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Living conditions of people with psychotic disorders living in slums in Santos, Southeastern Brazil

ABSTRACT

OBJECTIVE: To describe the living conditions and sociability among people with severe mental disorders living in slums.

METHODOLOGICAL PROCEDURES: A qualitative study was carried out among adults living in slums in the central region of Santos, Southeastern Brazil, conducted in 2004-2006. Ethnographic observations were made in four slum properties, and in-depth semi-structured interviews were conducted with eight women who were living with individuals with psychotic disorders. The analysis method used was qualitative, based on anthropology.

ANALYSIS OF RESULTS: The slum properties presented specific characteristics regarding sociability. The difficulties with psychotic patients came from breakage of the minimal rules. In one of the slum properties, one resident acted as a caregiver for the patients and kept closely in touch with the healthcare services. Despite day-to-day contact with such patients, the participants did not have any information about such disorders and believed that the patients were mad, nervous or mentally weak. They believed that such individuals should live in places other than the slum property.

CONCLUSIONS: The population living in these slum properties did not deal with the individuals with psychotic disorders any differently from the general population, because of lack of knowledge, discrimination and stigmatization. The living conditions were poor for everyone, without any difference for the residents with psychotic disorders, except for those living in the collective residence with a greater number of patients, which was organized around them and was economically dependent on their benefits.

DESCRIPTORS: Psychotic Disorders. Social Conditions. Poverty Areas. Qualitative Research.

INTRODUCTION

Psychotic disorders have low prevalence in the general population (from 0.5% to 1.0%),¹ but are a large burden on society. Schizophrenic disorders, for example, are ranked eighth among disease with the highest proportions of days of life without quality (2.6%), for individuals aged 14 to 44 years.²² Schizophrenia is a severe disorder that starts between the ages of 15 and 25,² has chronic evolution and requires long-term treatment. It is characterized by impairments of thought, language, perception and self-perception; and by psychotic experiences such as delirium and hallucinations.

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The clinical condition leads to loss of functional capacity and affects the individual's life as a whole. Despite advances in treatment, the prognosis remains poor and its main consequence is impaired social functioning.¹³ This impairment, along with stigma, contributes towards the descent of social class that is seen among individuals with schizophrenia, thereby increasing the prevalence of this disorder among the poorer and more socially vulnerable population,⁷ with high incidence of public disorder and crime, and little social interaction among people living in such situations.¹¹ This migration to vulnerable communities has been described internationally since the 1950s and is associated with the change from a hospital-centered care model to a community-centered model. Thus, chronically ill individuals remain in the community, in socially degraded or disadvantaged regions. This phenomenon is considered to be a new form of social exclusion: "exclusion without walls".¹⁶

The links between disease characteristics, poverty and social vulnerability may contribute towards impaired living conditions and quality of life among individuals with such disorders. The social behavior of individuals with such disorders may increase the social disorganization, perception of fear and crime levels in these communities, thus generating negative attitudes among their residents. Conversely, stigmatization and prejudice expressed by the community may result in increasing such individuals' anxiety and stress, thus worsening their mental illness and precipitating acute episodes or starting the disorder.¹¹

Degraded regions of Santos, Southeastern Brazil, with poor housing (slum dwellings), drug trafficking and prostitution, have high prevalence of individuals with mental disorders (2%) (SEPLAN 2003).³ According to Andreoli et al,³ the community psychiatric care service for these regions is the one with the largest number of severe cases (44%) in the city, including schizophrenia.

Santos was one of the first Brazilian cities to implant a community care model for individuals with mental disorders, in 1989. The care network provides wide-ranging community care, it is easy to access, it has multiprofessional attendance and the hospitalization rate is low. These indicators show its effectiveness.³

Through the process of deinstitutionalization that was started more than 20 years ago, together with the high numbers of individuals with severe mental disorders living in slum dwellings, it may be supposed that the phenomenon of exclusion without walls is occurring in Santos. The aim of the present study was to describe the living conditions of individuals with severe mental disorders living in slum dwellings.

METHODOLOGICAL PROCEDURES

This was a qualitative study among adults living in slum dwellings in the central region of Santos, conducted between January 2004 and August 2006.

The city of Santos has 424,665 inhabitants,^b is the biggest port in Latin America and is the 33rd richest city in Brazil, with a human development index of 0.87 and literacy rate of 96.9%.^c Despite good social indicators, 10% of the population lives on the poverty line, especially in the central region. The region is characterized by having a prostitution zone and many old and poorly conserved buildings that have been transformed into slum dwellings. In 2003, 3.5% of the population was living in slum dwellings, and 2% of this population was suffering from some form of mental disorder.^a

To be included in this study, the participants needed to have been living in the region for at least six months, and to have been living with individuals with psychotic disorders. Out of 20 slums in this region, residents in four properties agreed to participate. The main reasons for refusing to participate were a desire not to get involved, a lack of returns from previous surveys and frustrated desire to obtain assistance through their participation, as well as not attending the interview. In total, eight women participated, from slum dwellings A, B, C and D, with respectively five, six, two and two residents presenting disorders. The participants' names were replaced initials.

Dense ethnographic observations and in-depth semi-structured interviews^{4,15} were conducted until reaching saturation of the guideline content. The data were recorded and transcribed. The analysis consisted of reading the transcriptions and grouping the content categories. The results were interpreted taking cultural concepts as theoretical references.^{4,10} Acts, events, words and interpretations were used to form a logical model that explained this reality, which was generally inaccessible to the individuals.¹²

The study was approved by the Research Ethics Committee of UNISANTOS (COMET; procedural no. 4648.20.2005). The participants signed a free and informed consent statement.

RESULTS AND DISCUSSION

The Table presented the characterization of the study participants.

The slum dwellings were located in buildings presenting a high degree of physical degradation (dripping water, infiltrations and damp in the walls) and

^a Secretaria Municipal de Planejamento. Levantamento de saúde dos moradores de cortiços na cidade de Santos. Santos: Seplan; 2003.

^b Fundação SEADE. Sistema Estadual de Análise de Dados Estatísticos. Informações dos municípios paulistas – IMP. São Paulo; 2005 [cited 2009 Sep 20]. Available from: <http://www.seade.gov.br/produtos/imp/index.php?page=tabela>

^c Instituto Brasileiro de Geografia e Estatística. Censo demográfico 2000. Rio de Janeiro: IBGE; 2000 [cited 2007 Dec 19]. Available from: <http://www.ibge.gov.br/censo/>

were overcrowded. The rooms were restricted spaces used for many functions. They were dirty, unhygienic and lacking in comfort. The bathroom, kitchen and laundry sink were shared and provided little privacy. The use and cleaning of these areas were frequent topics of discussion. The residents did not have any formal contract with the landlord (the bedrooms were sublet) and were unprotected by the current legislation.

As well as having low schooling levels,^a the residents could be considered to be socially deviant, such as: former convicts, sex workers and people living off odd jobs, petty theft and donated food baskets. Some of them frequently use illicit psychoactive substances and are alcohol abusers. Despite high turnover of occupants, it was common to find a “key holder”: a person who explicitly led and organized the slum dwelling. Women occupants were more communicative, while men were mistrustful and non-participative. These characteristics, together with the fear of exposure, partly explained the refusal to be interviewed, especially among men.

There were families living in all the slum dwellings. In slum dwelling B, individuals with mental disorders who were using the public service for mental healthcare (*Setor Núcleo de Atenção Psicossocial*; SENAPS II) accounted for the majority of the residents. Only one elderly woman (Mrs. M) and her family did not present mental disorders. She played the role of “key holder” and was the reference point for the residents’ healthcare at SENAPS II. The occupants of slum dwelling B lived together harmoniously and the turnover was low (thus differing from the other slum dwellings), since most of the residents had lived there for more than six

years. Mrs. M. said that she preferred to have residents who were SENAPS users, because they had a monthly income because of their disorder, consisting of (for example): continued benefit provision under the organic law for social assistance (LOAS); or a retirement pension due to disability, paid by the social security institution (INSS). Thus, rental payments were made at the correct times. There was also one individual who worked at a garbage recycling cooperative and another who received a pension from his brothers.

This housing organization model, regardless of the precariousness of the infrastructure, appears to be an alternative for these individuals to live within society. It is funded by resources coming from social benefits, in association with autonomous management with supervision and reference from the healthcare services. This is backed not only by the successful experience of slum dwelling B, but also through the idea of using the space as an exercise in coping existentially. Through this, psychological distress gains meaning and individuals start to establish strategies for living and for strengthening their reference points.⁶

Coping existentially is an important factor in individuals’ inclusion in society. However, the characteristics of the disorder mean that a caregiver and monitored treatment are fundamental necessities. Care provided by the family has an essential role within social inclusion,⁹ but the high degree of distress and the burden on individuals and their families often make this process difficult or impossible. Natural support systems involving spontaneous relationships outside of the family, in churches, in voluntary associations,

Table. Characterization of participants. Santos, Southeastern Brazil, 2003-2004.

Participants	Schooling level attained (school year)	Age (years)	Conjugal situation	Place of birth	Religion	Activities performed
LD	5 ^a	45	Single	Brejois, Northeastern Brazil	Spiritualist	Domestic employee
DM	4 ^a	80	Married	São Paulo, Southeastern Brazil	Evangelical	Key-holder of a slum dwelling where most of the residents have psychotic disorders and use SENAPS II
V	5 ^a	38	Single	Mogi, Southeastern Brazil	Evangelical	Informal work (crafts)
L	5 ^a	34	Living together	Tacaimbó, Northeastern Brazil	Catholic but attended Umbanda	Informal (odd jobs)
R	7 ^a	31	Married	Santos, Southeastern Brazil	Spiritist	Housewife
E	6 ^a	58	Widowed/ living together	Poços de Caldas, Southeastern Brazil	Catholic	Unemployed
MG	5 ^a	42	Living alone	Northeastern Brazil	Evangelical	Peddler
F	2 nd year of high school	48	Married	Northeastern Brazil	Catholic	Cleaner and caretaker

among neighbors or with bar owners, among others, may contribute towards halting or reversing the process of social withdrawal. Acceptance within these environments makes it possible to form social niches, in which individuals with mental disorders would be tolerated and perhaps encouraged.⁸

In slum dwelling B, even though Mrs. M's motivations were related to guarantees of keeping payments up to date, through the benefits that the individuals with mental disorders received, the residents' acceptance and lack of turnover made this space a natural support system that enabled the creation of support networks that connected people without family ties and linked them to the mental healthcare service.

Daily life in slum dwellings

The space in the slum dwellings was small and different people were living together in them: people who were strangers to each other, with superficial relationships, who were living there for a wide variety of reasons, leveled through poverty and exclusion. The impaired social functioning characteristic of individuals with psychotic disorders was exacerbated in this environment in which it was difficult to live together. Behavior involving invasion of privacy, breaking of rules, lack of hygiene and aggressiveness generated lack of understanding and conflicts, but for most of the time, there was tolerance, help, compassion and solidarity.

The physical proximity between the rooms made it difficult to have privacy, thus favoring conflicts within day-to-day life.

"Ah! Intolerable, because she's there: you close the door to sleep, and she's there all the time: Oh Li, give me this... O Li, can you give me a cigarette? So, you do and she goes off. Soon afterwards, five minutes, she's there: Oh Li... Well, the time comes when you can't stand it anymore... It gets you, you swear at her to see if she'll go to sleep, because there are times that she's intolerable..." (E)

There was great fear regarding safety, because it was feared that the individuals with disorders might physically harm the other residents.

"Sometimes, we get worried because of the gas, which she leaves on... She leaves the gas open... Often, she was there and didn't notice... 'But I turned it off!' 'Really, J?' 'Everything's off...' (laughs) You know? The other day, we even thought of talking to Mr. Almeida, so that... To get her to do it, you know? When she does the meals... She make the most of the days she's at SENAPS and turns off the gas, because it's dangerous, you know?... The cigarette that she's smoking, you know? We get very worried... Because sometimes she might fall asleep... Because she takes medications that

make her sleep... And it'll catch fire, you know? So we... Our concern about her, here, it's just this... But, well... bothering us, no, you know? She's a person who doesn't bother people..." (LD)

There were also concerns about the lack of hygiene.

"Oh... For me, it's this and the dirt, isn't it? Because it's just too much, isn't it? It's a smell that... These days, the housewife here... Got her foot into it... And cleaned it up... It's a smell that's blocked her, so everything goes to our house. It's no good... You take care and she doesn't... So, she does her stuff in a bucket... Sometimes she leaves it two or three days there! This heats things up... There's the smell... There's the smell filling up here inside, so you can't stand being inside... So, you turn on this fan... Not even the fan can take it out [...]"

Aggressiveness was considered to be unacceptable behavior.

"There's one here that... is aggressive... He's going to leave!" (Mrs. M). She meant that she was no longer going to accept this resident with psychotic disorders as a tenant.

There was some understanding, tolerance and help towards neighbors with psychotic disorders.

"But when you're subjected to living in her situation..., like her... I think you have to do more than understand, you know? You try to help, don't you? With what's needed, you know? Sometimes... saying things like 'ah, because J. never does coffee?' 'Ah! Guys, give her a bit of coffee' 'But she has her own!...' 'She has, but don't you have some in your home? You can, you know?'... She doesn't like doing it; she's lazy about doing it. It's her way." (LD)

"R. was another one who I talked to... His brother and his uncle also talked to him, but he said 'F, talk to him because he's...he's... Today he's having a crisis. So, he gave the orders, sometimes from there to here, and he stayed with me all day... 'Do you want lunch? Do you want some coffee? Do you want this? Go and watch a cartoon!' He calmed down with me [...]" (F)

Other attitudes indicated compassion.

"[...] I get on with everyone. As you were speaking of J, she comes here: "LD, is there any coffee here?" 'There is, J., 'Hang on a moment, OK?' ... So then, me and her... Well, really good, you know? I try to understand her, the poor thing... It's really her... isn't it? Like in the story, isn't it? She's a poor thing; she lives alone here, comes in, goes to NAPS (sic) for her medicine, you know? In fact, I have lot of pity for her, you know." (LD)

The residents highlighted the need to set limits.

“I live together very well! Well, I know how to live together with all sorts of things. Except that I know when something’s right, it’s right and when something’s wrong, it’s wrong. There’s a time to put the brakes on.”(L)

At the same time as they signaled deviant behavior, they revealed calm relationships of living together, such as conversations at the door or on the sidewalk, invitations to children’s birthday parties, visits by other SENAPS users, and other events, i.e. the relationships established were not necessarily negative within the precarious context of the slum dwelling.

Stigmatization and discrimination

Discrimination and stigmatization were evident when the participants were asked about where people with mental disorders should live. Most of the interviewees spoke about the need for a caregiver, preferably somewhere other than in the slum dwelling. Corrigan & Penn⁵ (1999) alleged that it was commonly believed that people with mental illnesses were rebels who should be feared and kept out of the community.

“So then, adults come in, don’t they? I think that they should all live together in one place. There should be a place to receive them, you know? For them to have possibilities, you know? And to have someone in charge, you know? Thus, in a place where they can be, you know? Giving some sort of help, you know? Because like you said...I don’t know... I think that she should not be here... Yes! I think that there should be a reception... a place to receive them, like SENAPS, you know? They already stay there during the day... That’s why they have to have a house, isn’t it? A house that they can stay in and have a life there, you know? So that they would be able to recover, because living here is bad [...]” (LD)

Others said that these individuals should be cared for by their own families:

“They have to have support from their families, don’t they? Because if families have this problem, what do they have to do? They have to help... It may also be that sometimes people have problems in their head, and not of internal cases. The family itself has to talk about this; they have to help...” (F)

Schizophrenic disorders are the ones with greatest stigma attached to them, and they continue to be associated with negative stereotypes such as violence and danger.¹⁸ This negatively influences the prognosis, clinical practice and recovery, and the quality of life of the individual with this disorder.^{20,21} Stigmatization leads to prejudice and discrimination. The impact of this on these individuals’ lives is just as harmful as the direct effects of the disease,⁵ since it limits opportunities and influences self-esteem.

Knowledge of mental disorders and their causes

The residents of the slum dwellings had little knowledge or technical information about what mental disorders might be. What little they had was probably acquired through living with such individuals. Some of the residents considered that the disorder was a condition of not having a “good mentality”. This would put the safety of the slum dwelling and its occupants at risk:

“[...] You know what I mean? I don’t have it, you have it... We can see that these people don’t have a good mentality. They are people who are sick... A mentality that isn’t good. A mentality that isn’t from their minds. They do things like setting fire to things or striking matches and setting fire...L...he wanted to get knives, get things, do you see what I mean? Sometimes [...]” (F)

Others understood the disorder as weakness of spirit, spiritual problems and lack of protective backing, like in other studies.^{14,17}

“Look, these disorders are in people who are weak in their minds... They are very weak; the enemy is at loose and gets them and ends their lives... You know why? I’ll tell you the truth: it’s the protective backing; they don’t have any more protection with God, so they seize people...” (MG)

In the present study, a variety of causes of the disease were put forward. Villares et al (1999)¹⁹ showed that the concepts of the disease included a notion of causality that brought together elements of popular, folkloric and medical knowledge. Thus the residents’ understanding of mental disorders was similar to that of the general population and the notions of common sense. This was so even among those who had the function of caregivers, such as the “key holder” (Mrs. M), who did not have a clear notion about what mental disorders and mental distress were.

FINAL REMARKS

The daily lives of the individuals with psychotic disorders were characterized by poor housing conditions in slum dwellings. Within this context, in which people who were considered to be socially deviant were living together, we imagined that individuals with psychotic disorders could suffer less discrimination or stigmatization. However, the population living in slum properties did not treat them very differently from how they were treated by the general population, since lack of knowledge, discrimination and stigmatization all existed. The living conditions were precarious for all the residents and were not different or worse for those with psychotic disorders.

The ethnographic approach not only showed tense daily life, stigmatization, discrimination and lack of knowledge, but also indicated possibilities for reference and use of particular spaces within the precarious living conditions of this type of housing. There were gradations of involvement with and tolerance towards the individuals with psychotic disorders. Living together in slum dwelling B was highlighted through the stability among the residents and the possibility of care through the “key holder”. It can be said that a system of natural support existed, under apparently adverse conditions.

The context of this study was specific, because of the proximity of the residents to the healthcare service, because of the mental healthcare model used by this municipality and because of the particular characteristics of the residents of the slum dwellings in this region.

Studies in other contexts within which individuals with psychotic disorders live in situations of poverty and vulnerability might contribute towards understanding the way in which deinstitutionalization of individuals with mental disorders has been put into effect in Brazil. It is suggested that it is important for mental health professionals to get to know the sociocultural realities within which individuals with mental disorders live, in order to identify possible collaborators other than family members.

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