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The economic costs of mental health-related discrimination

Osumili B, Henderson C, Corker E, Hamilton S, Pinfold V, Thornicroft G, McCrone P. The economic costs of mental health-related discrimination.

Objective: To estimate and compare the economic costs of mental health-related discrimination in the domains of health care, relationships and participation in leisure activities in England between 2011 and 2014.

Method: A subsample of the Viewpoint survey was interviewed using the Costs of Discrimination Assessment Questionnaire in 2011 and 2014. Information on the impact of discrimination on healthcare use, help seeking from family and friends and participation in leisure activities was recorded. Pattern of contacts, costs and predictor of costs were examined.

Results: Our findings showed higher costs of health service use for individuals who reported experiences of discrimination in healthcare settings in 2011 compared with those who did not (mean difference £625, P -value 0.019). Individuals who reported experiences of discrimination in relationships in 2014 had higher healthcare costs than those who did not (mean difference £418, P -value 0.034). There was some evidence of a reduction in overall levels of healthcare use, leisure activities and support from families over time. Discrimination did not significantly affect help seeking from family/friends or leisure activities.

Conclusion: There is some evidence that discrimination is related to increased healthcare costs. A prospective study is needed to better understand the consequences of these effects.

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Key words: health service use; mental health-related discrimination; welfare loss; costs

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Significant outcomes

- Discrimination in the areas of healthcare settings and relationships appear to result in increased healthcare costs.
- Overall, there was a reduction in the levels of health service use, help seeking from family and friends and participation in leisure activities between the 2 years.

Limitations

- The study only recruited participants currently registered with secondary mental health services, and therefore, it is not possible to assess the association between costs and discrimination for those who had disengaged or been discharged from secondary care services.
- The study design was cross-sectional, and therefore, it was not possible to examine the pathways by which experiences of discrimination could directly impact a reduction in health service use, help seeking from family and friends or participation in leisure activities.
- The recruitment process meant that participants were essentially self-selected due to low survey response rates, and this may have introduced biases.

Introduction

People with mental health problems often face discrimination in many aspects of their lives. Discrimination can affect access to housing, education, employment, income, social activities, and health care (1). Studies have shown that mental health discrimination is experienced most from those with whom individuals with mental health problems have closest contact (2–5). For people with mental health problems, the consequences of discrimination can lead to breakdown in, or exclusion from, personal relationships (3, 6), reduce the use of mental health services (7), reduce participation in social or recreational activities (7) and delay help-seeking behaviour, thus impacting on recovery (8).

Discrimination in relation to mental health problems may have associated social and economic costs both for an individual and for society, as we have shown previously (1). If individuals use specific services or engage in particular activities *more* because of discrimination, then this will lead to increased costs. However, they may also be deterred from using some services or engaging in leisure activities. While on the face of it we may regard this as saved resources, clearly there is a loss to the individual if they would otherwise benefit from such use or activities. In principal, this loss can be valued in monetary units. This, though, presents a clear methodological challenge. While both effects can be considered as a ‘cost’ in a broad sense, measuring the latter in monetary terms and treating them in a similar way to costs arising through increased resource use may be contentious.

Wright and colleagues (7) argued that reduction in health service use and engagement in leisure activities as a consequence of discrimination result in a noticeable ‘welfare loss’ for users of mental health services. Elsewhere, the cost of health service use was almost twice as high for individuals who reported discrimination in healthcare settings compared with those who did not (9). The same study also found that those who reported discrimination in healthcare settings or in relationships were less likely to participate in leisure activities.

Aims of this study

This study were to (i) estimate and compare economic costs associated with discrimination in the domains of health care, relationships and participation in leisure activities in 2011 and 2014 in order to see changes over time; (ii) estimate the monetary value of services and leisure activities

that are forgone or used more due to discrimination; and (iii) assess the impact of discrimination on costs and identify demographic and clinical characteristics associated with the costs incurred or value lost due to discrimination.

Methods

Sample

A subsample of participants from the Viewpoint survey of mental health discrimination (4) were invited to take part in an additional survey in 2011 and 2014 to provide information on service use and participation in community activities. Participants in the Viewpoint survey were recruited from five different National Health Service (NHS) Mental Health Trusts (provider organisations) across England each year. Trusts were selected based on the socio-economic deprivation level of their catchment area ensuring representation of all such trusts in the country. Within each participating trust, a random sample of persons receiving care for ongoing mental health problems was selected from the central patient database. Eligible participants were those aged 18–65 years, with a psychiatric diagnosis (excluding dementia), who had been in recent receipt of specialist mental health services (contact in the previous 6 months), and were currently living in the community. More detailed methodology is described by Corker et al. (3) and Henderson et al. (4).

Measures

Cost of discrimination assessment. The participants were interviewed by telephone using the Costs of Discrimination Assessment (CODA) Questionnaire, which records information on participants’ characteristics and the impact of discrimination on employment, healthcare use and leisure activities. These areas were included following consultation with service users and carers in a focus group (7). The questionnaire has been described in detail elsewhere (7, 9). In brief, the CODA covers a retrospective period of 6 months and records impact of mental health-related discrimination in the following areas: employment, contact with financial institutions, housing, health services, support from family and friends and leisure activities. For example, one question would ask whether the respondent has had more or less contacts with a general practitioner because of stigma or discrimination. The focus of this study is on the uptake of health services, support from family and friends and leisure activities and whether use has increased or

decreased due to discrimination, because these were seen as effects to which a monetary value could most appropriately be attached. Other areas stated above are not included in this study.

Health service use included general practitioners (GPs), specialist doctors, psychiatrists, mental health nurses, social workers and other professionals (including dentists, patient advocates and complementary health care). Other contacts such as police were also recorded. The leisure and recreational activities recorded included team sports, cinema/theatre, art galleries/museums, gym and pubs/restaurants. Participants were also asked to report the number of times help had been received from family and friends. This would have a cost as such informal care time could be used in alternative ways. If extra help is received from families because of discrimination, then this has a cost, while there is a welfare loss if desired help is not received because of discrimination. Informal care costs are frequently included in economic studies and it is common to value this time by using average wage rates as a proxy for the lost opportunities of carers.

Discrimination and stigma scale. The Discrimination and Stigma Scale (DISC) is an interview-based instrument used to measure experiences of discrimination attributed to people with a diagnosis of mental illness (10). The DISC has a 4-point Likert scale (not at all, a little, moderately and a lot) to ascertain experiences of discrimination across 21 life domains. For this study, the domains of discrimination were conceptually categorised into three areas: (i) health care (comprising discrimination in the following areas: physical health problems, mental health staff); (ii) community activities (comprising discrimination in the following areas: social life, religious practices, people in your neighbourhood); and (iii) relationships (comprising discrimination in the following areas: making or keeping friends; dating or intimate relationships; marriage or divorce; family; starting a family or having children; role as a parent to your children; being avoided or shunned). We examined experiences of discrimination over the last 12 months.

Cost calculations

For this study, the main activities measured were (i) contacts with healthcare professionals, (ii) contacts with family and friends to receive informal care and (iii) use of specific leisure activities. Clearly, cost can be readily attached to contacts with healthcare professionals and family and friends; however, the use of specific leisure

activities is less easy to regard as a service but may still contribute to the wellbeing or quality of life of an individual. We therefore regarded this as a care 'input' in an economic sense and so represented by a cost.

Participants were also asked to state the number of times they would have used a service or engaged in leisure activities if it had not been for discrimination. If they would have used the service less, then this is an excess cost due to discrimination. If they would have used the service more were it not for discrimination, then there is also a cost and that represents a 'welfare loss' to the individual. Estimating the value of the welfare loss is challenging. If an activity is paid for out of pocket and if there is a perfectly functioning market determining the price, then the value gained from activity is equal to the price. Consequently, the value of forgone activity can also be represented by the price of the activity multiplied by the number of times it is not used. We apply this approach to both reduced service use and leisure activities, although it is clearly more plausible in the case of the latter. For example, if the price of a visit to a museum is X Euros, then we assume the value of a visit is also equal to X, as is the welfare loss from not visiting the museum. The key assumption here is that market conditions are such that price is equal to value. We accept that this may not be the case and so this is a limitation. It is, though, a reasonable starting point for this valuation.

We previously assessed the economic impact of discrimination in 2011 using data collected from the earlier subsample of participants of the Viewpoint survey (9). The costs reported in the Evans-Lacko et al.'s (9) study were inflated to reflect 2014 costs with the exception of psychiatrist/psychologist, police and help from family and friends which were not reported and were estimated in the present analysis using 2014 national unit costs.

For the 2014 subsample, service costs were calculated by combining the service use data with appropriate national unit costs (11). Exceptions were for contacts with patient advocates and police where unit costs used in previous published studies were adopted [£50 per contact with patient advocates, taken from Evans-Lacko et al. (9), £16.58 per contact with police service, taken from Wright et al. (7)]. Help received from family and friends was valued using national average wage rates [£14.84/h (12)]. Similar to Evans-Lacko et al., we assumed each contact with a family member or friend would last 2 h. For leisure and recreation activities, no published unit costs were available. We assumed unit costs used by Evans-Lacko et al. and inflated these to 2014 costs: team sports, £4.65

per contact; cinema/theatre, £10.62 per contact; art galleries/museums, £5.06 per contact; gym, £4.65 per contact; and pubs/restaurants, £10.62 per contact.

Statistical analysis

Descriptive statistics on sociodemographic characteristics (gender, age group, ethnicity, education, and employment status); clinical characteristics (self-reported diagnosis and receipt of involuntary treatment); and experiences of discrimination in the domains of health care, relationships and leisure activities were presented for 2011 and 2014. To compare 2011 and 2014 samples for frequencies of experiences of discrimination from any domain, a binary variable – ‘no discrimination’ versus ‘any discrimination’ – was created from the DISC and was also presented as a descriptive analysis.

The analysis of the cost data took account of the fact that these are usually positively skewed. This can lead to a violation of the assumptions underlying linear regression models. In this study, standard parametric *t*-tests were used to compare changes in mean costs and the robustness of the tests was confirmed using nonparametric bootstrapping (13). Bootstrapping involves sampling with replacement from the original data set a sufficiently large number of times so as to approximate the population from which original data were drawn (14). Regression analyses were used to identify the factors associated with (i) costs of health service use, informal care received from family and friends and use of leisure activities and (ii) costs associated with the reduced or increased use of these services or activities. The regression model allowed for adjustment by the demographic and clinical characteristics described above as well as year of data collection. In these analyses, 2000 samples were generated, and for all independent variables, *P*-values and 95% confidence intervals (CI) were calculated according to the bootstrap-*t* method described by Barber and Thompson (13). A significance level of 5% was used, and statistical analyses were performed using STATA version 11.

Results

Participant characteristics

The sample sizes for 2011 and 2014 were 190 and 212 respectively. The majority of participants were White British, unemployed and were educated to below university level (Table 1). In both years, the mean age was 45 years and the majority of participants were women (61% in 2011 and 68% in

2014). In terms of clinical characteristics, the most prevalent psychiatric diagnoses reported in both years were depression and/or anxiety, bipolar disorder and schizophrenia spectrum disorders. In both years, nearly half of the participants reported experiencing discrimination in healthcare settings and community activities, while more than three-quarters reported experiences of discrimination in relationships.

Use and cost of services and leisure activities in the last 6 months

Table 2 shows the service use and costs for all participants and demonstrates the differences between the years. In both years, nearly all participants had

Table 1. Characteristics of study participants

Patient characteristics	2011 (N = 190) n (%)	2014 (N = 212) n (%)
Sociodemographic characteristics		
Gender		
Male	73 (38.4)	68 (32.1)
Female	116 (61.1)	144 (67.9)
Transgender	1 (0.5)	0 (0)
Age		
18–35	43 (22.9)	55 (25.9)
36–50	78 (41.5)	75 (35.4)
51–65	67 (35.6)	82 (38.7)
Ethnicity		
White	172 (90.5)	205 (96.7)
Non-white	18 (9.5)	7 (3.3)
University education		
Yes	61 (32.1)	67 (31.6)
No	129 (67.9)	145 (68.4)
Employment status		
Employed	51 (26.8)	70 (33.0)
Training/education	8 (4.2)	5 (2.4)
Not employed	135 (71.1)	137 (64.6)
Clinical characteristics		
Clinical diagnosis		
Schizophrenia/schizoaffective disorder	31 (16.3)	30 (14.2)
Bipolar disorder	37 (19.7)	39 (18.4)
Depression and/or anxiety	75 (39.5)	79 (37.3)
Personality disorder	15 (7.9)	18 (8.5)
Other disorder	32 (16.8)	26 (12.3)
Not known	0 (0)	20 (9.4)
Experienced discrimination		
Experienced discrimination in health care		
Yes	99 (52.1)	87 (41.0)
No	87 (45.8)	125 (59.0)
N/A	4 (2.1)	0 (0)
Experienced discrimination in community		
Yes	90 (47.4)	96 (45.3)
No	88 (46.3)	109 (51.4)
N/A	12 (6.3)	7 (3.3)
Experienced discrimination in relationships		
Yes	149 (78.4)	160 (75.5)
No	41 (21.6)	52 (24.5)
N/A	0 (0)	0 (0)
Experienced any discrimination		
Yes	159 (83.7)	183 (86.3)
No	31 (16.3)	29 (13.7)

Table 2. Use and costs of services and leisure activities

Service/activity	2011 (n = 190)			2014 (n = 212)			Mean difference* (P-value)
	n (%) users	Mean (SD) contacts	Mean (SD) costs (£s)	n (%) users	Mean (SD) contacts	Mean (SD) costs (£s)	
General practitioner	171 (90)	5.2 (5.1)	189 (206)	192 (91)	5.8 (6.7)	220 (277)	
Specialist doctor	108 (57)	3.0 (4.3)	240 (505)	103 (49)	3.1 (3.5)	212 (407)	
Dentist	129 (68)	1.5 (1.0)	51 (53)	143 (67)	1.4 (1.0)	80 (87)	
Psychiatric nurse	106 (56)	11.1 (13.1)	238 (431)	113 (53)	8.1 (8.7)	320 (559)	
Psychiatrist and psychologist	149 (78)	5.4 (7.5)	583 (963)	158 (75)	4.5 (6.6)	465 (829)	
Complementary health care	34 (18)	11.1 (30.7)	100 (684)	36 (17)	6.3 (9.3)	37 (156)	
Patient advocate	19 (10)	3.4 (5.8)	9 (52)	11 (5)	5.1 (6.9)	13 (94)	
Social worker	41 (22)	6.6 (6.5)	154 (439)	33 (16)	6.3 (7.8)	78 (301)	
Health service costs			1564 (1588)			1426 (1396)	138 (0.3539)
Police/emergency services	48 (25)	3.6 (5.7)	15 (54)	46 (22)	2.0 (1.6)	7 (19)	
Help in home from family/friends	100 (53)	37.2 (59.7)	581 (1396)	118 (56)	27.9 (46.7)	461 (1111)	
Help in community from family/friends	66 (35)	22.6 (40.8)	233 (779)	76 (36)	20.5 (36.2)	218 (704)	
Total service costs†		2394 (2580)			2112 (2190)	282 (0.2367)	
Sports	21 (11)	16.6 (18.7)	9 (37)	24 (11)	18.4 (17.5)	10 (38)	
Cinema/theatre	88 (46)	4.6 (5.4)	23 (46)	95 (45)	3.9 (4.3)	18 (37)	
Art galleries/museums	66 (35)	3.3 (3.1)	6 (12)	79 (37)	6.5 (20.3)	12 (65)	
Gym	39 (21)	30.2 (29.0)	29 (83)	36 (17)	32.8 (40.4)	26 (96)	
Pub/restaurant	143 (75)	16.9 (34.7)	135 (328)	156 (74)	13.5 (18.0)	105 (175)	
Total leisure costs			201 (364)			172 (236)	29 (0.3303)
Overall costs‡			2595 (2583)			2284 (2183)	311 (0.1908)
Any discrimination§	159 (84)		2575 (2502)	183 (86)		2349 (2225)	
No discrimination	31 (16)		2699 (3007)	29 (14)		1870 (1870)	

SD, standard deviation.

Costs are in 2013/14 £s.

*Two-sample mean comparison *t*-test.

†Included costs of health service, police/emergency services and help from family and friends.

‡Included costs of health service, police/emergency services, help from family and friends and leisure activities.

§Experienced discrimination in any of the services or activities.

contact with GPs in the 6 months preceding the interview and more than half of the participants saw a psychiatric nurse. About three-quarters had contact with psychiatrists and psychologists, while around two-thirds had contact with dentists. For psychiatric nurses and complementary health care, the mean number of contacts decreased significantly between 2011 and 2014. Also, there was a slight decrease in the mean number of contacts with psychiatrists and psychologists. The proportion of participants that had contacts with police and the proportion that sought help from family and friends remained fairly similar in both years. However, the mean number of contacts decreased between the 2 years.

In terms of leisure activities, about three-quarters visited a pub/restaurant, nearly half of the participants visited the cinema/theatre, while about one-third visited art galleries/museums in both years. For cinema/theatre and pub/restaurant, the mean number of contacts decreased between 2011 and 2014. For the remaining activities, the use increased between the 2 years.

The mean health service costs (not just those related to discrimination) for 2011 and 2014

were £1564 and £1426 respectively. The services contributing most to the overall health service costs in both years were psychiatrists and psychologists, psychiatric nurses, GPs and specialist doctors. The mean total service costs (costs of health service use, police and help from family and friends) were £2394 and £2112 for 2011 and 2014 respectively. Informal care provided by family and friends contributed most to total service costs. For leisure activities, the mean cost (likely to be out of pocket) was £201 and £172 for 2011 and 2014, respectively, and the activity contributing most was visits to pubs and restaurants.

When all costs were included, the mean overall costs were £2595 and £2284 for 2011 and 2014, respectively, with the cost of informal care provided by family and friends and the costs of psychiatrist/psychologist forming the largest proportion of this. No statistically significant difference was observed in the mean overall costs between the 2 years (mean difference: £311, *P*-value 0.1908). Across all services and activities, the costs for those who experienced discrimination were £2575 and £2349 for 2011 and 2014 respectively. The costs for

those who did not experience any discrimination were £2699 and £1870 for 2011 and 2014 respectively.

In the multivariate analysis of the health service costs (Table 3), those who reported discrimination in the domain of health care in 2011 had costs that were £625 higher than those who reported no discrimination ($P = 0.019$). Also, those who reported their clinical diagnosis as depression and/or anxiety had service costs that were £734 greater than for those with a clinical diagnosis of schizophrenia/schizoaffective disorder. In 2014, those who reported discrimination in the domain of relationships had health service costs that were £418 higher than those who reported no discrimination (P -value 0.034). In the analysis of total service costs (including the costs of health services, police and informal care provided by family), those who reported discrimination in healthcare settings in 2011 had costs that were £837 higher than those who reported no discrimination (P -value 0.017). In 2014, those aged 51–65 years had costs that were on average £932 lower than those aged between 18 and 35 years (P -value 0.045). No other discrimination domain was found to be statistically significantly associated with total service costs.

In the analysis of the cost of participation in leisure activities, in 2011, those who reported their clinical diagnosis as bipolar disorder had costs that were £162 greater than for those with a clinical diagnosis of schizophrenia/schizoaffective disorder (P -value 0.012). In 2014, those aged 36–50 years had costs that were £127 lower than those aged between 18 and 35 years; and those with no university degree had costs that were £114 lower than those with a degree. In both years, those who reported discrimination in healthcare settings had lower costs of participation in leisure activities and those who reported discrimination in relationships had higher costs of participation in leisure activities. These, however, were not statistically significant. When all costs were included (costs of health service use, police, help from family and friends and leisure activities), those who reported discrimination in healthcare settings in 2011 sample had costs that were £729 higher than those who reported no experience of discrimination (P -value 0.045). In 2014, the only significant variable was age and this showed that older participants (aged 36–65 years) had lower costs than those aged 18–35 years. In all domains (health service costs, total service costs, costs of leisure activities and overall costs), costs were lower in 2014 compared with 2011; however, this was not found to be statistically significant.

Cost of reduced or increased service use and leisure activities due to discrimination

Table 4 details the impact of mental health-based discrimination on reduced health service use, help seeking from family and friends and participation in leisure activities for 2011 and 2014. In both years, reduced use was most likely for GPs, psychiatrists and psychologist and help from family and friends. The mean number of times help was sought less because of discrimination from GPs and family and friends was generally greater in 2014 compared with 2011. The average value or welfare loss associated with ‘forgone’ service contacts was £288 and £275 over the 6-month period for 2011 and 2014 respectively. The mean total value lost (including health services, police contacts and help from family and friends) was £501 and £638 for 2011 and 2014 respectively.

In terms of leisure activities, nearly one-quarter of participants in both years reported that they had visited pubs/restaurants less as a result of discrimination. The impact of discrimination on other leisure activities was also relatively high. The value of forgone leisure use over the 6-month period was £99 and £69 per participant in 2011 and 2014 respectively. When all costs were included, the average welfare loss was £601 and £707 per participant in 2011 and 2014, respectively, with this difference being non-significant (mean difference: –£106, P -value 0.4150).

Table 5 details the increased use of health services, help seeking from family and friends and participation in leisure activities as a result of discrimination in 2011 and 2014. In both years, increased use was most likely reported for GPs, psychiatric nurse, psychiatrist and psychologists, social worker and help from family and friends. However, the proportion reporting increased use was far less compared with those reporting reduced health services and leisure activities use reported in Table 4. Between the 2 years, the proportion of participants reporting more frequent use of services or activities was far greater in 2011 compared with 2014. The costs associated with the increased service or activity (total costs) use were higher for 2011 (£92) compared with 2014 (£8), and the difference was found to be statistically significant (mean difference: £84, P -value 0.0118).

In the multivariate analysis of the total value of reduced or increased service contacts in the 2 years, those in the older age group (51–65 years) had a lower welfare loss (meaning they were less likely to have reduced contacts) compared with those in the younger age group (18–35 years) (see Table S1). In the analysis of reduced or increased

Table 3. Predictors of health service, informal care and leisure activities costs

	2011 (n = 190); Observed (95% CI)				2014 (n = 212); Observed (95% CI)			
	Health service costs	Total service costs†	Costs of leisure activities	Overall costs‡	Health service costs	Total service costs†	Costs of leisure activities	Overall costs‡
Age								
18–35	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
36–50	-221 (-961, 518)	-474 (-1550, 602)	-106 (-231, 19)	-580 (-1712, 553)	24 (-589, 638)	-945 (-1938, 48)	** -127 (-207, -46)	* -1071 (-2090, -52)
51–65	-215 (-1026, 595)	330 (-802, 1461)	-67 (-241, 107)	263 (-939, 1465)	-316 (-818, 186)	* -932 (-1846, -19)	-46 (-137, 44)	* -979 (-1925, -32)
Gender								
Male	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Female	-25 (-502, 453)	-285 (-1070, 499)	-45 (-155, 65)	-330 (-1109, 448)	126 (-276, 527)	166 (-488, 821)	27 (-44, 97)	193 (-475, 861)
Diagnosis group								
Schizophrenia/schizoaffective disorder	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Bipolar disorder	480 (-35, 995)	-193 (-1292, 906)	**162 (5, 289)	-31 (-1123, 1062)	-355 (-959, 250)	-405 (-1482, 673)	-40 (-185, 106)	-444 (-1480, 592)
Depression and/or anxiety	**734 (175, 1293)	357 (-806, 1521)	106 (-6, 218)	464 (-700, 1627)	-220 (-816, 376)	-813 (1840, 214)	-117 (-257, 23)	-929 (-1937, 78)
Personality disorder	393 (-558, 1344)	-62 (-1471, 1346)	27 (-98, 153)	-35 (-1483, 1412)	291 (-741, 1323)	232 (-1269, 1733)	-86 (-259, 87)	146 (-1336, 1628)
Other disorder	973 (-138, 2084)	1796 (-141, 3732)	65 (-76, 206)	1861 (-45, 3767)	-247 (-934, 441)	-90 (-1565, 1386)	-147 (-296, 2)	-237 (-1748, 1274)
University education								
Yes	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
No	-44 (-565, 476)	-783 (-1641, 75)	-24 (-117, 69)	-807 (-1652, 37)	2208 (-194, 611)	487 (-126, 1100)	** -114 (-186, -42)	373 (-256, 1002)
Experienced discrimination in health care								
No	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Yes	*625 (101, 1148)	*837 (149, 1525)	-108 (-264, 48)	*729 (17, 1440)	-15 (-454, 423)	187 (-481, 855)	-8 (-70, 54)	179 (-513, 870)
Experienced discrimination in community								
No	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Yes	67 (-421, 556)	-107 (-785, 571)	67 (-70, 204)	-40 (-739, 659)	-140 (-601, 321)	-97 (-746, 551)	-39 (-117, 39)	-137 (-790, 517)
Experienced discrimination in relationships								
No	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Yes	43 (-623, 709)	-251 (-1304, 802)	5 (-118, 128)	-246 (-1281, 789)	*418 (31, 805)	25 (-757, 808)	13 (-70, 95)	38 (-690, 766)
Constant	868 (-149, 1884)	2624 (664, 4585)	236 (43, 429)	2861 (889, 4833)	1276 (495, 2057)	2742 (1179, 4306)	392 (206, 578)	3134 (1587, 4681)
	$R^2 = 0.0093$	$R^2 = 0.0474$	$R^2 = -0.0041$	$R^2 = 0.0459$	$R^2 = 0.0011$	$R^2 = -0.0255$	$R^2 = 0.0940$	$R^2 = -0.0342$

CI, confidence interval; bootstrap statistics: the number of observation = 402, replications = 2000, 95% CI.

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$.

†Included costs of health service, police/emergency services and help from family and friends

‡Included costs of health service, police/emergency services, help from family and friends and leisure activities

Table 4. Impact of mental health-based discrimination on reduced health service use, and participation in leisure activities in the previous 6 months

Service/activity	2011 (n = 190)			2014 (n = 212)		
	Service/activity affected by discrimination n (%) users	Mean (SD) times help sought less because of discrimination	Mean (SD) value of forgone service use (£s)	Service/activity affected by discrimination n (%) users	Mean (SD) times help sought less because of discrimination	Mean (SD) value of forgone service use (£s)
General practitioner	38 (20)	4.4 (4.1)	37 (106)	52 (25)	5.9 (5.0)	61 (149)
Specialist doctor	10 (5)	2.8 (1.5)	21 (101)	19 (9)	3.6 (2.8)	46 (187)
Dentist	11 (6)	2.2 (1.6)	10 (52)	11 (5)	2.3 (1.7)	10 (52)
Psychiatric nurse	16 (8)	10.9 (11.2)	68 (324)	19 (9)	8.9 (8.0)	59 (256)
Psychiatrist/psychologist	20 (11)	7.3 (9.8)	106 (530)	24 (11)	4.2 (3.3)	66 (239)
Complementary health care	5 (3)	8.0 (7.1)	7 (58)	8 (4)	5.9 (6.0)	8 (55)
Patient advocate	7 (4)	2.6 (2.1)	5 (31)	2 (0.9)	5.0 (1.4)	2 (25)
Social worker	13 (7)	6.2 (3.7)	34 (145)	11 (5)	5.7 (6.9)	23 (156)
Health service costs			288 (773)			275 (661)
Police/emergency services	22 (12)	4.5 (6.0)	9 (41)	20 (9)	2.5 (1.9)	4 (15)
Help in home from family/friends	42 (22)	19.3 (31.4)	126 (495)	54 (25)	32.9 (48.8)	248 (842)
Help in community from family/friends	45 (24)	11.2 (13.6)	79 (241)	46 (22)	17.3 (21.4)	111 (362)
Total service costs‡			501 (1035)			638 (1397)
Sports	28 (15)	19.5 (22.1)	13 (50)	26 (12)	20.3 (15)	12 (40)
Cinema/theatre	26 (14)	6.8 (6.1)	10 (34)	23 (11)	4.7 (3.0)	5 (19)
Art galleries/museums	15 (8)	8.4 (9.5)	3 (17)	10 (5)	5.3 (4.0)	1 (7)
Gym	31 (16)	40.6 (46.0)	31 (110)	28 (13)	38.8 (32.4)	24 (82)
Pub/restaurant	39 (21)	19.3 (30.9)	42 (169)	44 (21)	12.0 (11.9)	27 (77)
Total leisure costs			99 (278)			69 (152)
Overall costs§			601 (1124)			707 (1441)

SD, standard deviation. Costs are in 2013/14 £s.

participation in leisure activities in the 2 years, those who reported their clinical diagnosis as bipolar disorder had a welfare loss that was £121 greater than those with a clinical diagnosis of schizophrenia/schizoaffective disorder; those with less than university education had a welfare loss of £68 greater than those with university degree; and those in the older age group (51–65 years) had a welfare loss of £77 lower than those in the younger age group (18–35 years). In the domains of health service, leisure and overall costs, the welfare loss was lower in 2014 compared with 2011; however, these were not found to be statistically significant. In the domain of total service costs (included the costs of health services, police and informal care provided by family), the welfare loss was greater in 2014 compared with 2011; this was also not statistically significant.

Discussion

This study estimates economic costs associated with mental health-related discrimination between 2011 and 2014 and finds modest effects that are different for each year. Here, we looked at discrimination in two forms: the impact of lifetime discrimination in help seeking and participation in leisure activities between 2011 and 2014 6 months preceding the study and the impact of discrimination experienced in the last 12 months as a

predictor of costs. It is therefore worth noting that even if recent experiences of discrimination are fewer, this does not necessarily lead to a change in behaviour among service users in terms of health service use, participation in leisure activities or help from family and friends. The impacts of these can be quite broad. Avoiding leisure activities can impact on physical health, social support, social relationships, identity, self-confidence, self-esteem, wellbeing and social capital. Reduced healthcare use can have more direct impacts on mental and physical health, while receipt of care from families/friends may affect social isolation and support.

Research into the economic costs associated with discrimination is an emerging field (2, 15–17). In this study in both 2011 and 2014, we found that the most commonly used health services were contacts with GPs, psychiatrists and psychologists. Our regression of service costs in 2011 (but not 2014) suggests that those who reported experiences of discrimination had higher costs associated with health service use. Although we controlled for demographic characteristics and some clinical factors, it is possible that there may still be some differences between the cohorts and so the link between discrimination and costs still needs to be treated with caution. A recent study by Clement et al. (8), which examined the association between experiences of discrimination by adults receiving care from community mental health team and

Table 5. Impact of mental health-based discrimination on increased health service use, and participation in leisure activities in the previous 6 months

Service/activity	2011 (n = 190)			2014 (n = 212)		
	Service/activity affected by discrimination n (%) users	Mean (SD) times help sought more because of discrimination	Mean (SD) value of increased service use (£s)	Service/activity affected by discrimination n (%) users	Mean (SD) times help sought more because of discrimination	Mean (SD) value of increased service use (£s)
General practitioner	4 (2)	12.3 (8.7)	11 (87)	3 (1)	5.7 (5.7)	3 (37)
Specialist doctor	4 (2)	1.5 (0.6)	4 (32)	0	—	—
Dentist	1 (0.5)	1 (0)	0.4 (6)	0	—	—
Psychiatric nurse	4 (2)	10.3 (9.3)	16 (140)	1 (0.5)	2 (0)	0.7 (10)
Psychiatrist/psychologist	3 (2)	6.3 (5.1)	14 (131)	2 (0.9)	2 (0)	3 (27)
Complementary health care	0	—	—	0	—	—
Patient advocate	0	—	—	0	—	—
Social worker	1 (0.5)	1 (0)	0.4 (6)	1 (0.5)	1 (0)	0.4 (5)
Health service costs			46 (224)			7 (50)
Police/emergency services	0	—	—	0	—	—
Help in home from family/friends	5 (3)	48.0 (73.5)	37 (391)	2 (0.9)	1.5 (0.7)	0.4 (5)
Help in community from family/friends	2 (1)	1 (0)	0.3 (3)	1 (0.5)	4 (0)	0.6 (8)
Total service costs‡			84 (466)			8 (53)
Sports	0	—	—	0	—	—
Cinema/theatre	0	—	—	0	—	—
Art galleries/museums	0	—	—	0	—	—
Gym	1 (0.5)	60 (0)	1 (20)	0	—	—
Pub/restaurant	1 (0.5)	120 (0)	7 (92)	0	—	—
Total leisure costs			8 (95)			
Overall costs§			92 (479)			8 (53)

SD, standard deviation. Costs are in 2013/14 £s.

engagement in health service, found an indirect relationship between discrimination and low service engagement in that perceived discrimination was associated with mistrust of services. It may be that lower engagement as a result of discrimination results in higher subsequent use if crises occur. Other studies have also showed negative attitudes of health and mental health professionals towards people with mental health problems (18, 19). Establishing cause and effect is challenging, and in our regression modelling, we essentially are identifying relationships. However, many of the questions do ask whether discrimination leads to increased/decreased service use.

While overall costs were higher if discrimination had been experienced in healthcare settings, certain services were still avoided or not used due to discrimination. In the analysis of forgone or increased health service use as a result of discrimination, the most avoided services reported were contact with GPs, psychiatrists and psychologists. The multivariate analysis of forgone or increased health service use showed that the welfare loss for older participants was much lower compared with younger participants. The reasons younger service users are more likely to avoid contact with health services if they experience discrimination need further investigation.

The proportion of participants who had contact with psychiatric nurses and complementary health

practitioners remained fairly similar between 2011 and 2014. However, we found a reduction in the mean number of contacts between the 2 years. For complementary health care in particular, the mean number of contacts decreased to just under half of what was reported in 2011. One possible explanation for this decrease is the change to the UK benefits system in 2011, which requires individuals on disability benefits to undergo an annual Work Capability Assessment following which the entitlement is withdrawn if the individual is found ‘fit for work’ (4). This could result in constraint in participants’ expenditure especially if a service such as complementary health care is from out of pocket expenses. Another possibility could be a result of loss of employment. A significant proportion of participants in 2011 and 2014 are not in any paid employment and therefore might not have the means to afford services such as complementary health if it is out of pocket expenses. However, other reasons may also be relevant and so we should not place undue emphasis on income effects.

The average number of contacts with patient advocates increased between 2011 and 2014. This could be a result of expansion of the patient advocacy role in 2009 which introduced Independent Mental Health Advocacy as part of amendments to the Mental Health Act (20). Further analysis of

this in future would need to make reference to in-patient data.

Between 2011 and 2014, we found a reduction in the mean number of times participants sought help from family and friends, specifically help within the house. When participants were, however, asked the number of times help would have been sought if not affected by discrimination, we found a significant increase in this domain for 2014 compared with 2011.

For participation in leisure activities, we found the use of all activities to increase between the 2 years except for visits to pubs/restaurant and cinema/theatre where the use decreased. This may reflect the relative cost differences between these activities. Our study also showed that individuals with a university degree had higher costs associated with participation in leisure activities.

Limitations

One of the limitations of this study is the relatively low representation of minority ethnic groups as well as men, and this limits the generalisability of these analyses. Another limitation is that the data collected were self-reported, and as with all self-report measures, recall bias may impact on data quality. Also, the design of the study was cross-sectional, and therefore, it was not possible to examine the pathways by which experiences of discrimination could directly impact the reduction in health service use, help seeking from family and friends or participation in leisure activities. Also, there might be other variables that better explain the variations observed which are not covered in this study; for example, living arrangements, marital status could explain the reduction observed in help seeking within the house. A prospective study is needed to better examine these pathways.

Furthermore, participants recruited were those currently registered with secondary mental health services (i.e. specialist services set-up specifically for mental health care often provided by a hospital), and therefore, it was not possible to assess the association between costs and discrimination for those who had disengaged or been discharged from secondary care services. In addition, in our analysis of increased/reduced service use/leisure activities, we have assumed that the value of contacts that did not take place represents a measure of welfare loss. This suggests that had these contacts taken place, there would have been a welfare gain reflected by the cost of the contact. This, though, suggests well-functioning markets where prices/costs equal benefits. Such an assumption can be

challenged because there is unlikely to be perfect competition between providers of services and leisure activities and perfect information available to recipients of these. Finally, the study did not attempt to define discrimination to respondents. While this may lead to variations in what people include as discrimination, we did feel it was important that this should be perceived discrimination and self-definition seemed appropriate.

The main findings are that there are increased healthcare costs associated with discrimination in the healthcare area in 2011 and higher costs associated with discrimination in the area of relationships in 2014. This suggests an effect of discrimination but one in which the location of that discrimination needs to be clarified. Is this a real change over time? What is of interest is that discrimination does not appear to reduce service use which may have been expected. For some though, this does happen and for them, this may have a negative effect on their health; however, a prospective study is needed to better understand this effect. In addition, it is not clear which direction changes observed in this study might move in future as a result of initiatives to address discrimination and this also needs to be investigated. Such initiatives should be evaluated and their cost-effectiveness assessed.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Table S1. Cost predictors of reduced/increased health service use, informal care and participation in leisure activities.