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Perceived and anticipated discrimination in people with mental illness – An interview study

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ABSTRACT

Background

Studies on perceived discrimination of people with mental illness are largely lacking. The purpose of the study was to investigate perceived discrimination in a sample of users in contact with mental health services in Sweden.

Methods

Interviews were conducted with 156 users, asking for perceived and anticipated discrimination during the last two years. Background characteristics were also collected.

Results

Perceived discrimination was common. Highest frequencies were reported regarding family (54%), avoidance by people who knew about the mental illness (53%) and in making or keeping friends (50%). A majority of those anticipating discrimination regarding job or education seeking, or starting a close relationship did not report having been discriminated in these areas. Previous hospitalizations were associated with discrimination, and age with anticipated discrimination.

Conclusions

Public stigma and self-stigma have been reported to have a number of negative consequences for people with mental illness. Discrimination is part of this complex situation and this study showed that this to a large extent affects a number of individual life areas posing an obstacle for social integration. Anticipated discrimination or self-stigma was also prevalent and it is pointed out that this to a great extent is an obstacle on its own without being promoted by actual experiences of discrimination.

Keywords: Perceived discrimination, self stigma, public stigma

INTRODUCTION

Public stigma against people with mental illness are still highly prevalent (1), and have been proposed to be a serious obstacle to successful treatment, rehabilitation and inclusion of people with mental illnesses in society. Unemployment, income loss (2), not seeking care or delayed care (3) a limited social network (, 5), impaired self-esteem (6), isolation and loneliness have been associated with stigma and discrimination. Although the public may be the major source of stigma it has been pointed out that mental health staff also is exhibiting stigmatizing attitudes and discriminatory behaviour (7, 8).

Stigma also affects disease progression and recovery (9). The impact of national anti-stigma campaigns has so far not been thoroughly evaluated and the results of these campaigns are viewed as equivocal, and it is largely unknown to what extent attitude changes are actually related to behaviour change (1).

The internalisation of negative stereotypes about mental illness occurs early in life and may lead to the development of self-stigma for people afflicted by mental illness later on in life. Self-stigma (or internalized or felt stigma) exists on the individual level and indicates that the individual endorses stereotypes of mental illness, finds these stereotypes relevant and anticipates social rejection (10). Self-stigma may also be a response to actual experiences of public stigma and discriminatory behaviour, which could result in consequences in a number of psychosocial life aspects: refraining from applying for work, avoiding contact with mental health care and social contacts (11, 12). The review by Livingstone and Boyd (12) draws attention to the fact that, while there is a rather vast scientific literature on self-stigma and its correlates, there is a lack of studies with a longitudinal design which may have increased the clinical value of this literature and increasing opportunities to develop and engage in interventions to cope with self-stigma.

The generally expanding scientific literature on mental illness stigma has so far no correspondence in studies on discrimination, where there still is a lack of studies. Discrimination deals with people's behaviour as captured by observational studies, by studies of structural discrimination, for example related to the judicial system, or by studies focusing on the experiences of people with mental illness. The INDIGO study (International Study of Discrimination and Stigma Outcomes) performed a quantitative cross-sectional study of people with schizophrenia covering 27 countries which showed that perceived discrimination

was common in a number of areas and most prevalent in areas of making or keeping friends, family members, and in finding and keeping a job (13). A majority of the participants also reported anticipated discrimination in applying for work/education and making close relationships. Almost 75% of the participants concealed their diagnosis to their social network. A further study from the INDIGO/ASPEN groups focusing discrimination in people with depression including 1082 people also showed that perceived discrimination was common, reporting that 79% had perceived discrimination in at least one area. This study also showed that anticipated discrimination was not always associated with perceived discrimination since almost half of the people reporting anticipated discrimination regarding finding and keeping a job or in their intimate relationships actually did not report any perceived discrimination in these areas (14).The GAMIAN study (Global Alliance of Mental Illness Advocacy Networks study) made a similar cross-country survey including people with schizophrenia and bipolar disorder (15, 16). This study focused more on perceived anticipated stigma and self-stigma. They reported, for both conditions, that a majority had moderate or high perceived discrimination, that almost half of people with schizophrenia reported moderate or high levels of self stigma, and that the equivalent figure for people with bipolar disorders was around one fifth of the participants.

The scarcity of studies investigating perceived discrimination makes this an urgent task in order to gain knowledge of the user perspective of discrimination. The main aim of the present study was to investigate experienced discrimination and anticipated discrimination in a sample of persons with mental illness in contact with mental health services. Correlates of discrimination in terms of a number of background characteristics was also a focus.

METHODS AND PARTICIPANTS

Design of the study

The study was performed as a cross-sectional study in a sample of persons in contact with mental health services in two Swedish counties. Patients visiting their outpatient mental health service were approached by designated staff and given oral and written information on the study. Child and youth services were not included in the study. The only exclusion criteria were currently being admitted to inhospital psychiatric services or inability to

understand and talk Swedish. Persons giving informed consent were contacted by a study coordinator who distributed participants among interviewers. The study was made by means of telephone interviews performed by trained interviewers. All in all 15 interviewers were involved in the study, out of which 6 had a user background. The efforts to include users as interviewers was related to the fact that user participation in the delivery and evaluation of mental health services has become an important policy element in the development of such services. In two earlier studies we have showed that this approach was both feasible and useful (17) and also mainly experienced as empowering by users exposed to user interviewers (18). The latter qualitative study also gave valuable information for further development of this approach.

Settings

The study was performed in two Swedish counties, one in the north of Sweden and one in the south of Sweden. Services included for approaching eligible participants were mental health care services and municipality social services focusing on persons with mental illness. The rationale for using services in two counties was to extend the population basis for inclusion of participants and also to check for possible biases in inclusion of participants.

Instrument

The instrument used for the interviews was DISC-12 (19). DISC-12 is an interview based 32-item measure including 4 subscales: Unfair treatment (21 items), Stopping self (4 items), Overcoming stigma (2 items) and Positive treatment (5 items). The interviewer is asking for the participant's perceived discrimination using a response scale with four steps. Each item is scored as 0 = no difference, 1=a little, 2=moderately and 3=a lot. A non-applicable scoring is available in each item for cases where the participant has never been involved in the particular area of life in question. The calculation of a mean and total score is available for each subscale. An overall frequency was calculated for each item made by adding frequencies of scores 1-3. A total score was calculated for each subscale by counting the number of items where the participant scored either 1 (a little), 2 (moderately) or 3 (a lot). The range for each subscale is thus for Unfair treatment (0-21), Stopping self (0-4), Overcoming stigma (0-2) and Positive treatment (0-5). There is also a possibility for the participant to give examples of

experiences in areas were discrimination is recognized. In this study a telephone version of the interview which has been developed was used. We used a Swedish version which was developed by translation into Swedish and back translated and checked by a native born English translator. In each interview the interviewer made checks that they were in contact with the right person and that the participant still were giving informed consent to participation. Instructions for conducting the interview, and data collection and storing procedures were also read to the participant. Participants were asked to consider experiences during the last two years. Demographic and psychiatric background data including a self-reported diagnosis were also collected during the interview. The length of the interview ranged between 30-45 minutes.

Participants

In total 156 patients from the two regional areas included in the study (106 + 50) gave informed consent to participation. No data were collected concerning persons who rejected participation, and thus we were not able to perform any analyses of the representativity of persons accepting vs rejecting participation. An analysis of participants from the two counties revealed no differences in background characteristics between the two sub samples and they were therefore analyzed as an overall sample. Self-reported diagnoses were categorized by the authors in four subgroups. Background characteristics are given in Table 1. Two-thirds of the participants were female, and the majority was living alone (54.5%) and not working (73.6%). The two major diagnostic subgroups were anxiety/depression (46.3%) and psychosis (38.5%), the mean number of years since first contact with psychiatric services was 15, mean number of hospitalizations was 5, and around one-third of the participants had ever been involuntary hospitalized. Participation was based on informed consent and the study adhered to the Helsinki Declaration of ethical principles for medical research involving human subjects.

Table 1 in about here

Statistics

Descriptive statistics were used to present the overall results from the interview. T-test and one-way ANOVA were used to analyze differences in discrimination between subgroups with regard to background characteristics. Stepwise multiple regression analysis was used to

identify correlates of discrimination with regard to background characteristics. Background characteristics included were sex, age, civil status, educational level, work situation, duration of illness, number of hospitalizations and ever been compulsory admitted. Collinearity tests did not indicate any significant covariation between the independent variables. Chi^2-test was used to analyze categories of perceived and anticipated discrimination. The level of significance was set to $p<.05$.

Ethical considerations

The study adhered to the Helsinki declaration and only included those giving informed consent. It was also made in accordance with Swedish research ethics legislation which in this case not requires formal approval from a research ethic committee.

RESULTS

The most common areas of overall experienced discrimination (been unfairly treated) were the family (53.9%), avoidance by people who knew about the mental illness (52.9%) and in making or keeping friends (50%), Table 2. Perceived discrimination was however quite frequent in a further number of life areas. Areas with the least perceived discrimination included religious practice (5.1%), starting a family (9.1%) and using public transport (11.5%). Areas where scores of "a lot" of perceived discrimination were most frequent were mental health staff (20.1%), the family (17.3%) and in marriage (16.8%). Although the family was reported as a major source of perceived discrimination, it was also evident that the family was a major source of support and positive treatment. Over half of the participants (58.7%) reported positive treatment from the family. The correlation between these two items was low and not significant indicating that the family was not both perceived as discriminating and supportive, but rather that the participant belonged to two separate subgroups in the sample with a very different relationship to the family.

Table 2 in about here

Reports of anticipated discrimination or self-stigma were quite frequent. A majority of participants reported that they had concealed their mental health problems from others (68.6%) and that they had stopped themselves from having close personal relationships

(53.8%). Reports were also quite frequent regarding stopping oneself from applying for work (43.5%) or education (41.5%).

Table 3 in about hear

In order to analyze the role of self-stigma, the relationships between anticipated discrimination and experienced discrimination were investigated by cross-tabulations of items regarding experienced discrimination in finding a job, in education and in making friends, with their respective item in the anticipated discrimination subscale. These analyses revealed that while 43.5% had stopped themselves from seeking a job, the majority of these (52.2%) reported no perceived discrimination in this area (x^2=25.2, p=.001). In the area of education, similarly, a majority (55.3%) of those 41.9% stopping themselves from applying for an education/training did not report any actually perceived discrimination (x^2=4.3, p=.039). Regarding close relationships, 52.3% of those stopping themselves from having a close relationship, 53.8%, did not report any perceived discrimination in this area (x^2=9.6, p=.01).

Calculating summary scores for the subscales of DISC-12 showed that the mean number of areas of reported perceived discrimination (max=21) was 6.3 (SD=3.9, range (0-18) and mean number of areas of anticipated discrimination (max=4) was 2.1 (SD=1.2, range 0-4). Mean number of areas where overcoming stigma was perceived (max=2) was 1.4 (SD=1.1, range 0-2) and areas where positive treatment was perceived (max=5) was 1.4 (SD=1.1, range 0-5).

The associations of background factors with perceived discrimination was tested by a multivariate regression analysis, using the sum score of the perceived discrimination subscale as dependent variable and demographic and psychiatric background factors as independent variables. The only background factor related to the summary score of perceived discrimination was number of hospitalizations which showed a modest positive relationship with perceived discrimination, accounting for 5.5% of the variation in the latter (F=5.04, p=.027). Regarding the subscale of anticipated discrimination there was a negative relationship with age (F=8.3, p=.005), younger people reporting more anticipated discrimination, accounting for 7.7% of the variation in anticipated discrimination, Table 4.

Table 4 in about here

DISCUSSION

This study showed that perceived discrimination was widespread and common throughout a number of life areas. The results mainly correspond with earlier studies investigating perceived and anticipated discrimination (4, 13-16. Perceived discrimination was most commonly reported in areas of close relationships, with the family or with friends. This may be explained by the fact that the family and friends are two life areas with a great exposure of contacts increasing the possibilities of making discriminating experiences. It is also noteworthy that the family was reported to be the most common source of positive treatment due to the mental illness among those areas investigated. It might nevertheless indicate that the family should be included and focused in anti-stigma campaigns or in working with anti-stigma interventions. This might be achieved by including such a focus in already developed evidence-based family interventions and psycho-educational interventions for people with mental illness (20, 21).

There is evidence from earlier studies that people with mental illness feel patronised, humiliated and punished in contact with services and that patients point out mental health staff as one of the groups which are the most stigmatizing (22). This was corroborated by findings from the present study, where mental health staff was pointed out as the group with the highest frequency of "a lot" of perceived discrimination during the last two years. Studies on mental health staff's attitudes have mainly focused on the prevalence of stereotypes and desire for social distance from people with mental illness. A rather recent review of these studies revealed that one of the main findings is that beliefs from mental health providers do not differ from the general public, or are more negative (23). Thus mental health staff also constitutes a target for anti-discrimination interventions. In an earlier study we investigated and compared attitudes towards mental illness among mental health staff and patients in contact with mental health services. We found that negative attitudes were prevalent among staff and that patient attitudes were similar to staff attitudes, with significant differences in only a few instances (24). These results confirmed that anticipated discrimination or self stigma is widespread among people with a mental illness (25), with all implications this may have for help seeking behaviour, self-image and restrictions in social life (26).

We only found a few sociodemographic or clinical correlates of discrimination. The finding of a relationship of younger age and a higher level of anticipated discrimination was somewhat surprising, and we unfortunately have no data to further elaborate this finding. This relationship was also found in a German study (27), where a tentative explanation was that younger people not yet had the same amount of experiences with people with mental illness and thus were more prone to carry common stereotypes of mental illness. Further tentative explanations might be that younger people, having a shorter duration of illness, are more prone to react on internalized stereotypes of mental illness and less to actual experiences of living with a mental illness. If this suggestions are correct it underlines the importance of intervening against self-stigma and stereotypes in early phases of the illness.

CONCLUSIONS

One of the major findings of the present study concerned anticipated discrimination. Not only was it common in the four areas investigated, but also to a large degree not related to perceived discrimination. We found that the majority of those reporting an anticipated discrimination in seeking a job or education, or in starting a new relationship, actually did not report any perceived discrimination in these areas during the last two years. Concealment of mental health problem from others was also reported by almost 70% of the participants. This indicates that anticipated discrimination is not only a reaction or integration of actual behavior from others but also a process independent of this. Link and Phelan (28) viewed this process as a part of their labeling theory, which presumes that all people learn stereotypes of mental illness and they become personally relevant to people who develop a mental illness causing a number of adverse outcomes. A construction of social networks and opportunities is then done in anticipation of rejection and discrimination. The internalization of stigma has also been labeled “role-engulfment” (29, defined as the acceptance of the patient role as the primary definition of the self. A conclusion of these findings might be that although anti-stigma campaigns focusing the public may be of some value they must be accompanied by interventions to address self-stigma and anticipated discrimination. The scientific literature on anti self-stigma interventions is scarce and it is an urgent task to develop such interventions and investigate their evidence. Some candidate areas of intervention has been proposed by Corrigan (30), including CBT oriented approaches, reduction of self-stigma via

disclosure, becoming the protagonist of a self-constructed narrative, which includes both psycho-educational strategies as well as reconstruction of an identity, and finally various empowerment oriented approaches.

The limitations of the present study are, among other things, that we do not have any firm evaluation of the representativity of the sample used, since no data concerning those who refused to participate were collected. However, there were no differences in background characteristics or levels of perceived discrimination in the two subsamples, which might speak in favour of the representativity of the sample.

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Declaration of interests

The authors declare that there are no conflicts of interests.

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Table 1. Background characteristics of participants (N=156 if otherwise not stated)

	N	%
Sex(N=153)		
Woman	99	64.7
Man	54	35.3
Age (m, SD	42 (13)	
Living situation (N=143)		
Alone	78	54.5
Partner	46	32.2
Parents	8	5.6
Other	11	7.7
Education (N=152)		
Primary school	27	17.8
Upper secondary school	69	45.4
University	56	36.8
Work situation (N=140)		
Working	37	26.4
Unemployed	33	23.6
Sick pension/old age pension	54	38.6
In education	16	11.4
Contact psychiatry		
Years since first contact (m, sd)	15 (11)	
N hospitalizations (m, sd., N=120)	5 (14)	
Ever involuntary hospitalized (N=149)	49	32.9

Self-reported diagnosis (N=136)		
Anxiety/depression	63	46.3
Psychosis	51	38.5
Neuropsychiatric disorder	16	11.8
Other diagnosis	6	4.4

Table 2. Experienced discrimination in different life domains. The table shows results in rank order (%) for the DISC-12 subscale perceived discrimination (unfair treatment) (N=156)

Question Unfair treatment subscale	Not at all	A little	Mode-rately	A lot	Overall	Not appl.
Have you been treated unfairly by your family?	45.5	14.1	22.4	17.3	53.9	0.6
Have you been avoided or shunned by people who know that you have a mental health problem?	44.5	20.0	18.1	14.8	52.9	2.6
Have you been treated unfairly in making or keeping friends?	47.4	15.4	21.8	12.8	50.0	2.6
Have you been treated unfairly by mental health staff?	52.6	13.0	14.3	20.1	47.4	0.0
Have you been treated unfairly when getting help for physical health problems?	59.0	9.0	14.7	15.4	39.1	1.9
Have you been treated unfairly in dating or intimate relationships?	48.1	13.6	9.1	14.3	37.0	14.9
Have you been treated unfairly in marriage or divorce?	31.6	11.0	7.7	16.8	35.5	32.9
Have you been treated unfairly in your personal safety and security?	60.6	7.1	12.9	15.5	35.5	3.9
Have you been treated unfairly in your education?	32.7	5.8	14.1	15.4	35.2	32.1
Have you been treated unfairly in getting welfare benefits or disability pensions?	61.3	5.8	14.2	14.8	34.8	3.9
Have you been treated unfairly in your social life?	67.3	12.2	10.9	5.8	28.9	3.8
Have you been treated unfairly in your levels of privacy?	68.6	9.2	9.2	9.2	27.6	3.9
Have you been treated unfairly in finding a job?	43.5	7.8	7.1	12.3	27.3	29.2
Have you been treated unfairly in your role as a parent to your children?	22.4	7.1	9.0	9.0	25.0	52.6

Have you been treated unfairly by the people in your neighborhood?	72.4	12.2	5.8	5.8	23.8	3.8
Have you been treated unfairly in keeping a job?	40.9	7.1	11.0	13.6	31.7	27.3
Have you been treated unfairly in housing?	78.1	4.5	5.8	3.9	14.2	7.7
Have you been treated unfairly by the police?	50.0	3.9	3.9	5.2	13.0	37.0
Have you been treated unfairly when using public transport?	82.7	5.1	4.5	1.9	11.5	5.8
Have you been treated unfairly in starting a family or having children?	32.9	0.0	5.2	3.9	9.1	58.0
Have you been treated unfairly in your religious practices?	42.3	0.6	3.8	0.6	5.1	52.6

Table 3. Anticipated discrimination in four life domains. The table shows results in rank order (%) for the DISC-12 subscale anticipated discrimination (Stopping self) (N=156)

Questions Stopping self subscale	Not at all	A little	Mode-rately	A lot	Overall	Not appl.
Have you concealed or hidden your mental health problem from others?	31.4	9.6	23.7	35.3	68.6	0.0
Have you stopped yourself from having a close personal relationship?	35.3	9.6	22.4	21.8	53.8	10.9
Have you stopped yourself from applying for work?	35.1	8.4	20.1	14.9	43.5	21.4
Have you stopped yourself from applying for education or training courses?	42.6	12.3	16.1	13.5	41.9	15.5

Table 4. the relationship between discrimination and social and clinical background characteristics (N=156). Stepwise multiple forward regression analysis. Significant independent variables included in the table.

Subscale/Variable	Beta coefficient	Adjusted R^2	F value	Significance
Perceived discrimination				
N of hospitalizations	.235	.055	5.04	.027
Anticipated discrimination				
Age	-.297	.077	8.30	.005