

Global pattern of experienced and anticipated discrimination reported by people with major depressive disorder: a cross-sectional survey



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Summary

Background Depression is the third leading contributor to the worldwide burden of disease. We assessed the nature and severity of experienced and anticipated discrimination reported by adults with major depressive disorder worldwide. Moreover, we investigated whether experienced discrimination is related to clinical history, provision of health care, and disclosure of diagnosis and whether anticipated discrimination is associated with disclosure and previous experiences of discrimination.

Methods In a cross-sectional survey, people with a diagnosis of major depressive disorder were interviewed in 39 sites (35 countries) worldwide with the discrimination and stigma scale (version 12; DISC-12). Other inclusion criteria were ability to understand and speak the main local language and age 18 years or older. The DISC-12 subscores assessed were reported discrimination and anticipated discrimination. Multivariable regression was used to analyse the data.

Findings 1082 people with depression completed the DISC-12. Of these, 855 (79%) reported experiencing discrimination in at least one life domain. 405 (37%) participants had stopped themselves from initiating a close personal relationship, 271 (25%) from applying for work, and 218 (20%) from applying for education or training. We noted that higher levels of experienced discrimination were associated with several lifetime depressive episodes (negative binomial regression coefficient 0.20 [95% CI 0.09–0.32], $p=0.001$); at least one lifetime psychiatric hospital admission (0.29 [0.15–0.42], $p=0.001$); poorer levels of social functioning (widowed, separated, or divorced 0.10 [0.01–0.19], $p=0.032$; unpaid employed 0.34 [0.09–0.60], $p=0.007$; looking for a job 0.26 [0.09–0.43], $p=0.002$; and unemployed 0.22 [0.03–0.41], $p=0.022$). Experienced discrimination was also associated with lower willingness to disclose a diagnosis of depression (mean discrimination score 4.18 [SD 3.68] for concealing depression vs 2.25 [2.65] for disclosing depression; $p<0.0001$). Anticipated discrimination is not necessarily associated with experienced discrimination because 147 (47%) of 316 participants who anticipated discrimination in finding or keeping a job and 160 (45%) of 353 in their intimate relationships had not experienced discrimination.

Interpretation Discrimination related to depression acts as a barrier to social participation and successful vocational integration. Non-disclosure of depression is itself a further barrier to seeking help and to receiving effective treatment. This finding suggests that new and sustained approaches are needed to prevent stigmatisation of people with depression and reduce the effects of stigma when it is already established.

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Background

Depression is the third leading contributor to the global burden of disease and the first in middle-income and high-income countries.¹ It can be reliably diagnosed in both primary care and specialised services. Antidepressant drugs and brief structured psychotherapy sessions are effective in 60–80% of individuals with depression.² However, fewer than half the people with depression are treated.³ Barriers to effective care include inadequate policy, mental health services, community resources, human resources, and funding,⁴ and stigma associated with having a mental disorder.⁵

Stigma is a mark or sign of disgrace usually eliciting negative attitudes to its bearer and, from a conceptual

point of view, can be seen as an overarching term including difficulties associated with knowledge (ignorance or misinformation), attitudes (prejudice—namely, affective distancing), and behaviour (discrimination—ie, exclusion from normal forms of social participation).⁶

Until a few years ago, the focus of most research was on investigation of stigma in people with mental disorders (mainly schizophrenia) through surveys of the general public's attitudes in specified scenarios, rather than the experiences of people with mental health problems. Without direct assessment of real behaviour, the assumption was that statements (usually about knowledge, attitudes, or behavioural intentions) were linked with behaviour.⁶

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Although, the association between stigma and depression has been reported in several studies,^{7–10} how discrimination (ie, the behavioural aspects of stigma) affects the lives of people with depression has only been reported in one study by Alonso and colleagues.¹¹ However, they used a one-dimensional approach and did not investigate the range of life domains potentially affected by discrimination.¹¹

In this study, we aim to fill a gap in the knowledge by investigating patterns of experienced and anticipated discrimination and their relations with socio-demographic and clinical variables in people with depression. We defined discrimination as rejection of and negative behaviour towards people with mental health problems. Discrimination can cause low rates of help seeking, lack of access to care, under treatment, material poverty, and social marginalisation.⁶ These effects can be a consequence of experienced (actual) discrimination (eg, unreasonable rejection after an application for work), or a consequence of anticipated discrimination (eg, when an individual does not apply for a job because he or she does not expect to be successful).

On the basis of previous reports, we wanted to address five questions. Is experienced discrimination positively associated with more episodes of depression?¹² Is experienced discrimination positively associated with having been admitted to hospital for psychiatric treatment?^{13,14} Is experienced discrimination positively associated with poorer levels of social functioning (in relation to education, employment, and marital relationships)?¹⁵ Are higher levels of anticipated and experienced discrimination associated with lower willingness to disclose a diagnosis of depression?¹⁶ Is anticipated discrimination more common in people with depression who have not experienced discrimination than in those who have?¹⁷

Methods

Study design

The study was a multisite face-to-face, cross-sectional survey undertaken in 35 countries. Data were gathered as part of the European Union (EU)-funded ASPEN (Anti Stigma Programme European Network) study and the INDIGO-Depression (International Study of Discrimination and Stigma for Depression) research network. Overall, there were 19 sites in 18 ASPEN EU-funded countries (Belgium, Bulgaria, England, Finland, France, Germany, Greece, Hungary, Italy [Brescia and Verona], Lithuania, the Netherlands, Portugal, Romania, Scotland, Slovakia, Slovenia, Spain, and Turkey) and 20 sites in 17 countries in the wider INDIGO research network (Australia, Brazil, Canada, Croatia, Czech Republic, Egypt, India, Japan, Malaysia, Morocco, Nigeria [four sites], Pakistan, Serbia, Sri Lanka, Taiwan, Tunisia, and Venezuela). Data were gathered at all sites from Jan 1, to Dec 31, 2010.

Participants

The design for this study was intentionally pragmatic so that as many low-income and middle-income countries as possible could participate using only locally available resources because no external grant provision was available. For the sampling frame, local research staff within each site were asked to identify people attending specialist mental health services (either outpatient or day care in the public and private sectors) in the local area with a diagnosis of major depressive disorder in the previous 12 months. Individuals invited to participate were therefore intended to be reasonably representative of this sampling frame. This method, also used in our previous study,¹⁸ was used to allow local staff to take into account the specific local service configuration and invite participants from the whole range of appropriate local services. Each site was asked to assess a minimum of 25 people with major depressive disorder (this number was determined by feasibility issues, particularly for sites without grant support). Staff at each site ensured that the sample comprised young (18–25 years), middle-aged (25–65 years), and elderly adults (≥65 years) and a 2:1 ratio of women to men (because major depressive disorder is twice as prevalent in women as in men).

Study inclusion criteria were clinical diagnosis of major depressive disorder (single episode or recurrent) according to the Diagnostic and Statistical Manual of Mental Disorders (fourth edition, text revision) criteria during the previous 12 months; ability to understand and speak the main local language; and age 18 years or older. Individuals who had been given psychiatric therapy as inpatients during recruitment were excluded. The study was approved by the appropriate ethical review board at each study site. All participants provided written informed consent.

Outcomes

Participants were assessed face-to-face by independent researchers not involved in the care process using the discrimination and stigma scale (version 12; DISC-12)—a structured interview for recording the discrimination experienced by an individual with a mental disorder.¹⁸ Full details of the psychometric properties of this scale are reported elsewhere.¹⁹ DISC-12 contains 32 questions about aspects of everyday life including work, marriage, parenting, housing, and leisure and religious activities. Items 1–21 are to ascertain experienced discrimination (eg, “Have you been treated unfairly in making or keeping friends?”); 22–25, anticipated discrimination (eg, “Have you stopped yourself from applying for work?”); 26 and 27, positive treatment (eg, “Have you been treated more positively by your family?”); and 28–32, coping strategies to overcome discrimination (eg, “Have you been able to use your personal skills or abilities in coping with stigma and discrimination?”). Participants’ responses were rated with a 4-point Likert scale (0=no difference, 1=a little

For the ASPEN study see <http://www.antistigma.eu>

different, 2=moderately different, and 3=a lot different). The DISC-12 items were divided into four subscales—experienced discrimination (0–21), anticipated discrimination (0–4), overcome discrimination, and positive treatment. Only the first two subscales will be addressed here. For each subscale a total score is generated by counting the number of items in which participants score 1, 2, or 3. DISC-12 also allows qualitative information to be gathered to add detail to the experiences rated,²⁰ providing a strong validation for the occurrence, direction, and severity of the discrimination rated quantitatively, which is not discussed in this report. Sociodemographic

and clinical information (age, sex, years since first contact with mental health services, work status, education, current mental health care, knowledge of diagnosis, and agreement with diagnosis) are also recorded.

Statistical analysis

Analyses were done with SPSS (version 17.0) and Stata (11.0) for Windows. All p values were two-tailed with an accepted significance level of 0.05. Non-normality of continuous variables was checked by visual inspection of distribution and probability–probability plots and confirmed with Kolmogorov-Smirnov tests; non-parametric tests were chosen to account for skewed distributions. Summary statistics for independent groups were compared with χ^2 for categorical variables and Mann-Whitney *U* test for continuous variables. Bivariable correlations between scores were assessed with Spearman's rank correlation coefficient. A series of univariable negative binomial regression models (nbreg Stata command) were estimated with the subscore for experienced discrimination as the dependent variable and a set of potential explanatory variables (anticipated discrimination, sex, age, knowledge of diagnosis, disadvantage of having major depressive disorder, current outpatient care, ever admitted to hospital for psychiatric treatment, six or more lifetime episodes of major depressive disorder, marital status [married or cohabiting as reference category], low

| | Participants (n=1087) |
|---|--------------------------|
| Age (years) | 44.9 (15.1) |
| Male sex | 370 (34%) |
| Education | |
| None, primary (age ≤12 years), secondary (≤15–16 years), or vocational qualification | 475 (44%) |
| Diploma, degree, or postgraduate qualification | 601 (55%) |
| Living status | |
| Alone | 197 (18%) |
| With partner or partner and children | 530 (49%) |
| With children but no partner | 109 (10%) |
| With other relatives, unrelated people, or individuals providing assistance | 243 (22%) |
| Marital status | |
| Married or cohabiting | 542 (50%) |
| Single or non-cohabiting partner | 296 (27%) |
| Widowed, separated, or divorced | 244 (22%) |
| Employment | |
| Full-time or part-time | 427 (39%) |
| Volunteer, or working in a sheltered accommodation or at home | 109 (10%) |
| Looking for a job | 120 (11%) |
| Unemployed or a student | 250 (23%) |
| Retired | 168 (15%) |
| Ethnic minority | 70 (6%) |
| Years since first contact with mental health services | 9.70 (10.9) |
| Six or more lifetime depressive episodes | 288 (34%) |
| Outpatient mental health care | 913 (84%) |
| Ever admitted for psychiatric care | 411 (38%) |
| Compulsory treatment ever | 85 (8%) |
| No advantage to have diagnosis of major depressive disorder as an explanation of mental health problems | 205 (20%) |
| Does not know the diagnosis | 132 (12%) |
| Agrees with diagnosis | |
| Yes | 919 (95%) |
| No | 9 (1%) |
| Unsure or does not know | 33 (3%) |

Data are number (%) or mean (SD). Total numbers of observations per category do not equal 1087 because of missing responses (<4% of all responses); percentages are based on valid responses.

Table 1: Sociodemographic and illness-related characteristics of participants

| | Disadvantage | No difference | Not applicable |
|---|--------------|---------------|----------------|
| Family | 431 (40%) | 631 (58%) | 20 (2%) |
| Avoided or shunned by other people | 367 (34%) | 682 (63%) | 31 (3%) |
| Making or keeping friends | 354 (33%) | 668 (62%) | 59 (5%) |
| Marriage or divorce | 248 (23%) | 477 (44%) | 331 (31%) |
| Keeping a job | 230 (21%) | 499 (46%) | 352 (32%) |
| Personal safety and security | 230 (21%) | 804 (74%) | 48 (4%) |
| Dating or intimate relationships | 226 (21%) | 530 (49%) | 324 (30%) |
| Mental health staff | 204 (19%) | 828 (76%) | 25 (2%) |
| Social life | 199 (18%) | 769 (71%) | 113 (10%) |
| Physical health | 184 (17%) | 845 (78%) | 53 (5%) |
| Personal privacy | 181 (17%) | 861 (79%) | 40 (4%) |
| Neighbourhood | 87 (17%) | 807 (74%) | 53 (10%) |
| Finding a job | 145 (13%) | 480 (44%) | 456 (42%) |
| Role as a parent | 135 (13%) | 524 (48%) | 421 (39%) |
| Education | 134 (12%) | 515 (47%) | 432 (40%) |
| Welfare benefits or disability pensions | 106 (10%) | 388 (36%) | 586 (54%) |
| Housing | 101 (9%) | 641 (59%) | 340 (31%) |
| Starting a family or having children | 83 (8%) | 453 (42%) | 546 (50%) |
| Public transport | 66 (6%) | 797 (73%) | 217 (20%) |
| Police | 65 (6%) | 662 (61%) | 354 (33%) |
| Religious practices | 54 (5%) | 731 (67%) | 293 (27%) |

Data are number (%). Total numbers for the rows do not equal 1082 and percentages do not equal 100% because of missing responses (<2% of all responses). Items are arranged in descending order of proportion of total responses represented by the combined disadvantage categories (a little, moderate, and a lot).

Table 2: Responses for experienced discrimination by the life domains assessed with the discrimination and stigma scale, version 12 (n=1082)

level of education, working status [full-time or part-time as reference category]) specifically selected to address the five research questions. For pairs of highly correlated independent variables, only one was chosen; years from first psychiatric treatment was not included because it is significantly associated with lifetime number of episodes of major depression; compulsory admission and living conditions were similarly excluded because they are significantly associated with voluntary admission to hospital and marital status, respectively. Subsequently, a multivariable negative binomial regression model was estimated, introducing as independent variables only those that were significantly associated ($p < 0.05$) with the dependent variable in the univariable models. All models had the cluster option, which specified that the observations were independent between groups (ie,

39 sites), but not necessarily independent within groups. The cluster option affected the estimated SE, but not the estimated coefficients, through replacement of the traditional calculation with the robust or Huber–White sandwich estimator of variance.

Role of the funding source

The sponsor of the study had no role in study design, data gathering, analysis, and interpretation, or writing of the report. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Results

Table 1 shows the characteristics of the 1087 study participants. Table 2 shows the profile of discrimination experienced by the 1082 individuals who completed DISC-12.

855 (79%) of 1082 participants had experienced discrimination in at least one domain of their lives. The domains reported most often were family, making or keeping friends, marriage or divorce, keeping a job, personal safety and security, and intimate or sexual relationships (table 2). Importantly, nearly a third of participants reported that they had been avoided or shunned by other people because of their mental health problems (table 2).

Table 3 shows that 37% of participants had stopped themselves from initiating a close personal relationship,

| | Anticipate* | Not at all | Not applicable |
|------------------------------------|-------------|------------|----------------|
| Close personal relationship | 405 (37%) | 558 (51%) | 118 (11%) |
| Applying for a job | 271 (25%) | 408 (38%) | 378 (35%) |
| Applying for education or training | 218 (20%) | 471 (43%) | 367 (34%) |

*Combined responses of a little, moderate, and a lot. Items are arranged in descending order of proportion of total responses represented by the combined anticipated discrimination categories. Total numbers in rows do not equal 1082 and percentages do not equal 100% because of missing responses (<4% of all responses).

Table 3: Responses for anticipated discrimination by the life domains assessed with the discrimination and stigma scale, version 12 (n=1082)

| | Univariable models | | Multivariable model | |
|---|---------------------------------|----------|---------------------------------|----------|
| | Regression coefficient (95% CI) | p value* | Regression coefficient (95% CI) | p value* |
| Anticipated discrimination | 0.408 (0.342 to 0.474) | 0.001 | 0.344 (0.276 to 0.413) | 0.001 |
| Male sex | -0.043 (-0.218 to 0.131) | 0.624 | .. | .. |
| Age | -0.011 (-0.017 to -0.006) | 0.001 | -0.003 (-0.006 to 0.001) | 0.080 |
| Does not know the diagnosis | -0.004 (-0.292 to 0.284) | 0.978 | .. | .. |
| Disadvantage to have this diagnosis | 0.181 (0.025 to 0.338) | 0.023 | -0.016 (-0.166 to 0.134) | 0.839 |
| Current outpatient care | -0.052 (-0.302 to 0.198) | 0.683 | .. | .. |
| Ever admitted for psychiatric treatment | 0.307 (0.165 to 0.449) | 0.001 | 0.285 (0.153 to 0.416) | 0.001 |
| Six or more lifetime depressive episodes | 0.360 (0.213 to 0.508) | 0.001 | 0.202 (0.087 to 0.318) | 0.001 |
| Marital status | | | | |
| Married or cohabiting | Ref | Ref | Ref | Ref |
| Single or non-cohabiting partner | 0.341 (0.186 to 0.497) | 0.001 | 0.034 (-0.148 to 0.216) | 0.716 |
| Widowed, separated, or divorced | 0.296 (0.127 to 0.464) | 0.001 | 0.098 (0.009 to 0.186) | 0.032 |
| Low level of education | -0.165 (-0.299 to -0.030) | 0.016 | -0.128 (-0.269 to 0.012) | 0.074 |
| Employment | | | | |
| Full-time or part-time | Ref | Ref | Ref | Ref |
| Volunteer, or working in a sheltered accommodation or at home | 0.144 (-0.193 to 0.481) | 0.401 | 0.345 (0.093 to 0.596) | 0.007 |
| Looking for a job | 0.232 (0.088 to 0.376) | 0.002 | 0.261 (0.095 to 0.427) | 0.002 |
| Unemployed or a student | 0.334 (0.182 to 0.485) | 0.001 | 0.220 (0.032 to 0.409) | 0.022 |
| Retired | -0.350 (-0.578 to -0.121) | 0.003 | -0.179 (-0.447 to 0.089) | 0.191 |

Ref=reference. *Adjusted for clustering.

Table 4: Negative binomial regression models for experienced discrimination with independent variables (39 sites, 1082 participants)

25% from applying for work, and 20% from applying for education or training. 766 [71%] of 1082 participants actively wished to conceal their depression from other people.

A multivariable negative binomial regression model was fitted with the experienced discrimination scale as the dependent variable (table 4). Participants who experienced most discrimination were those who had at least one lifetime psychiatric hospital admission; had several depressive episodes; had lost a spouse or partner (ie, divorced, separated, or widowed); were in unpaid employment; were looking for a job; were unemployed; and had greater anticipated discrimination. Overall, these variables accounted for 28·27% of the variance.

To address the effect of experienced and anticipated discrimination on disclosure of diagnosis, scores for experienced and anticipated discrimination were compared between participants who were willing to disclose their diagnosis (n=307) and those who concealed their diagnosis (n=766); nine participants did not complete the disclosure item of DISC-12. The group that concealed their diagnosis reported higher experienced (mean score 4·18 [SD 3·68] vs 2·25 [2·65]; Mann-Whitney $p < 0·0001$) and anticipated (1·95 [0·97] vs 0·51 [0·78]; $p < 0·0001$) discrimination than did those who disclosed their diagnosis. To account for possible effects of covariates, comparisons of groups were repeated with stratification by site, sex, educational level, marital status, current employment, type of mental health care, lifetime number of depressive episodes, admission for psychiatric care, compulsory treatment ever, advantage of having a diagnosis of major depressive disorder, and knowledge of diagnosis. Experienced discrimination and concealment of diagnosis lost association once site was accounted for (data not shown). The association between anticipated discrimination and diagnosis concealment also remained significant after controlling for site, because people who concealed their diagnosis reported significantly higher anticipated discrimination in nearly all sites (data not shown).

The relation between experienced and anticipated discrimination in terms of their four possible combinations was analysed for the two aspects of life for which comparable data (experienced and anticipated discrimination) were available—ie, work and intimate relationships. In the work domain, 316 (47%) of 668 participants reported anticipated discrimination despite 147 (47%) of these individuals not having experienced discrimination (table 5).

In the intimate relationships domain, 353 (41%) of 863 participants reported anticipated discrimination, but 160 (45%) of these had not experienced discrimination. Experienced and anticipated discrimination were significantly associated in both domains (finding or keeping a job, χ^2 test $p < 0·0001$; intimate relationship, $p < 0·0001$).

| | Experienced | Not experienced |
|--|-------------|-----------------|
| Finding or keeping a job* (n=668) | | |
| Anticipated | 169 (25%) | 147 (22%) |
| Not anticipated | 90 (13%) | 262 (39%) |
| Intimate relationships† (n=863) | | |
| Anticipated | 193 (22%) | 160 (19%) |
| Not anticipated | 156 (18%) | 354 (41%) |

Data are number (%). *Experienced discrimination was calculated by combining scores on item 8 (finding work) and item 9 (keeping work) of DISC-12; anticipated discrimination was calculated by combining scores on item 22 (stopped self applying for work) and item 23 (stopped self applying for education or training courses) of DISC-12. †Experienced discrimination was calculated by combining scores on item 3 (intimate or sexual relationships) and item 6 (marriage or divorce) of DISC-12; anticipated discrimination is the score on item 24 (stopped self from having a close relationship) of DISC-12.

Table 5: Relation between experienced and anticipated discrimination in finding or keeping a job and intimate relationships

Discussion

Overall, the results of our study show that rates of experienced discrimination in people with depression are high in the different countries, with rates in some life domains (eg, family and social relations) substantially similar to those in people with schizophrenia.¹⁸ The levels of discrimination in this study might be underestimates because people with very high levels of experienced or anticipated discrimination could have avoided service contact. However, overall levels of reported discrimination in people with depression seem to be slightly lower than those in people with schizophrenia,¹⁸ which is consistent with the results of surveys of public attitudes towards people with these disorders.²¹

The main source of reported discrimination is from family members, which is also the source of most reported support. Another key source of reported discrimination is employment. Notably, in these two important domains, nearly half the people surveyed reported anticipated discrimination in the absence of experienced discrimination. In other important life domains, such as housing, parenting, education, welfare benefits, and dealing with police, there were few cases of reported discrimination. Overall, our findings suggest that the social environment could be a source of support or discrimination, depending on the context or the personal resources of the individual.²²

This study has several limitations. Participants were selected from patients who were treated rather than true prevalent cases in the community, thus reducing the generalisability of results to all people with major depressive disorder living in the participating sites. Selection bias could have occurred because participants were recruited on the basis of the judgment of local research staff and on their willingness to participate, further reducing the generalisability of the findings. Disability and clinical severity measures were not used, therefore we could not realistically elucidate how much

discrimination reported by respondents was attributable to disorder-related impairments or to negative appraisal of life circumstances affected by current levels of depressive symptoms. The cross-sectional design of the study does not enable ascertainment of causal relations between putative predictors and levels of discrimination. Social desirability is another common limitation of self-report stigma measures, which might vary according to cultures.

The study has several strengths. This is the first study in which a detailed report is given of experiences of discrimination in a large international sample of people with depression, thus providing the basis for results that are comparable between countries and cultures. Interviews were used to gather direct self-reports from people with depression of discrimination that was actually experienced (rather than hypothetical scenarios or vignettes) and that which was anticipated. Most research into discrimination and depression has largely been descriptive, concerning surveys of public attitudes of hypothetical situations rather than how discrimination is experienced by people suffering from depression (panel). The gathering of self-reports of

discrimination might empower service users by giving them a voice and acknowledge the validity of their experience.

We discuss the study results in relation to each of the five key research questions. Is experienced discrimination positively associated with more episodes of depression? Having had several lifetime depressive episodes is a strong predictor of discrimination. This variable (with illness duration) can be a proxy of illness severity. Therefore, the association between number of lifetime depressive episodes and experienced discrimination levels might be spurious because current high depressive symptom levels might increase both reported discrimination and be associated with more past episodes. This reasoning is consistent with the results of a report that levels of reported discrimination are associated with greater depression severity in different countries and cultures.²³ Because current symptom levels were not assessed in this study, this hypothesis warrants further investigation. The association between reported discrimination and clinical severity represents an important clinical concern because discrimination can act as a barrier for people with more needs for care seeking treatment, which if not timely and appropriately given, might greatly increase the risk of suicide or self-harm behaviours.

Is experienced discrimination positively associated with having been admitted to hospital for psychiatric treatment? Having at least one lifetime psychiatric hospital admission is a strong predictor of reported discrimination. It can also be seen as a proxy for illness severity (most severely depressed people needing to be treated on an inpatient basis); or it might suggest that people with depression might perceive specific mental health-care facilities as more (eg, psychiatric hospitals) or less (eg, outpatient settings) stigmatising. Stigmatisation is lower in outpatients without schizophrenia who were treated in a general hospital than in those treated within large state psychiatric hospitals.¹³ There might be a service-specific effect on reported discrimination²⁴ with self-esteem having a mediating effect on service perception (ie, more coercive and institutionalising settings being associated with low self-esteem, and more empowering and recovery-oriented settings being associated with increased self-esteem).²⁵ These factors could negatively affect self-appraisal, thus leading to self-devaluation and anticipated discrimination.

Is experienced discrimination positively associated with poorer levels of social functioning? Experienced discrimination was positively associated with poor social functioning (as assessed in relation to employment and marital status). This finding is consistent with the findings in other studies.^{15,26} Direct evidence for a specific link between reported discrimination and decreased social functioning in people with depression was obtained with a standardised videotaped role-play test.²² Stigma-related functional impairment could result from

Panel: Research in context

Systematic review

We searched PubMed for original research published in any language and year with the search terms "depression", "depression, bipolar", "prejudice", and "social discrimination". We noted that there was not much literature in relation to depression and related discrimination. Much of it referred to racial discrimination towards African-American people in the USA and how this discrimination was associated with increased rates of depression.²²⁻²⁴ The focus of the other research was mainly on stigmatisation related to depression¹²⁻¹⁹ rather than perceived social discrimination related to depression. However, stigma and discrimination are not interchangeable or overlapping terms because stigma (a characteristic that is deeply discrediting and ascribed to individuals with psychiatric problems) covers problems of knowledge (ignorance), attitudes (prejudice), and behaviour (discrimination).⁸ In our report, we specifically addressed discrimination related to depression. Perceived discrimination in people with depression was addressed in only one other study,¹¹ in which a one-dimensional approach was used, without investigation of the broad range of life domains that might be affected by discrimination in people with depression.¹¹ Therefore, a comprehensive picture of how perceived discrimination affects the various life domains in people with depression worldwide is missing.

Interpretation

Our study is the first in which experiences of discrimination were investigated in a large sample of people with depression from all over the world. The main strength of this study was the use of interviews to gather direct self-reports of discrimination that was actually experienced and anticipated by people with depression. We noted that 79% of people with depression reported experienced discrimination in at least one domain of their lives and the most commonly affected domains were discrimination by family members (40%), making or keeping friends (33%), marriage or divorce (23%), and keeping a job (21%). 71% of participants actively wished to conceal their depression from other people, 37% anticipated discrimination when initiating a close personal relationship, and 25% had stopped themselves from applying for work. These findings led us to conclude that discrimination related to depression acts as a barrier to a satisfying social life and successful vocational integration in people with depression.

avoidant coping strategies such as behavioural avoidance by some people to prevent discrimination from people outside their family.²⁷ Those individuals with depression concerned about stigma adapt their social behaviour to avoid exposure to rejection or discrimination.²⁷ Thus, the relation might be bidirectional, establishing a vicious circle between the anticipation of stigma and the effect at a behavioural or functioning level.

Are higher levels of anticipated and experienced discrimination associated with lower willingness to disclose a diagnosis of depression? We noted that people with higher levels of anticipated discrimination are less likely to disclose their diagnosis of depression. This finding is consistent with the results of a study in patients with depression in the primary-care setting.²⁸ Non-disclosure of depression might be a barrier to help seeking and receiving effective treatment. People with depression might avoid treatment because of concern that they will be negatively judged or discriminated against by other people,²⁹ whereas others might avoid addressing issues related to their disorder because of its potential effect on their self-esteem, which is already compromised by depression.³⁰ Non-disclosure of mental health problems is also a crucial issue in employment because in some countries individualised reasonable adjustments or accommodations in the workplace for people with mental disorders can only be made if the employer has knowledge of the employee's disability.^{16,31} The issue of employment and disclosure is a complex one: complete or selective disclosure might work for some people whereas non-disclosure might be best for others, and the more correct approach (disclosure vs non-disclosure) might change as an individual moves through phases of recovery.³²

Is anticipated discrimination more common in people with depression who have not experienced discrimination than in those who have? Nearly half of participants who anticipated discrimination in the domains of employment and personal relationships had not actually experienced discrimination. This finding, which is in accord with that noted in people with schizophrenia,¹⁷ confirms that anticipated discrimination is not necessarily associated with actual experienced discrimination.³³ Those who anticipate discrimination might withdraw from social and occupational activities and give up important life goals (the why-try effect).³⁴

The introduction of methods to minimise discrimination towards people with depression at individual, institutional, and structural levels³⁵ and the identification of effective strategies to reduce anticipated discrimination by people with depression towards themselves might be necessary to tackle stigma and discrimination related to depression. To reduce discrimination by people with depression towards themselves, some possible interventions could be to foster empowerment that enhances their pursuit of social participation,³⁴ whereas other interventions could be to improve related attitudes and

behaviour in the general public.³⁶ In conclusion, our findings show that discrimination acts as a barrier to social participation and successful vocational integration for many people with depression, and suggest that new and sustained approaches are needed to prevent and reduce or eliminate discrimination.

Contributors

The original study design and protocol was written by AL, TVB, NS, and GT. AL, SZ, TVB, CB, DC, KW, SVB, CVA, JvW, BR, AG, ME, ML, SA, NS, and GT coordinated data gathering in the participating sites. AL, CB, DC, TVB, KW, and GT participated in the data analysis and interpretation. The report was written by AL, TVB, KW, SZ, and GT and was edited by all the authors, who also approved the final version.

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Conflicts of interest

We declare that we have no conflicts of interest.

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Depression and stigma: from attitudes to discrimination



In addition to their symptoms, people with depression have to cope with stigma and discrimination.¹ Stigmatising attitudes, either their own or those of other people, are often nominated as an important issue of concern by individuals with mental disorders and can have several adverse effects, including delayed help seeking, difficulties with personal relationships, and disruption to educational and vocational goals.²⁻⁴

Stigmatising attitudes towards people with a range of mental disorders, including depression, have been investigated in studies undertaken in several countries. Generally, participants' beliefs about people with these disorders, beliefs about the attitudes of other individuals, and a desire for social distancing have been assessed.⁵⁻⁸ Experiences of discrimination (ie, the behavioural aspects of stigma) have been assessed in only a few studies, and until now the focus was on severe mental illness, typically schizophrenia.^{9,10}

In *The Lancet*, Antonio Lasalvia and colleagues¹¹ increase our understanding of discrimination related to depression through their assessment of the nature and severity of experienced and anticipated discrimination reported by more than 1000 adults with depression, in 35 countries. Their investigation also included the links between experiences of discrimination and clinical history, health-care provision, social functioning, and disclosure of diagnosis. The strengths of Lasalvia and colleagues' study are the focus on actual reported experiences rather than attitudes to hypothetical situations, and the cross-national design. The findings that 79% of individuals surveyed had experienced discrimination, with nearly half reporting experiences in the key domains of family and workplace, offer a sobering insight into the lives of people with depression. Between 20% and 37% of respondents stopped themselves from doing something important because of anticipated discrimination, providing further evidence of the effect on social participation and vocational integration.

However, some questions that merit further investigation remain unaddressed. These relate to the true prevalence of depression-related discrimination in the population; the association between anticipated discrimination and delayed help seeking; the extent to which the degree of disability leads to discrimination,

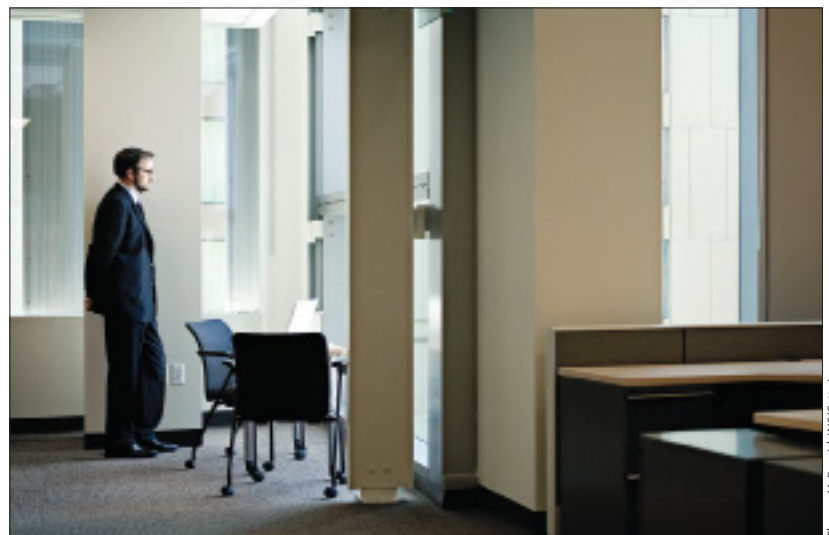
rather than the labelling or diagnosis of the disorder; and the extent to which depressive cognition contributes to the reporting of actual and anticipated discrimination.

For the question about prevalence, although the results suggest that depression-related discrimination is widespread, because of the use of a convenience clinical sample the results of Lasalvia and colleagues' study cannot be used to estimate prevalence. Since anticipated stigma might act as a barrier to help seeking, prevalence could be even higher if non-help seekers were included. An epidemiological survey, which would also include people not undergoing treatment and those with less severe disorders, could assist in establishing true prevalences, from the milder to the more severe end of the continuum of depression. In such a study, stigma could also be investigated as a barrier to help seeking—a huge clinical concern.

If such a study were longitudinal, the results would assist in further investigating the relation between depression, degree of disability, and discrimination. For example, the degree of discrimination experienced by an employee with depression who performs as expected in their job might be very different to that of someone who underperforms. The findings of Lasalvia and colleagues relating to the association of discrimination with the number of depressive episodes and hospital admissions suggest links between the degree of disability and experiences of discrimination. They also noted greater discrimination in the life domains of friends, family,

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and workplace than in the domains of housing, police, and education. Experiences relating to the domains of friends, family, and workplace are more likely to be affected by poor functioning than the domains of housing, police, and education. A longitudinal study with participants followed up from diagnosis, through treatment, and potentially to recovery, would play a valuable part in the investigation of discrimination related to diagnosis, degree of disability, and depressive cognitions that are often associated with the disorder.

Evidence from such studies could provide much-needed input into the design of anti-discrimination interventions—eg, public education about human rights and the effect of discrimination on the person with depression; action from health services to help overcome anticipated discrimination as a barrier to help seeking; and the incorporation into treatments such as cognitive behavioural therapy of techniques to address anticipated discrimination and symptoms.

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