Public stigma and schizophrenia in São Paulo city Estigma público e esquizofrenia na cidade de São Paulo

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Abstract

Objective: To assess public stigma in relation to people with schizophrenia and possible factors associated with this phenomenon. Method: A cross-sectional study was conducted with a probabilistic sample of 500 individuals who live in the city of São Paulo, Brazil, and are aged between 18 and 65 years. A structured questionnaire was used, and it was applied in person. Questionnaire began with the presentation of a vignette describing an individual with schizophrenia (according to DSM-IV and ICD-10 criteria). This was followed by questions that assessed perceived negative reactions and discrimination, perceived dangerousness and emotional reactions in relation to the case presented in the vignette. Results: People with schizophrenia were perceived as potentially dangerous by 74.2% of interviewees. In addition, 59.0% of the sample perceived them as capable of arousing negative reactions, and 57.2% as capable of arousing discrimination in society. However, emotional reactions reported by the interviewees themselves were mainly pro-social in nature. The most important factors associated with these responses were: attribution of "biological" causes and perceived dangerousness. Conclusion: This study indicated that beliefs related to public stigma towards people with schizophrenia are commonly held in São Paulo city. An important focus for future studies is to investigate the scope and impact of public stigma on the everyday experiences of people with schizophrenia in the Brazilian context.

Descriptors: Schizophrenia; Discrimination (Psychology); Public opinion; Attitude to health; Brazil

Resumo

Objetivo: Avaliar o estigma público em relação a pessoas com esquizofrenia e possíveis fatores associados a este fenômeno. Método: Foi realizado inquérito domiciliar com uma amostra probabilística de 500 indivíduos residentes na cidade de São Paulo, com idade entre 18 e 65 anos. Utilizou-se um questionário estruturado que se iniciava com a apresentação de uma vinheta descrevendo um indivíduo com esquizofrenia (segundo o DSM-IV e a CID 10), seguido de um questionário estruturado com questões sobre a percepção de reações negativas e discriminação, a percepção do risco de violência e as reações emocionais em relação ao caso apresentado na vinheta. Resultados: Pessoas com esquizofrenia foram percebidas como potencialmente perigosas por 74,2% dos entrevistados. Além disso, 59,0% da amostra acreditam que estas pessoas podem gerar reações negativas, enquanto 57,2% acreditam que podem provocar discriminação na sociedade. No entanto, reações emocionais relatadas pelos próprios entrevistados foram principalmente de natureza positiva. Os fatores mais importantes associados a estas respostas foram atribuição de causas "biológicas" e percepção de risco de violência. Conclusão: Este estudo indica que crenças relacionadas ao estigma público em relação a pessoas com esquizofrenia são encontradas com frequência entre a população da cidade de São Paulo. Um importante foco para futuros estudos é investigar o impacto do estigma público nas experiências diárias de pessoas com esquizofrenia no contexto brasileiro.

Descritores: Esquizofrenia; Discriminação (Psicologia); Opinião pública; Atitude frente à saúde; Brasil

Introduction

Stigma is a broad and multi-faceted term which has been receiving increasing attention in psychiatric research and policy making. It was defined by Goffman in his 1963 classic essay¹ as an "attribute that is deeply discrediting" so that the individual is disqualified from full social acceptance.

Public stigma was conceptualized by Corrigan and Watson and later their concept was utilized by Rüsch et al. to develop an integrative social cognitive model of stigma.^{2,3} According to these authors, "public stigma consists of these three elements – stereotypes, prejudice and discrimination – in the context of power differences, and it leads to reactions of the general public towards the stigmatized group as a result of stigma". When a person who belongs to the stigmatized group turns the public's stigmatizing attitudes against themselves, self-stigma arises.

1. Public stigma and schizophrenia

Public stigma in relation to mental disorders in general, and schizophrenia in particular, is pervasive across societies and

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Departamento de Psiquiatria, Universidade Federal de São Paulo. Rua Borges Lagoa, 570, 1º. Andar 04038-020 São Paulo, SP, Brasil Phone/Fax.: (+55 11) 5579-2828 E-mail: pelusoe@terra.com.br produces several deleterious consequences: notably to lower self-esteem, increase social isolation, hinder the search for and adherence to treatment, and lower the numbers of social opportunities such as finding housing, education and employment. These consequences contribute to the disability produced by the disorder and establish a vicious circle of disadvantage increasing the burden on patients and their families.⁴

Several studies on public stigma, undertaken in different countries, point to people with schizophrenia facing a great amount of stigma in society and also to schizophrenia being one of the mental disorders most stigmatized by the general population.⁵⁻⁹

Even though public stigma towards schizophrenia can be a problem that affects the majority of countries and cultures, it is important to understand how it is built and manifested in specific cultural contexts. In developing countries in general and in Latin America in particular, little is known about public stigma towards mental disorders and possible factors associated with this phenomenon.^{10,11}

The study of factors associated with public stigma is important to understand the construction of stigma and to develop antistigma strategies aimed at the population. Some recent studies have assessed the role of several factors, such as labeling, familiarity with mental illness, causal attributions, and socio-demographic characteristics, in the construction of public stigma in relation to schizophrenia. These studies reveal that people who attribute biological causes (such as brain disease and heredity) and use labels of schizophrenia or "mental illness" have more negative reactions.^{8,12-15} Conversely, those with personal experience or who are in contact with people suffering from mental illnesses have more positive attitudes towards people with schizophrenia,^{16,17} though not all the studies have revealed this association.¹⁰

Due to lack of information about this issue in the Brazilian context, this article aims to investigate public stigma towards people with schizophrenia in São Paulo, the largest city in Brazil. The following aspects will be considered in this study: perceived dangerousness, perceived negative reaction, perceived discrimination and emotional reactions. This article also aims to assess possible factors associated with public stigma: 1) Socio-demographic characteristics of the interviewees; 2) Labeling symptoms as a mental illness; 3) Personal experience with mental health problems in general; 4) Attributed causes; 5) Perceived dangerousness.

Material and methods

1. Sampling

In May and June 2002, a household survey was carried out to evaluate the population's perception of schizophrenia. The sample was composed of residents of the city of São Paulo aged between 18 and 65 years. A pre-determined number of interviews (500) were selected, and the sample size was estimated by means of the statistical software StatsDirect. Thus, a minimum number of 457 individuals was reached, utilizing, for this calculation, an estimated response frequency of 5%, with a 2% standard deviation and 95% confidence interval. Estimated frequencies were based on a pilot study and on international studies with similar methodology.^{8,18}

A random, multiple-stage sample with a substitution strategy was used. In this procedure, groups of 10 subjects would be interviewed across different districts in the city of São Paulo. This distribution was proportional to the population of these districts, according to the demographic census performed by the Instituto Brasileiro de Geografia e Estatística (IBGE, Brazilian Institute of Geography and Statistics) in 2000. The next step was to randomly select census tracts from the districts, and two blocks were thus selected in each census tract. A total of five interviews were conducted on each block. After selecting the blocks, the first household approached was defined through the random selection of a crossing of two streets or avenues. Other households were chosen using a systematic procedure. In each household, one resident aged between 18 and 65 years was chosen to participate in the interview, based on the birthday closest to the date of interview.

This study was approved by the Ethics Committee of the Universidade Federal de São Paulo (UNIFESP) (protocol number 0027/02) and all participants signed an informed consent form.

2. Instrument

Professional trained interviewers applied a structured questionnaire face to face. The questionnaire was elaborated based on questionnaires used in similar studies^{8,18} and on a pilot study using semi-open questions, carried out with the local population.

Assessment of the perception of schizophrenia began with the reading of a vignette that described a 20-year-old individual with symptoms of the disorder, according to the ICD-10 and DSM-IV diagnostic criteria. The vignette was constructed by the authors, similarly to previous models.¹⁸ To make sure that the vignette reflected an individual with schizophrenia, three experienced psychiatrists at UNIFESP evaluated the instrument first. The sex of the individual described in the vignette (John or Mary) was randomly distributed between interviews.

1) Vignette

The following vignette (originally in Brazilian Portuguese) was read by survey respondents:

"John is 20 years old and lives with his parents. In the last eight months he has stopped going to school and seeing his friends. Instead, he stays in his room and refuses to take a shower or eat. Even though his parents know he is alone, they hear him shout and argue as if there were someone with him. Sometimes John does not move for quite a long time. At other times, he says things that make no sense, for example, that he is being spied on by neighbors who can hear his thoughts. His parents know that he is not using drugs, because he does not leave the house and sees no one."

Information about the nature of the problem of John/Mary was not provided to respondents.

3. Dependent variables

1) Perceived dangerousness

Perception of dangerousness was evaluated by means of two questions. The first one examined this perception in general, without treatment: "In your opinion, could a person like John commit a violent act against other people?"

The second question evaluated the perception of dangerousness with treatment:

"If a person like John were receiving appropriate treatment, do you believe that he could commit a violent act against other people?"

2) Perceived negative reactions

"If people who spend time with John, such as friends, acquaintances and work colleagues, knew what had happened to him, do you believe they would have negative ideas about him?"

3) Perceived discrimination

"If people who spend time with John, such as friends, acquaintances and work colleagues, knew what had happened to him, do you believe they would avoid contact with him?"

4) Emotional reactions

Eight questions were presented, each evaluating a type of reaction: desire to help, friendliness, warmth, pity, fear, irritation, desire to be distant, indifference.

"Now I would like to know what reactions or feelings a person like John would provoke. Do you feel _____?"

4. Independent variables

1) Socio-demographic: sex (masculine, feminine), age (18-29 years old, 30-49 years old, 50-65 years old), religion (no religion, Catholic, Protestant), level of education (0-7 years of formal education completed, 8 or more years completed); social class (classes A/B/C, D/E, according to the classification system from Abipeme (Brazilian Association of Market Research Institutes).

2) Labeling the problem as a mental illness (yes/no)

"Do you believe that he has some mental illness?"

3) Personal experience with mental health problems in general (yes/no)

"Have you ever had a problem with your nerves (a common expression in Brazil that refers to psychiatric disorders), a mental or emotional problem, depression, or problems caused by the use of alcohol or drugs?"

4) Attributed causes

Causes attributed by the interviewers were evaluated through the presentation of 18 possible causes: isolation, unemployment, family or love problems, overworking, poor diet, drug use, recent stressful event, childhood problems, a hard blow to the head, weakness of character or lack of will power, lack of self love, nervousness, influence/evil eye/witchcraft, lack of faith in God, fate/predestination, virus or infection, birth problem, and brain problem. For each possible cause, the individual gave his responses, according to a scale of 5 points that varied from "agree completely" to "disagree completely".

Factor analysis (principal component analysis with quartimax rotation) indicated three factors: 1. psychosocial (eigenvalue 4.20, explained variance 23.33%): unemployment (factor weight 0.67), family problems (0.64), recent stressful event (0.59), isolation (0.51), childhood problems (0.49), overworking (0.46), drug use

(0.39); 2. religious/moral (eigenvalue 1.75, explained variance 9.72 %): fate/predestination (factor weight 0.65), influence/evil eye (0.62), lack of faith in God (0.60), lack of self love (0.54), weakness of character (0.53), nervousness (0.51), poor diet (0.46); 3. biological (eigenvalue 1.52, explained variance 8.47%): brain problem (factor weight 0.77), inherited problem (0.73), virus or infection (0.51), hard blow to the head (0.49). For more details, see Peluso, et al.¹⁹

The scores for each factor were included as an independent variable in the analyses of perceived dangerousness, negative reactions and discrimination.

5) Perceived dangerousness (without treatment) (yes/no).

Included in the analysis of perceived negative reactions and discrimination and emotional reactions.

5. Statistical analysis

Descriptive analysis (frequency distribution in percentages) was performed for the male vignette (John), female vignette (Mary) and total sample. Chi-square test was carried out to compare results between the male and female vignettes. Logistic regression and analysis of variance were employed in order to verify possible factors associated with responses given by the interviewees. Logistic regression analysis was carried out, and the dependent variables were the following: perceived negative reactions, perceived discrimination and perceived dangerousness (without treatment). The "enter" method was used and non-significant variables (p > 0.05) were manually removed, one by one, until the final model was constructed.

Analysis of variance was carried out with the questions about emotional reactions. These questions were initially submitted to factor analysis (analysis of the principal components with varimax rotation) to reduce the eight reactions to a smaller number of factors. Each of the factorial scores was treated as a dependent variable.

Statistical analyses were accomplished using the Statistical Package for the Social Sciences (SPSS), version 13 for Windows and the level of significance was defined as 0.05.

Results

Table 1 shows the main socio-demographic characteristics of the study sample and of the general population of the city of São Paulo (10,434,252 inhabitants according to the demographic census of 2000 produced by the IBGE).

The frequencies of each major variable by gender of the vignette are presented on Table 2. Perceived dangerousness was more frequent with the male vignette (John), whereas feelings of warmth were more often observed with the female vignette (Mary).

1. Perceived dangerousness

Results of the logistic regression analysis showed that labeling the vignette as a mental illness (p = 0.02, OR = 1.26, CI 95% = 1.02-1.55) and attributing "biological causes" (p = 0.00, OR = 2.26, CI 95% = 1.45-3.52) were associated with perception of dangerousness.

	Sample (n = 500) %	Total population ¹ %
Sex		
Male	51.6	47.1
Female	48.4	52.9
Age in years		
18-29	35.2	32.8 ²
30-49	38.2	42.0 ²
50-65	24.6	25.2 ²
Years of education		
0-3	9.0	15.7
4-7	30.6	32.4
8-10	21.0	19.4
11 or more	39.4	32.1

Table 1 – Socio-demographic characteristics of the sample and the total population of the city of São Paulo

¹ Data from the first findings of the 2000 Census from the IBGE, referring to the population of the city of São Paulo who was over 10 years of age

² Data for the population over 18 years of age

2. Perceived negative reactions and discrimination

Results of the logistic regression analysis showed that to attribute "biological causes" was associated with perceived negative reactions (p = 0.00; OR = 1.28; CI 95% = 1.06-1.55), while perceived dangerousness (p = 0.00; OR = 1.94; CI 95% = 1.25-3.01), upper social class (p = 0.02; OR = 1.60; CI 95% = 1.06-2.42), age (30-49 compared with 18-29 years old) (p = 0.02; OR = 1.65; CI 95%)= 1.05-2.60), and Protestants compared to Catholics (p= 0.02; OR = 1.78; CI 95% = 1.09-2.91) were associated with perceived discrimination.

3. Emotional reactions

Factor analysis:

Using a scree plot method, three factors were identified to retain for rotation. Altogether, they accounted for 52.95% of the variance.

Factor 1: "Positive reactions" (*eigenvalue* 1.47, variance accounted for 18.47%): warmth (factor weight 0.68), friendliness (0.63), pity (0.62).

Table 2 – Frequency of positive answers by gender of the vignette

	John (n = 250) %	Mary (n = 250)	Total (n = 500) %
		%	
Perceived dangerousness	80.0	68.4*	74.2
Perceived dangerousness with treatment	21.6	17.6	19.6
Perceived negative reactions	59.2	58.8	59.0
Perceived discrimination	57.2	57.2	57.2
Emotional reactions			
Pity	59.2	60.4	59.8
rritation	26.0	24.0	25.0
Friendliness	55.6	62.2	58.8
ndifference	9.6	8.0	8.8
Desire to help	98.8	99.2	99.0
Warmth	85.6	91.6*	88.6
Fear	15.6	12.8	14.2
Desire to be distant	8.8	7.2	8.0

* chi-square test, p < 0.05

Factor 2: "Distance/fear" (*eigenvalue* 1.47, variance accounted for 18.42%): desire to be distant (factor weight 0.79), fear (0.59).

Factor 3: "Indifference/irritation" (*eigenvalue* 1.28, variance accounted for 16.05%): indifference (factor weight 0.78), irritation (0.61).

The results of the analysis of variance indicate that younger individuals (18-29 years of age) (F = 9.08, p < 0.01), men (F = 6.84, p < 0.01) and individuals with higher levels of education (F = 4.42, p = 0.03) were the ones who most frequently reported "positive reactions".

Only perceived dangerousness was associated with "indifference/ irritation" (F = 6.63, p < 0.01), while no associations were found between the variables evaluated and the "distance/fear" factor.

Discussion

In this study we observed that the majority of our sample expressed notions related to the concept of public stigma towards people with schizophrenia: perceived dangerousness, negative reactions and discrimination. These results are greater than those observed in relation to people with depression and dementia^{20,21} and slightly lower than those observed in relation to people with alcohol dependence in São Paulo city,²² confirming data from international studies that indicated that schizophrenia is one of mental disorders regarded more negatively by the general population.

1. Perceived dangerousness

Violence is one of the main stereotypes related to mental disorders in general and to schizophrenia in particular.^{10,15} Several international studies showed that the public often make the association between violence and schizophrenia.^{67,9}

Our study reinforces this trend: the great majority of interviewees believe that individuals with symptoms of schizophrenia, especially if they are males, could commit dangerous acts against other people. Undergoing professional treatment, however, changes the perception of dangerousness substantially. People with this disorder would be substantially less likely to commit violent acts if they were under treatment. The relationship between schizophrenia and violence is a complex issue. Empirical studies indicate that there is a moderate association between schizophrenia and violence, even though the level of danger is much lower than that perceived by the population.^{23,24} Conversely, in agreement with the general view, scientific evidence suggests that individuals who undergo adequate treatment are less likely to commit violent acts.²⁵

Among the variables evaluated, labeling the vignette as "mental illness" and attributing "*biological causes*" showed statistical association with perceived dangerousness.

Labeling the schizophrenia vignette as "mental illness" seems to be an important factor for the perception of dangerousness in the population of São Paulo, as well as among the American population, where the term "mental illness" was also one of the main factors associated with the perception of dangerousness.²⁶

The attribution of biological causes, such as brain disease, was also associated with the perception of dangerousness in international studies.¹²

The use of "mental illness" or schizophrenia labels, and also of biogenetic causal explanations, has been a widely employed strategy in schizophrenia anti-stigma campaigns. However, there is evidence in the literature stating that this approach leads to an increase in the perception of dangerousness and also in negative reactions towards people with schizophrenia by the public.^{12-15,17} The use of the "mental illness" label and the attribution of biological causes to people with schizophrenia seem to function in a way that supports the notion of lack of self-control, unpredictability and dangerousness among the public, in addition to strengthening the notion that these individuals are categorically different from what is considered normal, rather than sharing our common humanity.^{13,15}

2. Perceived negative reactions and discrimination

The majority of individuals believe that the person with symptoms of schizophrenia would produce negative reactions and cause discrimination in the social environment. Similar tendencies were reported by Griffiths et al.:⁹ 75.9% of the Australian sample and 44.8% of the Japanese sample believed that a person with early schizophrenia would be discriminated against by others in the community.

To attribute biological causes to the symptoms of schizophrenia was statistically associated with perceived negative reactions. Perceived dangerousness and socio-demographic characteristics of the interviewer (social class, age and religion) were associated with perceived discrimination.

3. Emotional reactions

When questions about the interviewee's emotional reactions were asked, however, pro-social reactions such as the desire to help, and feelings of warmth, friendliness and pity predominated, especially in relation to the female vignette (Mary).

This same trend was observed by Angermeyer and Matschinger in two national surveys conducted in 1990 and 2001 in Germany: most people showed pro-social reactions, such as pity for and desire to help individuals with schizophrenia.¹⁴ There is an important difference between the reactions attributed to other members of society and those reported by individuals themselves. The emotional reactions mentioned by individuals are more "positive" than those attributed to others. In a survey conducted in Australia and Japan, Griffiths et al. also observed that stigma from others is always stronger than personal stigma.⁹

A possible explanation for this difference is that population questionnaires investigating attitudes, especially those carried out face-to-face, are subject to socially desirable answers. In addition, questions that can generate polemic responses are even more likely to generate these types of reactions. This makes it difficult to evaluate the presence of negative reactions, stigma and discrimination through this type of instrument.

According to our data, younger individuals (18-29 years of age), males and those with higher levels of education most frequently reported "positive reactions", while perceived dangerousness was associated with reactions of "indifference/irritation".

The association of young age and higher level of education with more positive reactions emphasize the findings from a recent literature review on public attitudes towards mental disorders.¹⁰ According to this review, in the majority of studies assessed, older individuals showed more negative reactions, while individuals with a higher level of education were less likely to be distant from the mentally ill, and also expressed more liberal views towards them.

Perceived dangerousness was associated with certain negative reactions by the interviewees, such as indifference and irritation, in addition to its association with perception of discrimination. Angermeyer and Matschinger also observed that perceived dangerousness and negative emotional reactions, such as fear and anger, are associated.⁸

Labeling symptoms as "mental illness", causes attributed and personal experience were not associated with the interviewee's type of emotional reaction.

4. Limitations

Some study limitations should be mentioned. Stigma evaluation is a complex issue and different measures have been utilized to investigate some of its components in international studies. In our study, we utilized questions that provide indicators of stigma and not a standardized measure that allows direct comparisons with similar studies. Reliance on a single brief vignette of a patient with minimal symptoms might have caused stigma to be underestimated. A more complex patient showing anxiety, comorbidity, suicidal ideation, recurrences or chronicity, might have magnified the findings. The cross-sectional nature of the study does not enable us to conclude that the associations previously indicated are causal in nature. Perhaps the factors that were associated depend on yet other factors which were not assessed by this study. As observed in population studies in general, people who agree to be interviewed may have characteristics that distinguish them from those who do not. In this study, where the replacement strategy for individuals who were absent or refused to participate was used, bias may have been stronger. However, as

regards the main socio-demographic characteristics, there were no relevant differences between the sample and the general population.

In conclusion, this is one of the first studies conducted with the general population in Brazil utilizing a probabilistic sample to deal with stigma towards people with schizophrenia. Results showed that people with schizophrenia face a great amount of public stigma in the city of São Paulo. Our findings also indicated that several factors (labeling symptoms as "mental illness", attributing biological causes, perceiving dangerousness and socio-demographic factors) are associated with one or two questions used to evaluate stigma but not with all of them. A positive role of personal experience with mental health problems on stigma was not observed.

It would be premature to draw conclusions for anti-stigma interventions to reduce public stigma in our context from these results. Our study, however, raised some topics that deserve attention like the importance of the issue of violence, and it provides some indications that the use of mental illness as a label and the focus on biological explanations might enhance public stigma towards people with schizophrenia.

Further research is needed to investigate stigma in the Brazilian context. One important focus for future studies is to investigate the scope and impact of public stigma on the everyday experiences of people with schizophrenia in the Brazilian context.

Disclosures

Writting group member	Employment	Research grant ¹	Other research grant or medical continuous education ²	Speaker's honoraria	Ownership interest	Consultant/ Advisory board	Other ³
Érica Toledo Piza Peluso	UNIFESP	FAPESP	-	-	-	-	-
Sérgio Luís Blay	UNIFESP	FAPESP	-	-	-	-	-

* Modest

** Significant

*** Significant: Amounts given to the author's institution or to a colleague for research in which the author has participation, not directly to the author.

Note: UNIFESP = Universidade Federal de São Paulo; FAPESP = Fundação de Amparo à Pesquisa do Estado de São Paulo. For more information, see Instructions for authors.

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