Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey

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Summary

Background Many people with schizophrenia experience stigma caused by other people's knowledge, attitudes, and behaviour; this can lead to impoverishment, social marginalisation, and low quality of life. We aimed to describe the nature, direction, and severity of anticipated and experienced discrimination reported by people with schizophrenia.

Methods We did a cross-sectional survey in 27 countries, in centres affiliated to the INDIGO Research Network, by use of face-to-face interviews with 732 participants with schizophrenia. Discrimination was measured with the newly validated discrimination and stigma scale (DISC), which produces three subscores: positive experienced discrimination; negative experienced discrimination; and anticipated discrimination.

Findings Negative discrimination was experienced by 344 (47%) of 729 participants in making or keeping friends, by 315 (43%) of 728 from family members, by 209 (29%) of 724 in finding a job, 215 (29%) of 730 in keeping a job, and by 196 (27%) of 724 in intimate or sexual relationships. Positive experienced discrimination was rare. Anticipated discrimination affected 469 (64%) in applying for work, training, or education and 402 (55%) looking for a close relationship; 526 (72%) felt the need to conceal their diagnosis. Over a third of participants anticipated discrimination for job seeking and close personal relationships when no discrimination was experienced.

Interpretation Rates of both anticipated and experienced discrimination are consistently high across countries among people with mental illness. Measures such as disability discrimination laws might, therefore, not be effective without interventions to improve self-esteem of people with mental illness.

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Introduction

Stigma is an overarching term including problems of knowledge (ignorance or misinformation), attitudes (prejudice), and behaviour (discrimination).[1–3] Stigma produces changes in feelings, attitudes, and behaviour for both the person affected (lower self-esteem, poorer self-care, and social withdrawal) and family members.[4–6] Research on stigma and mental illness has had several limitations: it has made few connections with clinical practice or health policy (for example in relation to help-seeking and access to care); it has largely been descriptive, concerning surveys of public attitudes, or the portrayal of mental illness and violence by the media; and systematic assessments of the experiences of people with mental illness in different parts of the world are few.[7–9]

Studies of stigma in Africa,[10] Asia,[11] Latin America and the Caribbean,[12] southwest Asia,[13] and Europe[14] have had generally consistent findings. There are few countries, societies, or cultures in which people with mental illness are as equally valued as people who do not have mental illness, as shown, for example, by little financial investment in mental-health services. The quality of information on discrimination is poor, with few comparative studies between countries or over time. There are clear links between popular understandings of mental illness and whether people in mental distress seek help or feel able to disclose their problems.[15] The core experiences of shame (to oneself or to one's family) and blame (from others) are common, although they vary between cultures. By comparison with other disorders, mental illnesses are typically more stigmatised, and this has been called the ultimate stigma.[16] Finally, the behavioural consequences of stigma (rejection and avoidance) seem to affect most people with mental illness; nevertheless, little is known about how such processes affect their everyday living.

Most research on stigma and mental illness consists of surveys of attitudes, investigating what people would do in imaginary situations or what they think most people would do, for example, when faced with a neighbour or work colleague with mental illness. Such investigations emphasise what healthy people might say, rather than the experiences of people with mental illness. The research also assumes that such statements (usually on knowledge, attitudes, or behavioural intentions) are linked with behaviour, without assessing behaviour directly. In short, with some clear exceptions, research has focused on hypothetical rather than real situations, has been shorn of emotions and feelings,[17] has been divorced from context,[18] has addressed stigma indirectly rather than directly, and has not provided clear answers on how to intervene to reduce social rejection.[19] In this Article, we define discrimination as unjust distinction in the treatment of different categories of people.

A growing body of qualitative evidence shows how users of mental-health services subjectively experience, describe, and cope with stigma. The improved understanding of the scope and dimensions of stigma, the personal consequences of stigma, views on antistigma campaign priorities, and the effect of stigma on families, has allowed the development of related scales.[20]

Discrimination can cause low rates of help seeking, lack of access to care, undertreatment, material poverty, and social marginalisation.[21] These effects can be the consequences of experienced (actual) discrimination (for example being unreasonably rejected in a job application), or they can be the consequences of anticipated discrimination (eg, when an individual does not apply for a job because he or she fully expects to fail in any such application).[22] The distinction between experienced and anticipated discrimination is closely related to what has been described as the difference between enacted and felt stigma. Enacted stigma comprises events of negative discrimination, whereas felt stigma includes the experience of shame of having a disorder and the fear of encountering enacted stigma,[23] and is associated with lower self-esteem.

We examine the occurrence of both experienced and anticipated discrimination, and their inter-relationships among people with schizophrenia, one of the most stigmatised mental disorders.[24] Because of the lack of research, we could not generate evidence-based hypotheses;[25] nevertheless, the primary focus of this Article is on the nature, direction, and degree of discrimination reported by people with schizophrenia. We develop a new scale to measure discrimination, and analyse the relation between experienced and anticipated discrimination.

	Finding
Age (years; n=731)	39·20 (11·32)
Sex	
Men	453 (62%)
Women	279 (38%)
Years of education (n=721)	12·61 (3·35)
Currently employed (n=726)	
Yes	213 (29%)
No	513 (70%)
Years since first contact with mental-health services (n=725)	14·32 (9·65)
Main type of mental health care (n=716)	
Inpatient	157 (21%)
Outpatient	386 (53%)
Home	47 (6%)
Day care	126 (17%)
Compulsory treatment ever (n=731)	
Yes	401 (55%)
No	330 (45%)
Knows the diagnosis (n=728)	
Yes	610 (83%)
No	118 (16%)
Agrees with diagnosis of schizophrenia (679)	
Agree	434 (59%)
Disagree	100 (14%)
Unsure	54 (7%)
Don't know	91 (12%)

Data are mean (SD) or number (%). Not all totals 732 (100%) because of missing responses.

Table 1: **Sociodemographic and clinical characteristics**

Methods

Participants

Study sites in 27 countries were identified through contact with members of the World Psychiatric Association (WPA) Global Programme Against Stigma and Discrimination Because of Schizophrenia,[26] and associated centres active in stigma-related research joined the WPA group to establish the INDIGO network (International Study of Discrimination and Stigma Outcomes). Within centres, site directors were asked to identify 25 participants who were, in their judgment, reasonably representative (as a group) of all people with a clinical diagnosis of schizophrenia in treatment with local psychiatric services, including those in inpatient, day-patient, outpatient, and community settings. 732 people with a clinical diagnosis of schizophrenia took part in the study. Participants provided written informed consent. The study was approved by the appropriate ethical review board in each of the sites.

Data collection

We developed the discrimination and stigma scale (DISC) to address the need for an internationally reliable measure of discrimination. By use of direct interview data, this scale provides an assessment of experienced and anticipated discrimination from the perspective of users of mental-health services. The scale allows for quantitative and qualitative appraisal of responses (although the qualitative components are not discussed in this paper).[27] For the development of the scale, candidate items were identified from a review of research,[4] and from detailed consultation with research teams in the 28 study sites. A Delphi process across all study sites reduced the item pool. Content validity and face validity were confirmed at this stage.[28] Field testing of the scale took place with every site piloting a draft version of the scale in face-to-face interviews with three individuals with schizophrenia, leading to further item modification and reduction to produce DISC version 10. A training manual was used by all sites to achieve consistent interpretation of all the scale items; several sites also received on-site or telephone training in the use of the scale. In the main study, five of the interviews at each site were recorded verbatim, transcribed, translated into English, and qualitatively analysed by the study coordinators, and the results of these analyses provided strong support for the choice of items retained in DISC-10. The necessity to add a specific example for every type of discrimination that was rated provided data that were subsequently analysed, providing strong validation for the occurrence, direction, and severity of the discrimination that was rated quantitatively.

Translation and cross-cultural adaptation of DISC-10 was done to ensure that we developed language-equivalent versions of the scale that were readily understood by people with schizophrenia and by the interviewers at all sites, taking into account the influence of local cultural factors. The scale was translated from English into the local (target) language with forward and back translation. A focus group with six to ten local people with a clinical diagnosis of schizophrenia at each site ensured that all the key terms were translated into local language equivalents before the final version was established.

	Disadvantage*	No different treatment	Advantage†	Not applicable
Advantage or disadvantage of having diagnosis of schizophrenia (Q32)	357 (49%)	120 (16%)	188 (26%)	49 (7%)
Making or keeping friends (Q1)	344 (47%)	316 (43%)	50 (7%)	19 (3%)
Treated differently by family (Q9)	315 (43%)	232 (32%)	174 (24%)	7 (1%)
Keeping a job (Q11)	215 (29%)	253 (35%)	47 (6%)	215 (29%)
Treated differently in other important ways (Q31)	209 (29%)	268 (37%)	50 (7%)	177 (24%)
Finding a job (Q10)	209 (29%)	249 (34%)	47 (6%)	219 (30%)
Relationships with neighbours (Q2)	211 (29%)	422 (58%)	52 (7%)	42 (6%)
In intimate or sexual relationships (Q3)	196 (27%)	340 (46%)	34 (5%)	154 (21%)
In personal safety and security (Q27)	191 (26%)	444 (61%)	10 (1%)	78 (11%)
In personal privacy (Q26)	172 (23%)	502 (69%)	22 (3%)	30 (4%)
When dating (Q7)	167 (23%)	298 (41%)	38 (5%)	223 (30%)
When wanting to start a family (Q28)	146 (20%)	199 (27%)	18 (2%)	352 (48%)
In education (Q6)	136 (19%)	229 (31%)	63 (9%)	298 (41%)
By the police (Q22)	122 (17%)	353 (48%)	66 (9%)	189 (26%)
For physical health problems (Q24)	111 (15%)	506 (69%)	57 (8%)	54 (7%)
In social life (Q21)	106 (15%)	481 (66%)	28 (4%)	114 (16%)
In terms of marriage or divorce (Q8)	101 (14%)	121 (17%)	19 (3%)	484 (66%)
With housing (Q4)	100 (14%)	331 (45%)	83 (11%)	215 (29%)
Act as a parent for child(ren) (Q30)	91 (12%)	107 (15%)	5 (1%)	514 (70%)
In religious practices (Q20)	74 (10%)	410 (56%)	56 (8%)	191(26%)
Getting welfare benefits/disability pensions (Q15)	72 (10%)	356 (49%)	129 (18%)	173 (24%)
When using public transport (Q12)	71 (10%)	537 (73%)	45 (6%)	78 (11%)
When getting or keeping a driving licence (Q13)	68 (9%)	259 (35%)	4 (1%)	400 (55%)
In becoming homeless (Q5)	58 (8%)	81 (11%)	16 (2%)	574 (78%)
Borrowing money or taking out a loan (Q19)	57 (8%)	224 (31%)	21 (3%)	429 (59%)
For dental problems (Q25)	46 (6%)	538 (73%)	67 (9%)	78 (11%)
In arranging payment for medical treatment (Q23)	45 (6%)	364 (50%)	85 (12%)	234 (32%)
Getting any type of insurance (Q18)	34 (5%)	301 (41%)	4 (1%)	388 (53%)
Opening a bank account (Q16)	26 (4%)	456 (62%)	23 (3%)	225 (31%)
Voting in elections (Q17)	20 (3%)	586 (80%)	9 (1%)	114 (16%)
During pregnancy and childbirth (Q29)	16 (2%)	39 (5%)	3 (0%)	647(88%)
When getting visas to visit other countries (Q14)	11 (2%)	189 (26%)	7 (1%)	523 (71%)

Items are arranged in descending order of proportion of total responses represented by the combined disadvantage categories. Percent calculated as proportion of total sample (732); not all totals 732 (100%) because of missing responses. *Disadvantage is the combined responses to slight, moderate, and strong disadvantage. †Advantage is the combined responses to slight, moderate, and strong advantage.

***Table 2:* Responses for positive and negative experienced discrimination**

The scale is administered by interviewers and contains 36 items. The interviewer asks the participants for a series of domains whether they have experienced discrimination because of their mental illness; what the direction (positive or negative) of such discrimination is; and what is its severity. The domains address key areas of everyday life and social participation, including work, marriage, parenting, housing, leisure, and religious activities. The first 32 items are scored on a seven-point Likert scale anchored at +3 as strong advantage and –3 as strong disadvantage, with a mid-point for no difference. A not-applicable category is also included. The structure of each question is in the following form: "Have you been treated differently from other people in finding a job because of your diagnosis of mental illness?".

The phrase "treated differently" was selected because it allowed participants to comment on both positive and negative discrimination and proved successful in translation and cross-cultural validation. For these first 32 items, for every occasion that participants report discrimination, they were asked to provide a detailed verbatim example, which was entered on the data-rating sheet by hand by the interviewer. This process provided a validity check; further interview probes were included if the example seemed incongruent with the scale rating.

The phrase "because of your diagnosis of mental illness" was successful in translation and cross-cultural validation, and was intended to represent all situations in which the participant reported that their mental illness was the reason for being treated differently. These situations include both those in which they had disclosed their mental illness, and those where they felt that others knew of their illness for other reasons. These first 32 items form the subscale of experienced discrimination. The scale also includes four items that address how far participants limit their own involvement in important aspects of everyday life, including work and intimate relationships. These items form the anticipated discrimination subscale, and these items were identified in the pilot stage (DISC-9) from domains that were most commonly rated for the presence of anticipated discrimination, with confirmation from the service user focus groups in all sites, and from the Delphi process of research staff in all sites, to finalise item selection.

Three subscores are generated. The first subscore indicates total positive experienced discrimination. This is a count of the total instances of endorsement of a positive scale-point (ie, slight, moderate, or strong advantage) for the first 32 items. The second subscore indicates total negative experienced discrimination and is calculated in the same way. A third subscore is generated from the four anticipated discrimination items (each scored as not at all, a little, moderately, and a lot), which assess how far the individual has stopped himself or herself from applying for a job; looking for a close relationship; undertaking another personally important activity; or has concealed the diagnosis.

Sociodemographic and clinical data were collected as part of the interview, and included age, sex, years since first contact with mental-health services, work status, education, current mental-health care, knowledge of clinical diagnosis, and agreement with diagnosis.

Data analysis

Analyses were done with SPSS (version 15) and Stata (version 9.2). Summary statistics for invididual countries were computed with ANOVA for counts of both experienced and anticipated discrimination. A regression analysis was done with experienced discrimination as the dependent variable and anticipated discrimination, sex, year since first contact with mental-health services (categorical), compulsory treatment, work status, years of education, agreement with diagnosis, and current type of mental-health care as independent variables. Variables were chosen because they had face value as explanatory variables. For highly correlated variables we chose only one: age was not included throughout, as it is highly correlated with years since first contact with mental-health services; knowledge of diagnosis was similarly excluded, as it is highly correlated with agreement with diagnosis. The effect of variation between countries on significance was accounted for with the cluster option and robust standard errors in Stata. The robust or Huber–White sandwich corrections to standard errors[29] are automatically calculated by Stata if clustering is specified. These take account of any non-normality of residuals and the variance inflation that would occur if clustering by country were ignored.

Role of the funding source

In the UK, this work was supported by a grant from the South London and Maudsley NHS Foundation Trustees. Financial support was also provided by the Department of Health SHiFT programme. In Germany, the interviews at the Düsseldorf and Munich centres were done as part of a research project of the German Research Network on Schizophrenia (Reduction of stigma and discrimination) and were funded by the German Ministry of Education and Research BMBF (grant 01 GI 9932/grant 01 GI 0332).

Results

Table 1 shows the characteristics of the 732 participants. Table 2 shows the overall profile of experienced discrimination for all 27 countries, with positive responses combined and negative responses combined. Figure 1 summarises these data. Across all countries the most common areas of negative experienced discrimination were making or keeping friends, discrimination by relatives, keeping a job, finding a job, and intimate or sexual relationships (table 2). Being treated differently by your family, welfare benefits or disability pensions, housing, and payment for medical treatment were areas of positive experienced discrimination. Positive experienced discrimination was rare—reported by fewer than 10% of respondents for most domains. Because positive experienced discrimination was so rarely reported, the remaining analyses focus only on negative experienced discrimination. Overall negative experienced discrimination scores were calculated by combining responses from the strong, moderate, and slight disadvantage categories (figure 1), with a possible range of 0–32. Average scores by country range from 3·44 to 7·92 with a mean of 5·60. Few patients (26%) reported having received the specific diagnosis of schizophrenia for their mental-health problems.

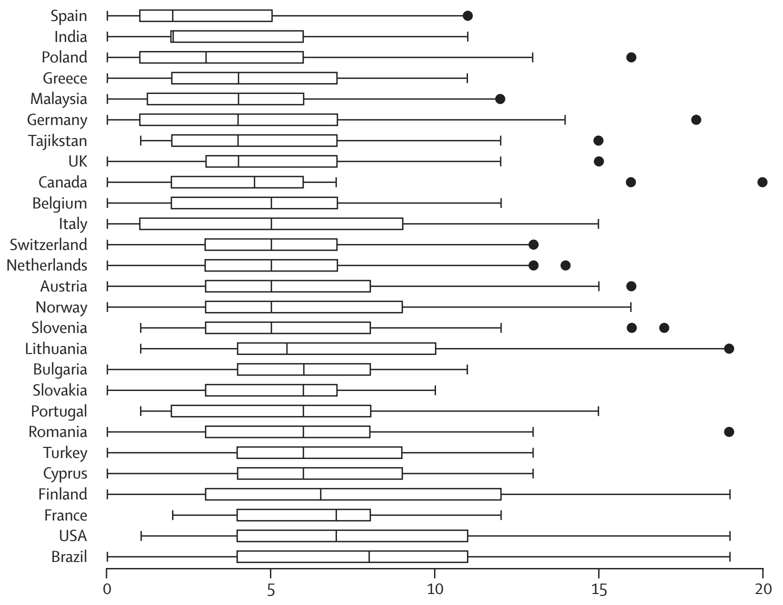

Figure 1: **Negative experienced discrimination by country**
Full range from least to most discrimination of 0–32. Data show medians, IQRs, total ranges, and outliers (1·5–3·0 IQRs from upper or lower quartiles).

Table 3 and figure 2 show the results for the anticipated discrimination subscore. Across all sites most respondents anticipated discrimination in the four key areas. The mean score by country ranges from

	Not at all	A little	A lot	Not applicable
Felt the need to conceal diagnosis (Q38)	195 (27%)	235 (32%)	291 (40%)	6 (1%)
Applying for work or training or education (Q33)	224 (31%)	164 (22%)	305 (42%)	30 (4%)
Doing something else important (Q35)	241 (33%)	182 (25%)	238 (33%)	61 (8%)
Looking for a close relationship (Q34)	291 (40%)	165 (23%)	237 (32%)	32 (4%)

Items are arranged in ascending order of proportion of total responses represented by the “not at all” category. Not all total 732 (100%) because of missing responses.

Table 3: **Responses for anticipated discrimination by category**

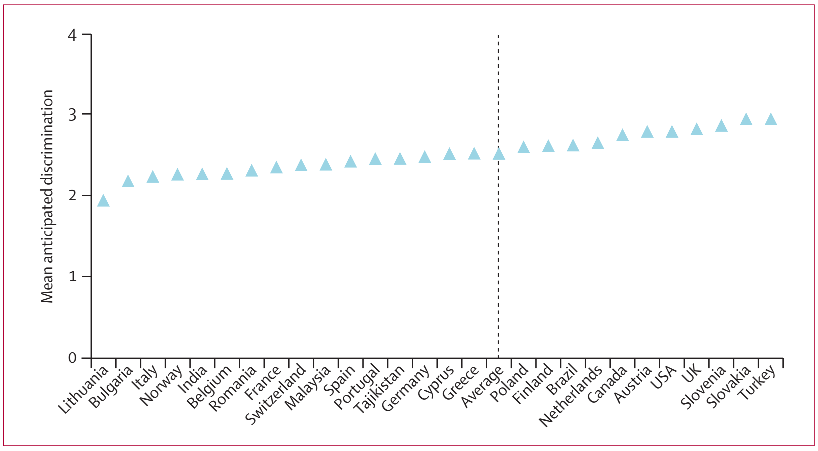

Figure 2: **Mean anticipated discrimination subscore by country**
Possible range 0–4.

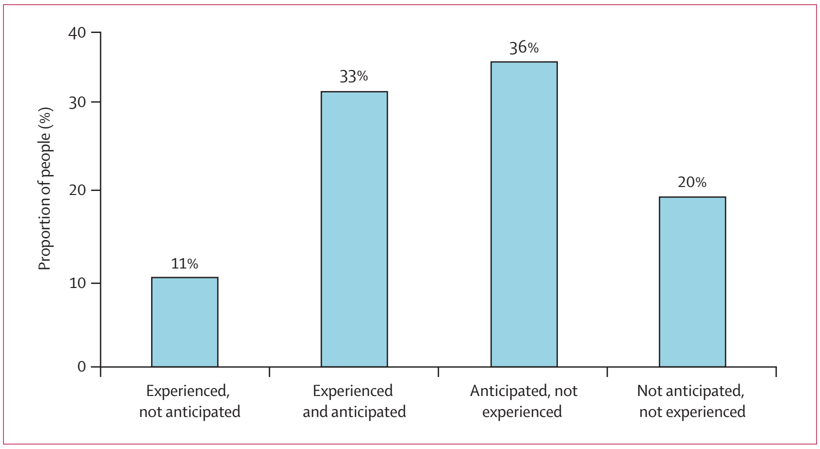

Figure 3: **Discrimination in finding or keeping work**

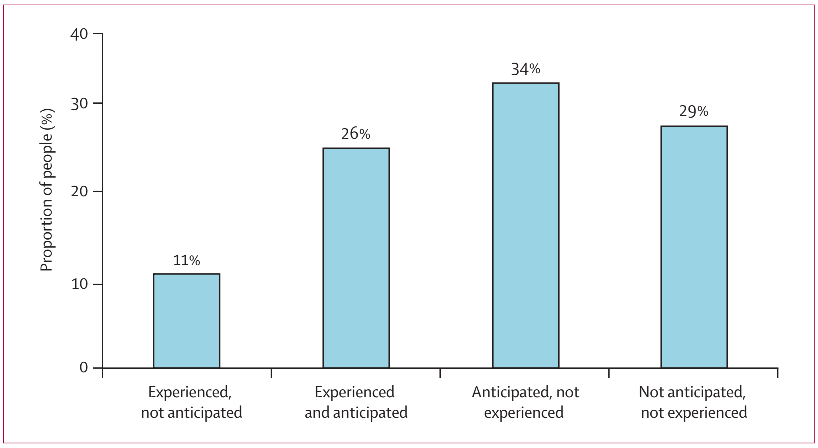

Figure 4: **Discrimination in intimate relationships**

1·91 to 2·92. The overall average total score is 2·49, within a possible range of 0–4.

Although experienced and anticipated discrimination are apparent in all countries, there is a difference in reported levels between countries. The analysis of variance for experienced discrimination indicated significant between-country variation (p<0·0001), Kruskal-Wallis (p=0·001). The estimated standard deviation within country is 3·92 and between countries it is 0·84. The intraclass correlation coefficient is 0·044 (95% CI 0·001–0·086). The analysis of variance for anticipated discrimination indicated no between-country variation (p=0·382), Kruskal-Wallis (p=0·47). The estimated SD within country is 1·23 and between countries it is 0·059. The intraclass correlation coefficient is 0·002 (0·000–0·024).

In the next stage of the analysis we explored the relations between experienced and anticipated discrimination in terms of their four possible combinations. Data on both experienced and anticipated discrimination were available for two domains: work and relationships. Figure 3 shows the results where experienced discrimination was calculated by combining scores on item ten, “finding work” and item 11, “keeping work”, and anticipated discrimination is the score on item 33, “stopped self looking for work/education or training”. Over two-thirds (69%) of respondents reported anticipated discrimination, most of whom (52%) had not experienced discrimination.

The second key domain was intimate relationships (figure 4). Experienced discrimination was calculated by combining scores on items three, “intimate or sexual relationships”, and eight, “marriage or divorce”. Anticipated discrimination is the score on item 33, “stopped self looking for a close relationship”. 60% of participants reported anticipated discrimination, but more than half of these (56%) had not experienced discrimination.

For the two variables discussed above, experienced and anticipated discrimination were positively associated with each other (p<0·0001, χ^2 tests for both variables). A regression model was fitted to total experienced discrimination. Time since diagnosis was associated with increasing negative experienced discrimination (table 4), such that as time since diagnosis moves from less than 5 years to greater than 15 years, so negative discrimination increased by 1·927 units on average (ie, about two extra items of negative discrimination are experienced by the group with longer duration illness). Participants who have been compulsorily treated had a negative experienced discrimination score, which is on average 1·006 units greater than participants who had not. As anticipated discrimination increased by one unit, experienced discrimination increased by 1·170 units on average. Overall, these three variables accounted for 18·69% of the variance in experienced discrimination scores. There were no significant differences in negative experienced discrimination for the remaining independent variables: sex, work status, years of education, current type of mental-health care, or agreement with diagnosis.

	Univariate models (n=679–732)			Multivariate (reduced) model* (n=726)		
	Coefficient	95% CI	p	Coefficient	95% CI	p
Increasing anticipated discrimination	1·184	0·926 to 1·442	0·001	1·170	0·923 to 1·417	0·001
Men	–0·020	–0·835 to 0·795	0·960	..	..	..
Years since first contact with MHS						
>15 years since first contact mental health services	2·220	1·393 to 3·047	0·001	1·927	1·194 to 2·660	0·001
5–15 years since first contact with mental health services	1·909	1·344 to 2·474	0·001	1·580	1·122 to 2·037	0·001
Has received compulsory treatment	1·217	0·630 to 1·805	0·001	1·006	0·520 to 1·492	0·001
Currently works	–0·028	–0·860 to 0·804	0·945	..	..	..
Increasing years of education	0·039	–0·064 to 0·142	0·448	..	..	..
Agreement with diagnosis						
Disagree with diagnosis	0·720	–0·414 to 1·854	0·203	..	..	..
Unsure/don't know diagnosis	–0·118	–0·921 to 0·685	0·764	..	..	..
Current type of mental healthcare						
Outpatient treatment	–0·055	–1·158 to 1·049	0·920	..	..	..
Treatment at home	0·121	–1·145 to 1·386	0·846	..	..	..
Day care	–0·728	0·129 to –1·683	0·228	..	..	..

Dependent variable is number of experiences of negative discrimination. p values are adjusted for clustering (27 countries).

Table 4: **Regression models for total experienced discrimination**

Discussion

People with schizophrenia commonly experience negative discrimination in making or keeping friends, from family members, in both finding and keeping jobs, and in intimate or sexual relationships. Positive experienced discrimination was rare, but most common in relationships with family members and obtaining welfare. Anticipated discrimination for job seeking and close personal relationships was more common than experienced discrimination in these domains.

This study opens a new arena of research characterising the nature and extent of discrimination against people with mental illness. We used interviews to gather direct reports from people with mental illness, both of discrimination that was actually experienced (rather than hypothetical scenarios or vignettes as used in stigma attitudes scales) and that which was anticipated, which may also have profound consequences.

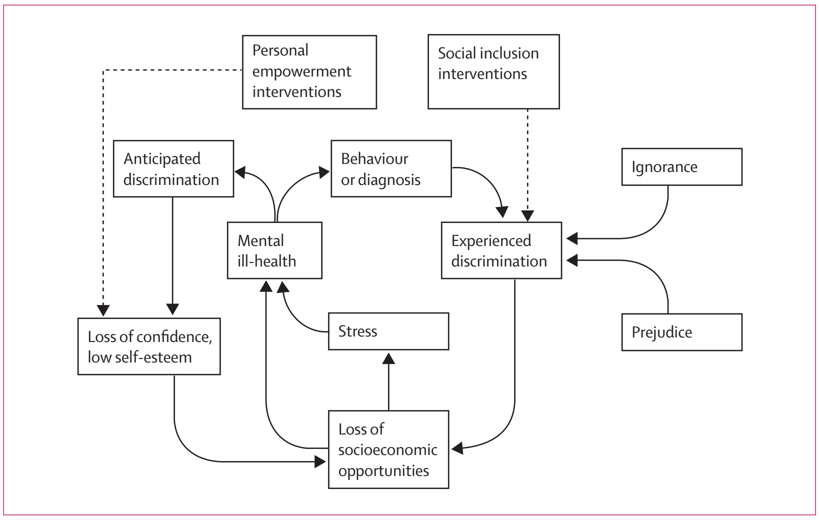

Figure 5: **Relationship between experienced and anticipated discrimination**
Reproduced with permission from the Foresight Mental Capital Programme, Department for Innovation, Universities and Skills (2008).

The key limitations of this study are that sample selection was based on individuals treated rather than on true prevalent cases, and that lifetime-ever experiences of discrimination were recorded without respect to when such events occurred. However, in most countries studied, most people with schizophrenia will receive treatment.[30] This approach was explicitly used at this stage to investigate the relation between duration of disorder and experiences of discrimination. Furthermore, we have deliberately focused on the direct reports of discrimination by people with mental illness for practical, ethical, and methodological reasons. Experiential information is easiest to obtain from service users and can lead directly to recommendations for service and policy changes. Whether it would be justifiable to approach individuals who have found a way to live with their disorder out of the reach of services is questionable. Finally, the DISC scale allows us to analyse the direct service user statements both quantitatively and qualitatively. In addition, in this study we have not taken account of how far experienced discrimination, as reported by service users, might be reasonable, for example a decision by an employer not to employ a job applicant who is very disabled by a mental illness, and so which cannot in fairness be attributed to discrimination. By the same token we have not assessed other possible reasons for discrimination against particular individuals, for example, in relation to age, sex, or ethnic origin, where these may be seen as unmodifiable sources of discrimination, whereas a mental illness is treatable. Such distinctions await further study.

The scoring method for the DISC-10 emphasises the number of areas of life in which perceived discrimination is experienced or anticipated. In this way, we gain a picture of the spread of discrimination. Although this scoring ignores the magnitude of these experiences by combining the slight, moderate, and severe categories. Our main reason for the decision to combine scores was to present an overview of the experiences of the total sample. Mean scores per patient could only be interpreted in the context of very specific experiences because several items had a high level of not applicable responses (eg, 88% of responders could not comment on being treated differently during pregnancy or childbirth). These scores measure the level of discrimination in only those factors in which discrimination was experienced at all. A total score measures discrimination from whatever source. A combined approach with both mean and total scores would be most appropriate for the results of individual participants, particularly with a view to tracking them over time.

Rates of experienced discrimination are high and consistent across countries. In two important discrimination domains (work and personal relationships), slightly more than half of participants anticipated discrimination but did not experience discrimination. This finding indicates the importance of including in strategies for stigma reduction methods that increase self-esteem of people with mental illness, and has important implications for education of employers about mental illness. For example, the implementation of relevant disability discrimination legislation might not be effective without interventions to reduce anticipated discrimination, so that people with mental illnesses apply for and gain jobs (figure 5). Interestingly this combination of anticipated and experienced discrimination has previously been reported for other disorders, such as HIV and Marfan's syndrome.[31,32]

This study has not been able to investigate in any detail the complex features of stigma and discrimination that might apply in culture or context specific settings. For example, there are indications in some cultures that shame, guilt, embarrassment and loss of "face" (both for individuals and for kinship groups) may be powerful factors that shape how stigma and discrimination are felt. What we have been able to show is that experienced discrimination scores vary among countries, but anticipated discrimination scores do not. Nevertheless, the effects of stigma and discrimination were identifiable across a broad range of domains of everyday life in all the countries studied.[5,6] The multiple regression analysis provides initial evidence for factors associated with higher levels of incidents of negative experienced discrimination: increasing years since first contact with mental-health services and having received compulsory treatment. Thus, even allowing for the possible effect of anticipated discrimination influencing patients' views of their experiences, negative experienced discrimination in many domains of life might be related to prior coercive mental health service intervention. If confirmed by further studies, this finding might guide mental-health services to promote social inclusion and to rely less upon compulsory treatment in the future.

Contributors

GT, DR, and NS are coordinators and prinicipal investigators for the INDIGO Study. EB did the data analysis under supervision and contributed to the writing of the paper. ML provided statistical advice and contributed to the writing of the paper. All authors participated in the INDIGO Study and have seen and approved the final version.

INDIGO Study Group

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Conflict of interest statement

We declare that we have no conflict of interest.

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