33):45–52.
[23] Saunders JB, Aasland OG, Babor TF, de la Fuente JR, Grant M. Development of the alcohol use disorders identification test (AUDIT): WHO collaborative project on early detection of persons with harmful alcohol consumption–II. Addiction 1993;88(6):791–804.
[24] Berman AH, Bergman H, Palmstierna T, Schlyter F. Evaluation of the Drug Use Disorders Identification Test (DUDIT) in criminal justice and detoxification settings and in a Swedish population sample. Eur Addict Res 2005;11(1):22–31.
[25] Wallwork RS, Fortgang R, Hashimoto R, Weinberger DR, Dickinson D. Searching for a consensus five-factor model of the Positive and Negative Syndrome Scale for schizophrenia. Schizophr Res 2012;137(1-3):246–50.
[26] Langeveld J, Andreassen OA, Auestad B, Faerden A, Hauge LJ, Joa I, et al. Is there an optimal factor structure of the Positive and Negative Syndrome Scale in patients with first-episode psychosis? Scand J Psychol 2013;54(2):160–5.
[27] Cannon-Spoor HE, Potkin SG, Wyatt RJ. Measurement of premorbid adjustment in chronic schizophrenia. Schizophr Bull 1982;8(3):470–84.
[28] Haahr U, Friis S, Larsen TK, Melle I, Johannessen JO, Opjordsmoen S, et al. First-episode psychosis: diagnostic stability over one and two years. Psychopathology 2008;41(5):322–9.
[29] Pedersen G, Hagtvet KA, Karterud S. Generalizability studies of the global assessment of functioning-split version. Compr Psychiatry 2007;48(1):88–94.
[30] Ustun TB, Chatterji S, Kostanjsek N, Rehm J, Kennedy C, Epping-Jordan J, et al. Developing the world health organization disability assessment schedule 2.0. Bull World Health Organ 2010;88(11):815–23.
[31] McKibbin C, Patterson TL, Jeste DV. Assessing disability in older patients with schizophrenia: results from the WHODAS-II. J Nerv Ment Dis 2004;192(6):405–13.
[32] Melle I, Friis S, Haahr U, Johannesen JO, Larsen TK, Opjordsmoen S, et al. Measuring quality of life in first-episode psychosis. Eur Psychiatry 2005;20(7):474–83.
[33] Lehman AF. A quality of life interview for the chronically ill. Eval Program Plann 1988;11:51–62.
[34] Thornicroft G, Brohan E, Rose D, Sartorius N, Leese M, Indigo Study Group. Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. Lancet 2009;373(9661):408–15.
[35] King M, Dinos S, Shaw J, Watson R, Stevens S, Passetti F, et al. The Stigma Scale: development of a standardised measure of the stigma of mental illness. Br J Psychiatry 2007;190:248–54.
[36] Wood L, Burke E, Byrne R, Enache G, Morrison AP. Semi-structured Interview Measure of Stigma (SIMS) in psychosis: assessment of psychometric properties. Schizophr Res 2016;176(2-3):398–403.
[37] Morrison AP, Burke E, Murphy E, Pyle M, Bowe S, Varese F, et al. Cognitive therapy for internalised stigma in people experiencing psychosis: a pilot randomised controlled trial. Psychiatry Res 2016;240:96–102.
[38] Ponte K. Stigma, meet hope. Schizophr Bull; 2019.