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Autonomy of long-stay psychiatric inpatients

Autonomia de pacientes em internação prolongada em hospital psiquiátrico

ABSTRACT

OBJECTIVE: To assess personal autonomy of long-stay psychiatric inpatients, to identify those patients who could be discharged and to evaluate the impact of sociodemographic variables, social functioning, and physical disabilities on their autonomy was also assessed.

METHODS: A total of 584 long-stay individuals of a psychiatric hospital (96% of the hospital population) in Southern Brazil was assessed between July and August 2002. The following instruments, adapted to the Brazilian reality, were used: independent living skills survey, social behavioral schedule, and questionnaire for assessing physical disability.

RESULTS: Patients showed severe impairment of their personal autonomy, especially concerning money management, work-related skills and leisure, food preparation, and use of transportation. Autonomy deterioration was associated with length of stay (OR=1.02), greater physical disability (OR=1.54; p=0.01), and male gender (OR=3.11; p<0.001). The risk estimate of autonomy deterioration was 23 times greater among those individuals with severe impairment of social functioning (95% CI: 10.67-49.24).

CONCLUSIONS: In-patients studied showed serious impairment of autonomy. While planning these patients' discharge their deficits should be taken into consideration. Assessment of patients' ability to function and to be autonomous helps in identifying their needs for care and to evaluate their actual possibilities of social reinsertion.

KEYWORDS: Mental disorders, classification. Personal autonomy. Deinstitutionalization. Length of stay. Mentally ill persons, classification. Questionnaires.

RESUMO

OBJETIVO: Avaliar a autonomia de uma população de pacientes com internação prolongada em um hospital psiquiátrico, identificar indivíduos com possibilidades de desinternação e avaliar o impacto de variáveis sociodemográficas, do funcionamento social e de incapacitações físicas sobre a autonomia.

MÉTODOS: Foi avaliado o total de 584 indivíduos de um hospital psiquiátrico de Porto Alegre, RS, com internação prolongada (96% dois pacientes), entre julho e agosto de 2002. Foram utilizados os instrumentos, adaptados para a realidade brasileira: *independent living skills survey* (inventário de habilidades de vida independente), *social behavioral schedule* (escala de avaliação do comportamento social) e questionário de avaliação do grau de invalidez física.

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RESULTADOS: Os pacientes apresentaram grande comprometimento de sua autonomia, principalmente com relação à administração de dinheiro, ocupação, lazer, preparo de alimentos e transporte. A deterioração da autonomia esteve associada com o tempo de internação (OR=1,02), com severa incapacitação física (OR=1,54; p=0,01) e com o sexo masculino (OR=3,11; p<0,001). A estimativa do risco de ter um comprometimento moderado a grave da autonomia foi 23 vezes mais alta entre os indivíduos com severo prejuízo no funcionamento social (IC 95%: 10,67-49,24).

CONCLUSÕES: A população avaliada apresentou sua autonomia seriamente deteriorada. Concluiu-se que no planejamento da desinternação prolongada desse tipo de paciente deve-se levar em conta seus déficits funcionais. A avaliação do funcionamento social e autonomia auxilia na identificação das necessidades e na determinação da viabilidade do processo de desinternação e reinserção social desses indivíduos.

DESCRITORES: Transtornos Mentais, classificação. Autonomia pessoal. Desinstitucionalização. Tempo de internação. Pessoas portadoras de deficiência mental, classificação. Questionários.

INTRODUCTION

Over the last century the world has witnessed great improvements in mental health care: development of psychotropic drugs, replacement of the hospital-centered model with community care aiming at patients' comprehensive care and their social reinsertion.[4] In this process, a significant proportion of the population in psychiatric wards was deinstitutionalized.

However, worldwide, there still remain the so-called exclusive psychiatric institutions and their institutionalized patients. This remaining population mostly comprises chronic patients who became incapable to socially interact again.[18] Such patients represent one of the greatest challenges to deinstitutionalization – their severe disabilities make them in need of constant social support and care.

An assessment of these individuals' personal autonomy and daily life skills is needed before their discharge to provide them with more appropriate care. However, most of the studies designed to assess the deinstitutionalization process were performed in developed countries.[12] The lack of systematic assessments of this process in developing countries[8] means that many patients are being discharged without prior appropriate assessment of their dependency levels and planning for their care.

For this reason, the Pan American Health Organization (PAHO) is encouraging investments in this field in developing countries. Therefore, a project* was developed to evaluate the profiles of in-patients of two large Brazilian psychiatric hospitals hosting chronic patients, one in the city of Porto Alegre (Southern Brazil) and the other in the city of Rio de Janeiro (Southeastern Brazil).

The objective of the present study was to describe personal autonomy and daily life skills of psychiatric inpatients in order to identify those who can be discharged and be included in a deinstitutionalization program. The impact of sociodemographic variables, social functioning, and physical disabilities on this population's autonomy was also evaluated.

METHODS

This was a cross-sectional study, part of a follow-up and assessment project* of the psychiatric reform process in Brazil. It was performed in a hospital established in 1884 and has sheltered approximately 6,000 patients in Porto Alegre, Southern Brazil. Since the 1970s, the health system restructuring determined the gradual reduction of inpatient population, which comprises about 600 individuals nowadays.

Over the recruiting period (July through August, 2002), there were 608 individuals institutionalized. Of this population, only patients with more than one year of institutionalization were selected. Of them, five died, two were discharged, one refused to participate in this study, assessment was not possible in five individuals, and 11 were admitted to the hospital less

*"Follow-up and Assessment of the Psychiatric Reform at São Pedro Psychiatric Hospital". Financed by the Brazilian Ministry of Health. Institutions: Secretaria de Saúde do Estado do Rio Grande do Sul, Universidade Federal do Rio Grande do Sul, Centro Universitário Metodista IPA. Coordinator: Miriam G. Dias. 2002.

than one year before. Thus, 584 (96%) long-stay inpatients were assessed.

Interviews took place inside wards and were conducted with formal caregivers, mostly health professionals with a high school degree (nurse assistants), chosen based on their acquaintance on each patient's daily life.

The following sociodemographic data were collected: gender, educational level, employment status, income, place of birth, service unit where person is an in-patient, starting date of present confinement; psychiatric diagnosis from medical records (according to the International Classification of Diseases - ICD-10); clinical diagnosis; number of visitors over the previous six months; type of visitors; legal confinement and restraint. Some information was obtained through medical records, social work registers and interviews with the technical team.

The Independent Living Skills Survey (ILSS),[20] adapted to the Portuguese language and validated by Lima et al[10] (2003) (ILSS-BR), was applied to assess the frequency patients carried out daily activities necessary to their independent functioning in the community in the previous month. Based on a Likert scale of five points (0=never, 1=sometimes, 2=often, 3=usually, 4=always), lower scores means more severe impairment of autonomy. When patients did not have any opportunity of showing the skill the word "no" was entered (no opportunity).

ILSS comprises 112 items, reduced to 84 in the ILSS-BR, spread over nine areas (subscales): feeding, personal care, domestic activities, preparation and storage of food, health, money management, transportation, leisure, and employment. Each subscale has from seven to 13 items. The result of each subscale is represented by the mean points of its items.[10] The interview was carried out with formal care providers who were well acquainted with the patients, familiar with their behavior over the previous month.

The Social Behavioral Schedule (SBS)[21,22] was utilized to assess impairments in social behavior of long-stay inpatients, approaching issues that investigate social withdrawal, embarrassing social behavior, depression and anxiety, hostility and violence, among others. In this study, it was used a version validated and adapted to the Portuguese language (SBS-BR[11]), for indirect application (interview with formal care provider), which comprises 21 items ranging from zero to four points. According to the instrument's authors, there is a problem when the score ranges from two to four and no problem when it is either zero or one.

The Physical Disability questionnaire (PD)* assesses visual and auditory deficits, urinary and respiratory conditions, difficulties to use the limbs for self-care and difficulties in moving. These deficiencies are classified according to four levels of severity (none, mild, moderate or severe disability). The instrument was not validated but it was adapted and considered adequate by the project consultants.

Six psychology students and four occupational therapy students were previously trained as interviewers by two psychiatrists familiar with the instruments used. Over the second week of training, a pilot study with 60 patients randomly selected was performed in order to assess the level of agreement of interviewers' findings.

A multivariate logistic regression model was used to better understand the determinants affecting the level of autonomy. The inclusion criterion of variables was fitting a model of interference in the autonomy.

A cutoff point was selected in the five-item answer scale, converting it into a dichotomous scale (none and mild versus moderate to severe impairment), according to the methodology previously used in other studies.[6] This cutoff point was 2 as it represents the option that discriminates between the ones who frequently have good autonomy performance from those who rarely or never have it. Then, using the multivariate logistic regression, it was evaluated the association between independent variables (age, gender, educational level, social functioning and physical disability) and autonomy impairment (2 or more points in the scale = moderate to severe impairment).

Values were considered statistically significant when $p<0.05$. All procedures were carried out using SPSS and Epi Info software programs, version 6.4.

The study protocol was approved by the respective Institutional Review Board/Ethics Review Committee where the study was carried out. All study participants or their legal representatives signed an informed consent form.

RESULTS

Most inpatients had been hospitalized for quite a long time (mean=26 years; range: 1-67); non-significant predominance of women (54%); mean age of 55 years (range: 22-102); 81% were near-illiter-

*Desviat M. Criterios de invalidez física de la residencia asistida del. Madrid: Instituto Psiquiátrico José Germain; 2002.

Table 1 - Sociodemographic profile of a psychiatric hospital population. Southern Brazil, 2002.

Variable	Number of individuals	Percentage
Gender		
Male	268	45.9
Female	316	54.1
Educational level		
Near-illiterate	475	81.3
Elementary school	50	8.6
High school	6	1.0
University	1	0.2
Not informed	52	8.9
Visitors (in the previous 6 months)		
More than 20	9	1.5
1 to 20	77	24.0
None	474	81.2
Not informed	24	4.1
Diagnoses*		
Schizophrenia/other psychotic disorders	290	44.5
Mental retardation	296	45.4
Mood disorders	25	3.8
Organic mental disorder	26	4.0
Other disorders	15	2.3
	Range	Median
Age (in years)	22-102	54.8
Time in hospital (in years)	1-67	26.0

*Note: Some patients had more than one diagnosis.

ate; 8% had some regular paid activity, mostly through rehabilitation programs in the hospital; 47.5% had an income, mostly through disability welfare; 81.2% had no visitors over the six-month period previous to the study; long-lasting psychotic disorders and mental retardation were the prevailing diagnoses (Table 1).

In regard to physical limitations of the study population, 53.4% presented some degree of disability: 112 (19.2%) showed mild disability, 139 (23.8%) moderate, and 61 (10.4%) had severe disability.

Assessment of social functioning by means of the SBS scale showed that the study population has a marked tendency to presenting social behaviour which was related to negative symptoms (deteriorated personal appearance and hygiene; poor communication; difficulties to interact and make social contacts; inactivity). Table 2 displays the proportion of individuals with moderate to severe impairment of their social functioning (scoring 2 or higher in SBS).

Means and standard of the study population in each one of ILSS scales are presented in Table 3. The lowest averages obtained were related to money management (0.56), work-related skills (0.66) and leisure (0.87). The number of individuals per subscale was different due the large number of unanswered questions.

Most individuals had quite impaired capacity of autonomy. The Figure shows that more than 70% had moderate to severe impairment in activity domains, except for feeding skills (eating appropriately without help), personal and health care.

Table 2 - Percentage of psychiatric hospital individuals showing moderate to serious impairment of their social functioning. Southern Brazil, 2002.

Social Behavior Schedule Items	Percentage
Appearance and personal hygiene	59.2
Communication: taking the lead	53.1
Concentration	48.1
Social interaction: appropriate social contacts	46.7
Idleness	42.7
Conversation: incoherence	37.5
Habits or socially-accepted manners	32.1
Laughing and talking by oneself	30.8
Slowness	29.3
Social interaction: ratio of hostile social contacts	29.1
Restlessness and hyperactivity	26.3
Behavior not specified elsewhere which prevents progress	23.2
Stereotypes and idiosyncratic behavior	23.0
Conversation: eccentricity/inappropriateness	21.4
Social interaction: provocative behavior	18.1
Panic and phobic attacks	10.6
Depression	10.2
Destructive behavior	8.3
Improper sexual behavior	7.1
Suicidal ideas or behavior or self-aggression	2.6
Realization of bizarre thoughts	2.4

Table 3 - Mean and standard deviation of scores from subjects in the nine subscales and in the ILSS-BR global scale. Southern Brazil, 2002.

Subscale	Mean	Standard deviation	N
Feeding	2.05	0.90	584
Personal care	1.57	1.2	584
Domestic chores	0.96	1.28	569
Food preparation	0.88	1.23	567
Health	1.51	0.98	581
Money management	0.56	1.03	407
Transportation	0.92	1.09	442
Leisure	0.87	0.86	584
Employment	0.66	1.12	379
Global scale	1.13	0.79	584

ILSS-BR: Independent Living Skills Survey, Brazilian version.

The association between autonomy capacity (assessed through ILSS) and sociodemographic variables, social functioning (SBS) and physical disability (DP) were assessed by means of a logistic regression (Table 4). The results obtained through the instruments were dichotomized and, for this analysis, the dependent variable was considered to show moderate to severe impairment of daily life activities, according to ILSS.

Among independent variables, the most important was deterioration of social functioning, associated with the dependent variable ($p<0.001$). Risk estimates of moderate to severe impairment of autonomy was approximately 23 times higher among individuals who showed severe impairment of their social functioning (95% CI: 10.67-49.24).

The association with length of hospital stay was also significant ($p=0.02$). The longer the hospital stay, the more severe the impairment of autonomy and daily life skills (OR=1.02).

Individuals with severe physical disability are more prone to showing a moderate to serious impairment of their autonomy (OR=1.54; $p=0.01$). The logistic regression showed that men have higher risk of moderate to severe impairment of their capacity of autonomy than women (OR=3.11; $p<0.001$).

Educational level and age showed no significant association with the dependent variable.

DISCUSSION

Institutionalized psychiatric inpatients had severe impairment of their capacity of autonomy and daily life skills. This finding was expected, since analogous studies performed in developed countries showed similar results.[11,12,15]

The correlation between different variables showed that patients with severe impairment of their social functioning have more significant deficits in their autonomy. The studied population often showed the so-called negative social behavior, which suggests high cognitive impairment and low involvement in specific activities. This finding might be the consequence of a "negative" selection of patients over the

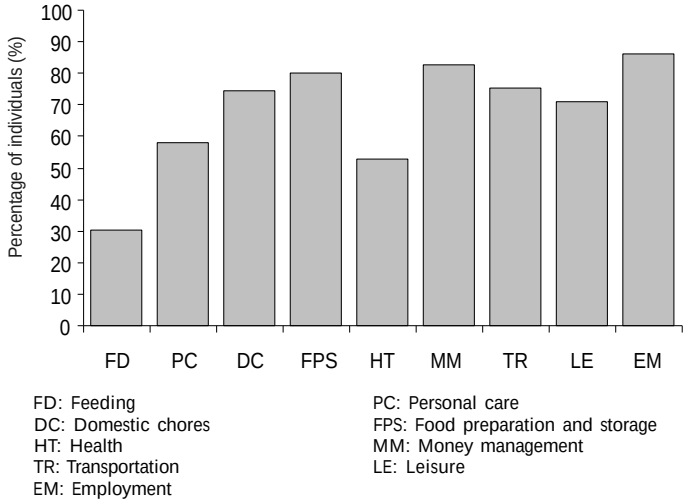

Figure - Percentage of individuals showing moderate to serious impairment of their capacity of autonomy in psychiatric hospital. Southern Brazil, 2002.

Table 4 - Multiple logistic regression model assessing the association between (moderate to serious) impairment of autonomy and sociodemographic variables, social functioning, and physical disability. Southern Brazil, 2002.

Variables	Crude			Adjusted		
	OR	95% CI	p-value	OR	95% CI	p-value
Social functioning	27.70	13.42-57.17	0.00	23.20	10.67-49.24	0.00
Time in hospital	1.02	1.00-1.03	0.02	1.02	1.00-1.04	0.02
Educational level (low)	1.94	1.18-3.18	0.01	1,54	0.85-2.81	0.16
Physical disability	1.94	1.49-2.52	0.00	1.54	1.13-2.12	0.01
Age	1.01	0.99-1.02	0.19	1,01	0.99-1.03	0.59
Gender (male)	1.92	1.22-3.02	0.01	3.11	1.77-5.45	0.00

years, when individuals with better functioning were discharged, and those with the worst functioning and autonomy remained in hospitals.[15]

Some individuals had no previous chance to perform some of the activities assessed by means of the ILSS instrument. In such cases, the assessment of domains was not applied. The domains with higher losses were money management, use of transportation and work-related skills.

A negative assessment, i.e., low performance in several domains may also be due to a tendency of a caregiver (and, sometimes, of the patients themselves) to regard some activities as inappropriate to such patient.[17]

On the other hand, interviewees might have underestimated the patients' ability by perceiving this research study as an indirect means for assessing their own professional performance. This approach, however, would make the study findings more conservative, that is, the actual dysfunction of these patients would be even higher than that reported.

Assessing inpatient's autonomy in order to assess their rehabilitation needs and mainly the feasibility of their discharge has become paramount. In this sense, the use of the ILSS-BR is important because it allowed to understand patients' level of independency and helped to identify who can actually be discharged. Similar studies are scarce in the Latin-American medical literature.[5,8]

With regard to demographic characteristics of the studied population, it should be highlighted long stay, high illiteracy, poor involvement in occupational/work activities and loss of familial bonds (assessed by means of visits of the patients' families over the previous six months). Records of length of hospital stay were quite similar to those found among inpatients in some British psychiatric hospitals in the TAPS project (Team for the Assessment of Psychiatric Services).[12]

Mean age was lower (55 years) in the present study when compared to 60 found in Friern and 61 in Claybury Hospitals in the TAPS project.[12] This could be explained by the fact that part of the study inpatients (approximately 100 individuals) came from an institution that provided support to needy minors, transgressors and/or disabled people and were transferred to the study hospital 10 years before. Besides explaining the reduced mean age, this might also explain the high prevalence of mental retardation in the study population.

The prevalence of social behaviors related to negative symptoms confirms the results of previous studies,[2,15] which showed a tendency of remaining as inpatients severely mental ill individuals with predominantly negative symptoms.

Approximately one third of the individuals had moderate to severe physical disability. This subpopulation showed significant impairment of their daily life skills which might be incompatible with an autonomous life and make discharge not possible. These results were expected since previous studies had shown high morbidity and mortality rates associated to a variety of medical illnesses in psychiatric patients.[13,14]

The performances of this population in different domains (subscales) of the ILSS were similar to those obtained by Cyr et al[3] (1994), showing that the ability to prepare food and manage money are among the most impaired skills.

Another very important finding is related to the difficulty of this population to perform occupational activities, to look for and keep a job. The dysfunction in this area was the most dramatic, with 86% of the population showing some kind of impairment. According to a research study carried out by Sturt & Wykes[17] (1987) in an institutionalized psychiatric population, all patients (n=66) showed some serious dysfunction in this area.

The present study results corroborate those from other studies, showing that women have better autonomy than men.[1] This also supports data presented by the World Health Organization[9] showing better prognosis for chronic psychotic disorders in women.

Length of hospital stay was also associated with patients' autonomy. Since this was a cross-sectional study, it was not possible to establish a cause-effect relationship, i.e., long-term hospital stay leads to lower capacity, or lower capacity leads to longer hospital stay. These two variables probably have an interactive relationship.

However, the impact of the length of hospitalization on impairing daily life skills might reflect the difficulty of using such skills inside an institution. Without an adequate training and continuous stimulation, these individuals gradually lose their ability to function properly.[15]

Progress in the psychiatric reform in Brazil will depend on an accurate assessment of those who remain inpatients. The lack of a systematic assessment process can generate disastrous consequences. Other countries have faced problems related to this population's discharge as they did not provide appropriate alternatives and supportive structures in the

communities. Even when such structures do exist, there are no guarantees that a patient will make progress in the community.

It is important that mistakes and successes of the deinstitutionalization process in other countries be used and adapted to each country.[7,16,19] This is particularly important in developing countries, where resources allocated to health are scarce and information available from other countries' experiences could be useful. Although the opportunity of social reinsertion is an individual's right, its actual viability should be constantly challenged. Individualized assessment of patients' ability to function and to be autonomous helps providers to identify their needs for care. When the needed care is not available in the community, moving a patient out is not recommended. This also poses an ethical problem since discharging inpatients without means to meet their needs might implicate in risk either to the patient or to their communities.

Even those individuals who cannot be discharged, they need continuous stimulation, training and support so that they can function with autonomy in their communities.

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