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Long-stay patients in a psychiatric hospital in Southern Brazil

Pacientes de longa permanência em um hospital psiquiátrico no sul do Brasil

ABSTRACT

OBJECTIVE: To describe the demographic profile, social functioning, and quality of life of a population of long-stay care patients in a psychiatric hospital.

METHODS: A study was carried out in Porto Alegre, Southern Brazil, in 2002. A total of 584 (96%) long-stay patients were assessed by means of the following instruments: the World Health Organization Quality of Life, the Social Behavior Schedule, the Independent Living Skills Survey, the Brief Psychiatric Rating Scale and another instrument for assessing disability (Questionnaire for Assessing Physical Disability).

RESULTS: The average hospital stay was 26 years (SD: 15.8) and 46.6% of inpatients had no physical disability. Patients had their social functioning skills and autonomy largely impaired. Few of them (27.7%) answered the instrument for assessing quality of life, and showed significant impairments in all domains. The Brief Psychiatric Rating Scale evidenced a low prevalence of positive symptoms in this population.

CONCLUSIONS: The institutionalized population studied presented significantly impaired social functioning, autonomy, and quality of life. These aspects need to be taken into consideration while planning for their deinstitutionalization.

KEYWORDS: Inpatients. Mentally ill persons. Hospitals, psychiatric. Health care reform. Questionnaires, utilization. Cross-sectional studies.

RESUMO

OBJETIVO: Descrever as características demográficas, funcionamento social e qualidade de vida de uma população de pacientes recebendo cuidados de longa duração em hospital psiquiátrico.

MÉTODOS: O estudo foi realizado em Porto Alegre, RS, em 2002. Foram avaliados 584 (96%) indivíduos sob hospitalização de longa duração usando quatro questionários validados (*World Health Organization Quality of Life - Brief Social Behaviour Schedule, the Independent Living Skills Survey, the Brief Psychiatric Rating Scale*) e um outro (*Questionnaire for assessing Physical Disability Degree*) para avaliar grau de incapacidade.

RESULTADOS: O tempo médio de hospitalização foi de 26 anos (DP: 15,8) e 46,6% dos indivíduos não apresentavam incapacidade física. Os pacientes tiveram suas habilidades de funcionamento social e autonomia acentuadamente afetados. Poucos (27.7%) conseguiram responder o questionário de avaliação de qualidade de vida,

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apresentando importante comprometimento em todos os domínios. A *Brief Psychiatric Rating Scale* evidenciou prevalência baixa de sintomas positivos na população estudada.

CONCLUSÕES: Os achados revelaram haver importante grau de comprometimento no funcionamento social, nível de autonomia e qualidade de vida dos idosos. Tais aspectos devem ser considerados no planejamento da internação de longa duração de pacientes idosos.

DESCRITORES: Pacientes internados. Pessoas mentalmente doentes. Hospitais psiquiátricos. Reforma dos serviços de saúde. Questionários, utilização. Estudos transversais.

INTRODUCTION

Mental health care has improved over the last century due to advancements in many fields. The progress in scientific knowledge, development of psychotropic drugs, replacement of the hospital-centered model by community care aiming at patients' comprehensive care, and their social reinsertion are factors that should be stressed. Among the numerous consequences this "revolution" has lead to, there were changes in patients' profiles, and goals and length of hospitalization.[22] Consequently, old psychiatric hospitals have become general hospitals or, inversely, psychiatric wards were created inside general hospitals.[12]

However, some chronic patients were unable to socially interact again. This problem is particularly important in countries with lack of investments in alternative treatment proposals. Therefore, worldwide, either in small or large scale, there are still institutions similar to the old-style psychiatric hospitals.

Most of the studies designed to assess the population profile of psychiatric institutions and the deinstitutionalization process were carried out in industrialized countries.[4,11,14,18] Little is known about these institutions and their residents in Latin American countries. For this reason, the World Health Organization (WHO) is encouraging investments for assessing this information. Therefore, a project has been developed to assess the profile of long-stay inpatients of two Brazilian psychiatric hospitals: one in the city of Porto Alegre, Southern Brazil, and the other in the city of Rio de Janeiro, Southeastern Brazil.

The aim of the present study was to describe the demographic and symptom profile, social functioning, autonomy and quality of life of the inpatient population of these hospitals.

METHODS

During the recruitment period (from March to November 2002), there were 608 individuals in the hospital studied. Among them, five died, two were discharged, one refused to participate, five were not able to undergo the assessment, and 11 had been living in the institution for less than a year. A total of 584 (96%) subjects who had been confined for a long period of time (over one year) were studied.

The assessed sociodemographic and symptom data were: gender; educational level; employment situation; income; origin; service unit where he/she is an intern; starting date of present confinement; psychiatric diagnosis according to the International Classification of Diseases (ICD-10); clinical diagnosis; number of visitors over the last six months; type of visitors; legal confinement and restraint. This information was obtained from medical records, social work registers and interviews with the technical team. The variables quality of life, autonomy, social functioning and psychopathology were assessed by means of the following instruments:

World Health Organization Quality of Life (WHOQOL-Bref),[21] a questionnaire about quality of life, used to assess four domains: psychological, psychical, social relations, and environment, and was adapted to the Portuguese language.[7,8] Although it is a self-administered instrument, it can be administered by an interviewer if the patient has reading or visual impairment.

- Independent Living Skills Survey (ILSS)[26] – assessment of patient's daily life abilities within nine domains: feeding, personal hygiene, domestic chores, preparation and storage of food, health, money management, transportation, leisure, and employment. A version adapted to and validated in the Portuguese language was used for indirect

application (interview with a formal carer).[13]

- Social Behavioral Schedule (SBS)[24] – assessment of limitations in the social behavior of long-term patients, raising issues in order to evaluate social withdrawal, embarrassing social behavior, depression and anxiety, hostility and violence, among others. A version adapted to and validated in the Portuguese language was used for indirect application (interview with a formal carer).*
- Brief Psychiatric Rating Scale (BPRS)[1,16] – an instrument for assessing general psychopathology of psychiatric patients, adapted to the Portuguese language.[19] The Structured Interview Guide for the Brief Psychiatric Rating Scale (SIG-BPRS) was used to apply the scale.[1]
- Questionnaire for assessing Level of Physical Disability (LPD)[5] – an instrument used to classify patients' physical conditions into four levels: none, mild, moderate or severe disability.

The interviewers were six senior psychology students and four senior occupational therapy students, previously trained by two psychiatrists knowledgeable of the instruments used. They were responsible for obtaining the sociodemographic and symptom data, and the application of the WHOQOL-Bref, ILSS, SBS and LPD. The information needed for filling out indirect assessment instruments (ILSS, SBS) were obtained in interviews with formal caretakers who had wider knowledge of their patients' routine, mostly high school professionals (nursing technicians).

Another group, consisting of 20 mental health providers, was trained to apply the BPRS.

Descriptive statistical analysis was reported in tables for every variable in the sample. For each instrument, except the LPD, the five-item Likert scales were transformed into a dichotomic scale (absent *vs* present) using a methodology already used in other studies.[9] Outcomes were expressed in percentage of individuals presenting both levels of impairment, quantitative variables were expressed as averages and standard deviations. The data were processed and analyzed using the SPSS software, version 10.

RESULTS

Among 584 inpatients assessed, the average hospitalization length of stay was 26 years (SD: 15.8), and the longest confinement period was 67 years. Approximately 60% of the inpatients have been in the hospital for longer than 15 years and 24% of them for longer than 40 years. Fifty-four percent of them were female. The average age was 55 years (SD: 16.0); 59% aged between 35 and 65 years and 27% were older than 65. Eighty-one percent were functionally illiterate, 8.6% had complete elementary school, 1% had complete high school and only one subject was an undergraduate. There was no information available on the educational level of 10% of the population. Around 8% had regular jobs, mostly through rehabilitation programs inside the hospital itself. As to personal income, 277 subjects (47.5%) earned some, most of them (n=255) through benefits (pension or disability welfare). Over the six months prior to this study, 474 inpatients (81.2%) had no visitors. Only nine subjects (1.5%) had weekly visitors along this period. Diagnostic distribution is shown on Table 1. Around 12% inpatients were diagnosed with more than one psychiatric disorder.

As to inpatients' level of disability, 272 (46.6%) subjects showed no deficit which might impair their physical integrity. Of the remaining subjects, 112 (19.2%) had mild, 139 (23.8%) moderate and 61 (10.4%) severe physical disabilities.

Assessment of social functioning, by means of the SBS scale, showed that the study population had significant impairments in this area (Table 2). There was a trend showing a high percentage of impaired subjects expressed by items assessing social behaviors related to negative symptoms. This is opposed to what we it was observed regarding positive symptoms in inpatients' social behavior. The items indicating higher impairment were looks and personal hygiene, communication, concentration, social interaction, and idleness. Among items revealing the least degree of inpatients' impairments were: panic attacks and phobias, depression, destructive behavior, improper sexual behavior, ideas and behavior indicating suicide risk or self-aggression, and realization of bizarre thoughts.

Overall the studied population showed strong impair-

Table 1 - Distribution of diagnoses in the institutionalized population of the psychiatric hospital. Porto Alegre, Southern Brazil, 2002.

Diagnosis*	N (%)
Schizophrenia and other psychotic disorders	290 (44.5)
Mental retardation	296 (45.4)
Mood disorders	25 (3.8)
Organic mental disorder	26 (4)
Global developmental disorders	7 (1.1)
Personality disorders	6 (0.9)
No diagnosis	2 (0.3)
Total	652 (100)

*Some patients presented more than one diagnosis

*Lima L, Lovisi G, Gonçalves S. Validação e estudo de confiabilidade da Social Behavior Schedule (SBS) para uma população de pacientes de longa permanência. Arquivos da Unidade Hospitalar Franco da Rocha, Rio de Janeiro, 1999.

Table 2 - Proportion of subjects showing moderate to severe impairment of their social functioning (scoring two or higher in SBS items) in the psychiatric hospital. Porto Alegre, Southern Brazil, 2002.

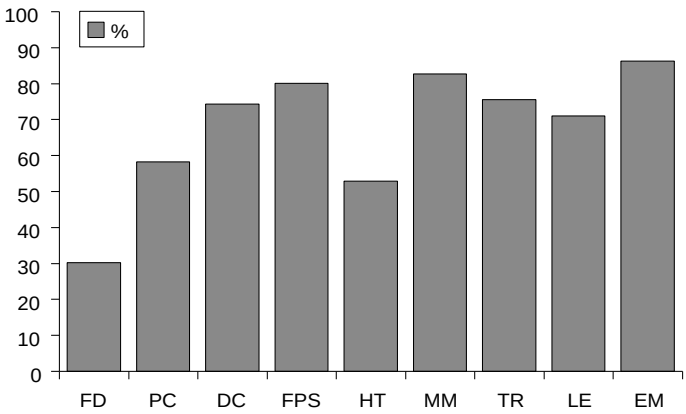
SBS item		Percentage
17.	Looks and personal hygiene	59.2
1.	Communication: taking the lead	53.1
20.	Concentration	48.1
4.	Social interaction: appropriate social contacts	46.7
19.	Idleness	42.7
2.	Conversation: incoherence	37.5
13.	Habits or socially accepted manners	32.1
10.	Laughing and talking by oneself	30.8
18.	Slowness	29.3
5.	Social interaction: ratio of hostile social contacts	29.1
9.	Restlessness and hyperactivity	26.3
21.	Behavior not specified elsewhere which prevents progress	23.2
12.	Stereotypies and idiosyncratic behavior	23.0
3.	Conversation: eccentricity/inappropriateness	21.4
6.	Social interaction: provocative behavior	18.1
8.	Panic and phobic attacks	10.6
15.	Depression	10.2
14.	Destructive behavior	8.3
16.	Improper sexual behavior	7.1
7.	Suicidal ideas or behavior or self-aggression	2.6
11.	Realization of bizarre thoughts	2.4

SBS: Social Behavioral Schedule

ment of their autonomy according to the ILSS, see Figure. Their performance was better only in feeding. In domains related to money management, leisure, cooking, employment, domestic chores, and transportation, more than 70% of the population presented moderate to severe impairments.

In regard to quality of life, assessed through the WHOQOL, a low proportion of subjects was able to answer to all 26 items of this instrument. Response rate ranged from 21.4 to 31.7% (average 27.7%). The reasons for unanswered questionnaires were patients who had problems in understanding the questions, and hearing and/or visual impairments.

Due to the small number of subjects who were able to answer WHOQOL, it was decided to calculate scores per domain for subjects who scored 50% or more in the 26-item instrument (respondents). This subpopulation comprised 153 (26%) subjects (Table 3).



ILSS (Independent Living Skills Survey) items: FD: Feeding; PC: Personal care; DC: Domestic chores; FPS: Food preparation and storage; HT: Health; MM: Money management; TR: Transportation; LE: Leisure; EM: Employment.

Figure - Proportion of subjects showing moderate to severe impairment of their autonomy (scores lower than 2 in ILSS items) in a psychiatric hospital. Porto Alegre, Southern Brazil, 2002.

Psychiatric symptoms were assessed by means of the BPRS. Due to the characteristics of the population studied, it was not possible to assess every item in all subjects. The items requiring objective assessment from the interviewer had more responses, e.g., social withdrawal, motor disorders, hostility, lack of cooperation, numbness, and psychomotor restlessness. In all items mentioned above, the number of respondents was over 400, meaning that more than 70% subjects were prone to be assessed. As to items demanding subjective assessment, like feelings of guilt, exaggerated self-esteem, and hallucinations, the response rate was around 30%.

In Table 4, BPRS items are presented in frequency order. Disorientation and confusion stood out as the most frequent item among this population. Items of intermediate prevalence include those related to negative symptoms (emotional withdrawal, lack of cooperation, psychomotor retardation, and numbness, conceptual disorganization, and motor disorders). There was a small prevalence of positive symptoms in this population.

DISCUSSION

The main global result of the present study is that the population of the hospitals studied had significant impairments in most of the different dimensions assessed, particu-

Table 3 - Average and standard deviation of scores in the WHOQOL domains from respondents in the psychiatric hospital. Porto Alegre, Southern Brazil, 2002.

Domain	Average	Standard deviation
Physical	55.2	14.6
Psychological	56.4	16.0
Social interaction	62.9	20.2
Environment	53.8	17.1

WHOQOL: World Health Organization Quality of Life

larly in respect to their autonomy. Although this finding was expected, its importance lies in the fact that it was based on a systematic assessment of the total population of inpatients in a century-old public Brazilian institution, designed for long-term care of psychiatric patients. There are no similar studies on this subject in Latin American literature.[6,10]

The demographic data of the population studied mostly show long hospital stays, high level of illiteracy, poor engagement in occupational/job activities, and situations where familial bonds had been cut off (assessed through the presence of family visitor within the last six months).

The average stay rate exceeded the average rate established by some authors when referring to "long-stay". Cyr et al,[2] in Canada, assessed a long-stay population after 3.06 years from their last admission. However, these average rates are quite similar to those found in some British psychiatric hospitals in the so-called British project, Team for the Assessment of Psychiatric Services (TAPS).[14]

A comparison between findings of the present study and those described in the TAPS project is worth mentioning.[14] The demographic profile of the population studied showed a prevalent female distribution (54%), opposed to the prevalent male population in the TAPS project findings (57% at Friern and 56% at Claybury). The average age in the psychiatric hospital studied was lower (55 years) compared to 60 at Friern and 61 at Claybury. As to psychiatric diagnoses, more than 90% of the patients were schizophrenic in the British study, while in the Brazilian sample case diagnoses of schizophrenia and mental disorder were almost equally distributed, both accounting for 90% of all diagnoses. Differences in these sociodemographic profiles could be explained by historical issues leading to the creation of health policies in both countries, as well as the gap in the availability of alternative resources for these patients.

In regard to the level of physical disability, in the present study, 53.4% of the population had some level of disability, which corroborates data in the literature.[15] On the other side, 10.4% of the patients had severe physical disability, similar to the 10% found at Friern and 9% at Claybury. The prevalence of physical disability is a critical factor to select the type of the alternative resource a long-stay inpatient must be exposed to in a policy towards deinstitutionalization.

Social behavior, measured by the SBS scale, showed impairment mainly in domains related to damage to or lack of important attributes in social life (e.g. looks and personal hygiene, start of a conversation, concentration, interaction, idleness). Those domains associated to symptoms of acute mental illness were the least prevalent (e.g. realization of bizarre thoughts, suicidal behavior, improper social behavior, destructive behavior, and depression). The present study SBS findings were similar to the those of British patients in the TAPS project.[14] Among 10 items stating the poorest performances, nine items are identical in both studies, revealing that long stays in hospital are associated to similar social behavior problems, despite demographic, diagnostic, and cultural differences.

Assessment of inpatients' autonomy showed a significant proportion of moderate to severe impairment (over 50%) in all dimensions but "feeding". The degree of autonomy measured by the ILSS has never been used before for assessing long-stay inpatients. Scores obtained in the present study, especially in the domains related to "money management" and "personal care", differ from those found in a Canadian study[2] in elderly living in the community. However, this latter study utilized a self-administered instrument, which makes it difficult to compare the results. The autonomy degree is undoubtedly an important variable in planning the course of treatment for psychiatric long-stay inpatients. As the present

Table 4 - Proportion of subjects showing moderate to severe impairment due to psychiatric symptoms (scores equal or higher than two in BPRS items) in the psychiatric hospital. Porto Alegre, Southern Brazil, 2002.

BPRS item		Percentage
18.	Disorientation and confusion	78.2
3.	Emotional withdrawal	48.6
4.	Conceptual disorganization	44.1
16.	Numbness or improper behavior	43.6
13.	Psychomotor retardation	37.2
7.	Specific movement disorders	35.3
14.	Lack of cooperation	31.4
12.	Hallucinations	25
15.	Bizarre thoughts	22.5
11.	Suspiciousness	16.7
1.	Somatic concerns	15.3
17.	Psychomotor restlessness	15.3
2.	Psychical anxiety	12.9
9.	Depressive mood	12.7
10.	Hostility	12.2
5.	Self-depreciation and guilt	8.3
6.	Somatic anxiety	7.5
8.	Exaggerated self-esteem	6.7

BPRS: Brief Psychiatric Rating Scale

study had a cross-sectional design, a cause-effect relationship between long-stay hospitalization and autonomy cannot be established. There is likely a mixture of both factors and in some dimensions (e.g. transportation) long-term stay in hospital might have prevented inpatients from increasing their autonomy. On the other hand, dimensions like personal care might be more often influenced by variables internal to the patient and be partially affected on a long-stay in a psychiatric institution. Nevertheless, a plan for long-stay inpatients' deinstitutionalization will certainly require rehabilitation actions aimed at developing inpatients' abilities which have been lost or not even attained during long-term hospitalization. Concomitantly, establishing a support network consisting of health providers and within the community is necessary in order to restore the dimensions of autonomy impaired by the disease.

The quality of life assessment, although potentially important, poses particular methodological challenges when its target population is formed by subjects suffering from serious mental illnesses and going through long-term stays in institutions. The subjective perception is a key element in the concept known as "quality of life".[21] Researchers studying subjects who experience serious and enduring mental illnesses have emphasized the importance of the subjective aspect, besides recognizing the importance of including objective aspects.[17] However, the inclusion of objective aspects in qualify of life concept tarnishes its limits, making its distinction very difficult from neighboring concepts, such as standard of living, quality of services indicators, among others. WHOQOL is a generic instrument of quality of life and has not been designed or validated for use with severe psychiatric patients.[20] The present study is the first one in the literature using a generic instrument of quality of life for a population of long-stay psychiatric inpatients. It was noticed that it was very difficult for severely impaired inpatients to answer to the WHOQOL questions, even when they were administered by an interviewer. Only 26% of the patients were able to answer at least 50% of the instrument. It is remarkable that the scores in the WHOQOL domains are very low, compared to the those from the original paper on the validation of the WHOQOL in Brazil. Although the respondents represent a small and non-significant percentage of the inpatient population in the psychiatric hospital, it can be assumed that they are precisely the ones who have higher degree of autonomy and better social relationships, since they constitute the group of patients able to answer to an instrument composed of predominantly subjective questions. Thus, it can be inferred that their scores in quality of life instrument are even higher to those from non-respondent inpatients.

Scores in the BPRS scale indicated a higher prevalence of negative symptoms (e.g. emotional withdrawal, numbness, psychomotor retardation) than positive symptoms (e.g. delusions, hallucinations) or even acute non-psychotic symptoms (e.g. anxiety, depressed mood). The initial study in the TAPS Project[14] obtained similar results by using the Present State Examination instrument. These findings are consistent with the profile of chronic psychiatric patients under antipsychotic psychiatric medication.

Although almost all hospitalized patients were included in the study, the severity of cognitive impairment in this population made data collection, especially subjective information, difficult. Thus, the main sources of information were formal caregivers, usually nursing assistants directly in charge of patient care. A likely setback of these providers would be overestimating patients' abilities, as they perceive the study as an indirect form of assessing their professional performance. Such setback, however, would make the present study findings more conservative, that is, the actual dysfunction of these inpatients would be even more serious than that found. Another limitation refers to the methodology applied for establishing a psychiatric diagnosis: hospital records, instead of structured diagnostic interviews. However, and for this reason, variables strictly related to a stratification based on diagnoses were avoided. It is worth stressing that other important studies in this area also used hospital records to carry out a diagnosis process.[14]

In spite of these limitations, a study on the characteristics of a long-stay population of psychiatric hospitals stands out as an important contribution to the study of the necessary measures to meet the purpose of improving the existing conditions for health treatment of this population due to at least two reasons: 1) it allows for managing interventions concerning specific aspects (e.g. autonomy); 2) it establishes standard measurements for this population so that the impact of future interventions can be estimated.

However, there are further challenges in the search for successful alternatives for the deinstitutionalization of inpatients, especially in developing countries. The inexistence of a theoretical model of "social inclusion,"[3] which is not based on a radical dichotomy between social alienation on one hand, and total integration on the other, seems to be one of the greatest concern in the development of realistic actions for this population.

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