O cenário da desinstitucionalização em Pernambuco: perfil sociodemográfico e clínico de usuários de hospital psiquiátrico

# The scenario of deinstitutionalization in Pernambuco, Brazil: sociodemographic and clinical profile of psychiatric hospital users

El escenario de la desinstitucionalización en Pernambuco, Brazil: perfil sociodemográfico y clínico de usuarios de hospital psiquiátrico

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**RESUMO: Objetivo:** traçar o perfil sociodemográfico e clínico dos usuários de longa permanência de um hospital psiquiátrico em Pernambuco que se encontra em processo de fechamento. **Método:** pesquisa descritiva realizada com dados secundários de 49 pacientes, obtidos pela Secretaria Estadual de Saúde de Pernambuco (SES/PE). Os dados foram analisados por estatística descritiva e apresentados em termos de frequência absoluta e porcentagem. **Resultados:** a população foi caracterizada como predominantemente do sexo masculino (95,9%), analfabeta (34,7%), solteira (71,5%), com rede social ou de suporte limitada à família (42,9%), com escassas informações sobre tipo ou fonte de renda (30,6%), com período de hospitalização em torno de 6 anos, sem saída do hospital após a internação (38,9%). Os principais diagnósticos foram esquizofrenia (49,4%) e retardo mental (36,5%). **Conclusão:** esta pesquisa visou a contribuir com a construção de políticas e ações voltadas à desinstitucionalização. Sugere-se o acompanhamento de processos como esse até seu desfecho.

**Descritores:** Desinstitucionalização, Hospitais psiquiátricos, Saúde mental, Serviços de saúde mental.

**ABSTRACT : Objective:** outline the sociodemographic and clinical profile of long-stay users of a psychiatric hospital in Pernambuco, Brazil, which is going through a process of closing down. **Method:** descriptive study carried out using secondary data from 49 patients, obtained from the Pernambuco State Department of Health (SES/PE). Data were analyzed by descriptive statistics and shown in terms of absolute frequency and percentage. **Results:** the population was characterized as predominantly male (95.9%), illiterate (34.7%), single (71.5%), having a social or support network limited to the family (42.9%), having little information about the type or source

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Descriptors: Deinstitutionalization, Psychiatric Hospitals, Mental Health, Mental Health Services.

**RESUMEN : Objetivo:** delinear el perfil sociodemográfico y clínico de los usuarios de larga estadía de un hospital psiquiátrico de Pernambuco, Brasil, que está atravesando un proceso de cierre. **Método:** investigación descriptiva realizada con datos secundarios de 49 pacientes, obtenidos del Departamento de Salud del Estado de Pernambuco (SES/PE). Los datos se analizaron por estadística descriptiva y se muestran en términos de frecuencia absoluta y porcentaje. **Resultados:** la población se caracterizó por ser predominantemente masculina (95,9%), analfabeta (34,7%), soltera (71,5%), con una red social o de apoyo limitada a la familia (42,9%), con poca información sobre el tipo o fuente de ingresos (30,6%), con un período de hospitalización de alrededor de 6 años, sin salir del hospital después de la admisión (38,9%). Los principales diagnósticos fueron esquizofrenia (49,4%) y retraso mental (36,5%). **Conclusión:** esta investigación tuvo como objetivo contribuir a la construcción de políticas y acciones dirigidas a la desinstitucionalización. Sugerimos monitorear procesos como este hasta su desenlace.

**Descriptores:** Desinstitucionalización, Hospitales Psiquiátricos, Salud Mental, Servicios de Salud Mental.

## **INTRODUCTION**

Psychiatric hospitals, characterized by full-time and long-term hospitalizations, reached the second half of the XX century as targets of accusations for human rights violations and low rehabilitation effectiveness in the treatment of people with mental disorders. Such criticisms of this model of care led to reforms in the sector, coming from the United States and Europe, with two distinct segments: one that defended reformed psychiatry, implying the internal reformulation of these institutions in order to become, in fact, therapeutic, and another which proposed to extend the psychiatrist to the public space<sup>1</sup>.

The Brazilian Psychiatric Reform Movement (MRPB) began in 1970, influenced by the ideas of the italian movement, through the mobilization and denunciation of the "industry of madness", in which the country experienced a significant expansion of psychiatric hospitalizations. For example, in the period following the military coup of 1964, one can observe the consolidation of the articulation between asylum internment and privatization of care, with the increasing contracting of beds in clinics and psychiatric hospitals paid for by the public sector<sup>2</sup>.

In search of spaces that incorporated different actors – workers, users and family members – the MRPB was promoted in different events, mainly with the 8th National Conference of Health, in 1986 in Brasília-DF; the 1st National Conference on Mental Health, in 1987, in Rio de Janeiro and the 2nd National Meeting of Workers in Mental Health, also in 1987, in Bauru. This last one was configured as the milestone of the articulation of different social movements around the Psychiatric Reform, where the motto was agreed "by a society without asylums"<sup>3</sup>.

Among the international events that contributed to the changes in the brazilian mental health are the Regional Conference for the Restructuring of Psychiatric Care, held in 1990, in Caracas, under the auspices of the Pan American Health Organization. In this event, with the representation of the Brazilian Ministry of Health, the final document entitled "Declaration of Caracas" was promulgated, in which the participating countries has committed to develop the restructuring of psychiatric care, critically review the hegemonic and centralizing role of the psychiatric hospital in providing services, safeguard the personal dignity and human and civil rights, in a model of community health service<sup>4</sup>.

The perception that the care provided in brazilian psychiatric hospitals was inadequate fostered legislative actions in the mid-1980s, such as Law n° 3657/1989, of the deputy Paulo Delgado, a precursor of Ordinary Law n° 10216/2001 which provides for the protection and the rights of people with mental disorders and redirects the mental health care model. At the state level, Rio Grande do Sul acted in a pioneering way and presented a significant political mark, with the approval of State Law n° 9.716/1992, which prescribes the psychiatric reform in Rio Grande do Sul, inciting other brazilian states<sup>5</sup>.

Nevertheless, in Pernambuco, the Legislative Assembly enacted Law n° 11.064/1994, which provided for the gradual replacement of the Psychiatric Hospitals by the network of integral attention to mental health, which at that moment did not count on the deinstitutionalization strategies foreseen in the Network of Psychosocial Attention (RAPS) instituted by Ordinance n° 3088/2011. However, even the deinstitutionalization strategies proposed by the RAPS have already been subsidized by projects created in previous periods such as the Residential Therapeutic Services by Ordinance n° 106/2000 and the Back Home Program created by Law n° 10.708/20035.

Against this background, it is observed that the deconstruction of the psychiatric hospital as an organization and as an institution has been effected through a political, theoretical and practical struggle that points to a community service network3. That is, deinstitutionalization appears as the shift from the center of the attention of the institution to the community, and as a deconstruction of an archaic model focused on the disease to treat the subject in his concrete conditions of life, not in captivity<sup>6</sup>.

However, for the adequate closure of psychiatric hospitals a planned and assisted exit of the users is essential, likewise, the creation of other resources in the community that serve as social support in the reinsertion, rehabilitation and (re)constitution of citizenship3. In addition, it is necessary to emphasize the reconstruction of clinical practice so that the reductionist interventions of these institutions, such as normalization and disciplinary strategies, are not reproduced. But, reinventing this clinical practice as a construction of possibilities and subjectivities, taking responsibility for human suffering and other paradigms centered on care, taking responsibility and citizenship as an ethical principle<sup>6</sup>.

In the Northeast, the reform of the Assistance to Psychopaths of Pernambuco implemented by Ulysses Pernambuco, from 1930 has brought important changes to the mental health scenario of the time that remain current as a constituent part of the national guidelines for mental health care. The study conducted by Facundes, Bastos, Vasconcelos, Lima Filho7 pointed out that between the years 2006 and 2009 there was a progressive reduction of 16% of the beds in psychiatric hospitals and the concomitant but not sufficient implantation of a network of extra-hospital services concentrated in the metropolitan region.

Data from the State Health Secretariat of Pernambuco refer to the operation of eight psychiatric hospitals, three of which are public and five private, which together total 1.073 beds, although six hospitals have been closed in the last five years. Among private services, four are in the process of being uncredited from the Unified Health System (SUS)<sup>8</sup>.

Despite the epidemiological magnitude of the mental disorders that make them one of the main points of the strategic agenda of the World Health Organization, the production of research developed with the focus on the population of psychiatric hospital residents is limited by the fragility of the structure of the service network of mental health of the SUS, training programs in the area or by the absence as priority of research built by the convocation of public policy<sup>9-10.</sup>

Therefore, in the conjuncture of the MRPB, it is indispensable, with the help of science, to know the long-term population of psychiatric hospitals and to devise the best way to deinstitutionalize these patients and the most appropriate destination after discharge hospital<sup>10</sup>. Thus, the present study aimed to trace the sociodemographic and clinical profile of long-stay users in one of the psychiatric hospitals in Pernambuco, in the process of being disqualified.

#### **METHOD**

This is a descriptive research using secondary data obtained from the State Health Secretariat of Pernambuco (SHS/PE), about the process of loss of accreditation of the Unified Health System (SUS) of a psychiatric hospital located in the region metropolitan of Recife/PE. The data consist of the information recorded in an instrument of the own body, used after authorization by means of a declaration of consent of the organ.

The instrument analyzed was prepared by SHS/PE in 2010, aimed at the closure of psychiatric hospitals in the state and consists of a census with 68 items, distributed in 6 categories (Figure 1).

Categoria	Descrição
Identification	Full name, date of birth, sex, nationality, country of birth, parentage, reference address, documentation (general registration and social security number), religion and color
Socio-demographic data	Schooling, productive or labor activity, bond with social security institution and housing
Legal situation	Guardianship
Social bonds	Marital status, bonding with relatives, friends, neighbors or persons of care groups, maintenance of these bonds through visits during the period of hospitalization, fulfillment and conditions of leaving the institution during the period of hospitalization
Institutional path and clinical-psychiatric data	Health care before current hospitalization, date of first psychiatric hospitalization and current hospitalization, duration of current hospitalization, diagnostic hypothesis, treatment and care by multidisciplinary team
Deinstitutionalization process	Assessment of the level of dependence of the user on the activities of daily living, institutional context and therapeutic indications for the discharge project

# Figure 1. Description of the thematic categories of the instrument of the State Health Secretariat of Pernambuco

SOURCE: secondary data obtained from the State Health Secretariat of Pernambuco (SHS/PE)

The data collection took place in the second semester of 2015 after the completion of the stage of completion of the instrument by SHS/PE professionals. The data obtained from the instrument were selected from four categories and analyzed by descriptive statistics, presented in terms of absolute frequency and percentage, using the Microsoft Excel 2007 spreadsheet for Windows 7. The diagnostic hypotheses were defined according to the 10th International Classification of Diseases (ICD-10) 11.

The research was developed in accordance with the ethical procedures recommended by Resolution 466/12 of the National Health Council (CNS) and approved by the Ethics Committee on Human Research of the Integral Medical Institute Professor Fernando Figueira – IMIP (CAAE nº 49887915.7 .0000.5201).

# RESULTS

The researched population consisted of 49 long-term users, that is, with a period of one year

or more of hospitalization, of a psychiatric hospital in the metropolitan region of Recife/PE.

Table 1 presents the sociodemographic profile of these users. The majority were men, 95.9% male and 4.1% female. The average age was 46.5 ( $\pm$  11.7) years, an information that was ignored for 8 users. In relation to schooling, the majority were illiterate (34.7%), with no record of higher education. At the time of admission, 32.7% had some occupation, and this information was ignored for 53%. The listed occupations were: farmer, mason assistant, clerk, hairdresser, weeder, carters, maid, house cleaner, street cleaner, painter, servant, salesman and guard. The bond with social security institution was mostly ignored and registered only for 30.6% of the population. Retirement was the main type of income presented (28.6%).

С.—	Ν	%
Sex Male	47	95,9
Female	2	4,1
Schooling		
Illiterate	17	34,7
Literate	1	2
Primary school incomplete	10	20,4
Primary school complete	2	4,1
High school incomplete	3	6,1
High school complete	2	4,1
Unreported	14	28,6
Occupation at time of hospitalization		
Did not have	7	14,3
Had	16	32,7
Unreported	26	53
Bond with social security institution		
Does not have	11	22,5
Have	15	30,6
Unreported	23	46,9
Type of income		
No income	9	18,4
Benefit	7	14,3
Others (retirement)	14	28,6
Unreported	19	38,7

 

 Table 1. Socio-demographic data of long-stay users of a psychiatric hospital in Pernambuco in the process of deinstitutionalization

Issues related to social bonds and legal aspects were set out in Table 2. The most represented civil status was single (71.5%). Since 42.9% of the users had the family as a social or support network, only 18.4% had registered guardianship. Family visits occurred for 44.9% of the population, with weekly frequency in 20.4% of the cases.

Although hospitalized in a closed regimen, 26.5% of users had a term provided by the

person in charge, attached to medical records, with the authorization and conditions to leave the institution. Among the conditions for discharge 22.4% needed companion and 2% could leave without companion. Nevertheless, 38.9% of users never left the hospital after hospitalization.

	N	%
Marital status		
Single	35	71,5
Married / Stable union	1	2
Divorced	1	2
Unreported	12	24,5
Guardianship		
Under guardianship	9	18,4
No guardianship	8	16,3
Unreported	32	65,3
Social or support network		
Not identified	13	26,5
Familiar	21	42,9
Unreported	15	30,6
Visitation		
Not receiving visitors	12	24,5
Relatives	22	44,9
Unreported	15	30,6
Frequency of visits during hospitalization		
Not receiving visitors	12	24,5
Weekly	10	20,4
Biweekly	5	10,2
Mensal	4	8,2
Eventual	3	6,1
Unreported	15	30,6
Exit of the user of the institution during hospitalization		
Does not leave the institution	19	38,8
Weekly	1	2
Biweekly	2	4,1
Eventual	10	20,4
Unreported	17	34,7
Conditions for leaving the institution during hospitalization		
Does not leave the institution	19	38,9
Do leave without companion	1	2
Do leave with companion	11	22,4
Unreported	18	36,7

 Table 2. Social bonds and legal aspects of long-stay users of a psychiatric hospital in Pernambuco

 in the process of deinstitutionalization

Table 3 presents information on the institutional course and clinical data. It is observed that 53.1% already received assistance through a psychiatric hospital, giving continuity to the treatment, either by re-hospitalization or by transfer from another institution. There was no record of care in

the RAPS substitute services, although the municipality had in its network two Psychosocial Care Centers and a Street Clinic team. The data indicate that 43% of the users were hospitalized in the interval of 4 to 6 years and 16.3%, for 10 years or more. This period was ignored for 6.1% of users, for whom there was no record of the current hospitalization date.

Regarding the diagnostic hypotheses, 49.4% were related to schizophrenia and 36.5% to intellectual disability. Of the cases of mental disorder due to the use of psychoactive substance, two were for alcohol use and one for multiple drug use, with periods of hospitalization of 14, 9 and 2 years, respectively. The records indicate that 89.8% of the users were treated with multiple medications, while for 10.2% this information was ignored.

Health care before current hospitalization	N	%
Did not receive care before hospitalization	1	2
Psychiatric hospital	26	53.1
Others	4	8.2
Unreported	18	36.7
Duration of current hospitalization		
1 to 3 years	8	16.3
4 to 6 years	21	43
7 to 9 years	9	18.3
10 years or more	8	16.3
Unreported	3	6.1
Diagnostic hypothesis		
Schizophrenia	24	49.4
Intellectual disorder	5	10.2
Intellectual disorder and other mental disorders	13	26.3
Mental disorder due to the use of psychoactive substance	3	6
Other disorders	2	4
Unreported	2	4.1
Information on drug treatment		
Multiple medicines	44	89.8
Unreported	5	10.2

Table 3. Institutional path and clinical-psychiatric data

The attendances by the multidisciplinary team did not reach the totality of the population, as indicated in Table 4. Nursing and social services assisted the largest number of users (85.7%), followed by psychology (81.6%) and occupational therapy (79.6%). Of the medical specialties, psychiatry and medical clinic attended 83.7% and 53.1% of users, respectively.

	N	%
Nursing	42	85.7
Social service	42	85.7
Psychiatry	41	83.7
Psychology	40	81.6
Occupational therapy	39	79.6
Clinical medicine	26	53.1
Nutrition	3	6.1
Physiotherapy	1	2
Odontology	1	2
Unreported	6	12.2

Table 4. Attendance by professional category to the long-stay users of a psychiatric hospital in
Pernambuco in the process of deinstitutionalization

### DISCUSSION

The records on the history of psychiatry in the northeast indicate that Recife and Olinda received by initiative of the public power and of the Holy Houses, one of the first establishments in the country destined exclusively to patients with psychiatric disorders, the (Hospício da Visitação de Santa Isabel (Visitation Hospice of Santa Isabel, free translation), in 1864, replaced in 1883, by the Hospício de Alienados (Estranged Hospice, free translation), known as the Tamarineira. About a century and a half later, the permanence of such institutions with the financing of public power returns to the discussion with the loss of accreditation of the psychiatric hospital of Olinda of the SUS.

Based on the analysis of the results of the users of the agreed psychiatric hospital, located in the metropolitan region of Recife/PE, the population can be characterized as mostly male, illiterate, single, with a social network or limited family support, with scarcity of information about type or source of income, with a period of hospitalization of around 6 years, in which the majority had not left the hospital after admission, and diagnoses related to schizophrenia and intellectual disability. Recent studies in other states in the northeastern and southeastern regions corroborate with the data found in Pernambuco, in which the majority of the population institutionalized in brazilian psychiatric hospitals are men, in an economically active age group, single, with weakened social ties, living permanently in the hospital or had no license to leave. However, no studies on multidisciplinary team care were found, limiting the relation of human resources linked to the field of medicine or nursing<sup>10,13-14</sup>.

Regarding the socioeconomic aspects of the studied population, the main types of retirement income and the Continuous Cash Benefit (BPC) are highlighted, established by laws n° 8.213/1991 and n° 8.742/1993, and altered by those of n° 13.457/2017 and n° 12.470/2011, respectively. Observed the conditions of the National Social Security Institute (INSS) for the granting of disability retirement<sup>15-16</sup>, it is inferred that these users were formally employed for a minimum

period of one year, and for BPC<sup>17-18</sup>, that the condition of a person with a disability has been proven, as well as the impossibility of providing for their own maintenance or having it provided by their family. However, the conditions of the present research did not allow to explain the reasons related to the permanence and exit of the labor market, as well as the inclusion in the non-contributory Social Security Policy.

The importance of work in this context is in the positive influence on mental health and overall functioning of the individual, highlighted by the improvement of self-esteem, psychological functioning and symptom control when compared to individuals without work or underemployed<sup>19</sup>. For Andrade, Burali, Vida, Fransozio, Santos (2013), the issue of work constitutes one of the axes of the MRPB along with the rearguard assistance through substitute services, housing through the System of Therapeutic Residences and economic reparation through the Back Home program, established by Decree/GM n<sup>o</sup> 106/2000 and Federal Law 10.708/2003.

In addition, events such as the 1st National Workshop on Income Generation and Work of Mental Health Service Users, held in 2004, can be taken as a historical landmark in the constitution of the Intersectoral Policy on Mental Health and Solidarity Economy, which has as institutional mechanisms the Brazilian Network of Mental Health and Solidarity Economy and the Registry of Social Inclusion Initiatives for Work (CIST), of the Ministry of Health. Such mechanisms would represent one of the possibilities for social inclusion of users assisted in mental health services, rescuing the autonomy of these subjects from the economic point of view<sup>20</sup>.

The data on the social bonds of the users of this research show us in its majority a network of support restricted to the family, visits with some frequency and the existence of conditions of exit during the period of hospitalization. It is observed that for users leaving the institution there is an attendance frequency and condition, except for a user who could leave without supervision. A study carried out with relatives of ex-"inhabitants" of a psychiatric hospital enrolled in the Network of Psychosocial Attention of Maringá - PR, concluded that

[...] the recurrence and longevity of the psychiatric hospitalization of the "inhabitants" caused loss of social roles and affective bonds, as well as signs of chronic mental disorder, reinforcing that the asylum model entails injuries that could be avoided with the treatment consonance with the precepts of psychosocial care (Frazatto, 2013:257, free translation).

Therefore, if the role of the specialized hospital is to provide health care, the long stay in psychiatric hospitals is not justified by the clinical situation, but rather as a place of residence, due to family, social, cultural, economic and political aspects<sup>21</sup>.

The institutional path analyzed reinforces what was said previously about the type of care provided by the psychiatric hospital. The main diagnoses found in this study – schizophrenia and intellectual disability – have characteristic symptoms that can bring innumerable limitations related

to language and communication, independence in the basic activities of daily living, as well as, for school, work or leisure activities, and consequently, to reach the expectations of the population in which the individual is inserted. Among the damages of the internalization of stigma is the process of identity transformation, in which the individual starts to adopt a stigmatized view about himself, preventing the formation of beneficial social relations<sup>22</sup>.

That is, if the assistance proposal of the institution is not to rehabilitate to reinsert this individual, the problems that led to his/her hospitalization will remain as an impediment to return to the family and community. Therefore, the importance and commitment of social facilities in care bring representativeness to the principles of health promotion, prevention of injuries and psychosocial rehabilitation of SUS, since their actions favor the social construction of living spaces and the expression of diversity<sup>23</sup>. This fact can be observed in the item on health care before the current hospitalization, where more than half of the patients continued treatment for rehospitalization or transfer from another psychiatric hospital without registration of care in substitutive services.

In Rio Grande do Norte<sup>24</sup> a research was carried out in the reference psychiatric hospital, which identified the causes of difficulties in mental health care: the inadequate functioning of extrahospital services, difficulty in accessing substitute services, the issue of chemical dependency in the context of psychosocial care, difficulty of users, family caregivers and professionals in joining the mental health network devices, lack of knowledge of psychiatric hospital professionals about the mental health care network. In addition to the above, it is highlighted the influence of social stigmas on access to health services in different sectors, such as basic care<sup>25</sup>. In the present study, it was not possible to identify which factors influenced the choice of service/place of care.

In a different context regarding mental health care, but not far from the objectives pursued in Brazil, an european study developed a specific instrument and analyzed the quality of psychiatric and social care for adults with long-term mental health problems. In this international research, it was found that the quality of care was higher in smaller units with mixed sex, with a maximum length of stay and where not all patients were seriously incapacitated<sup>26</sup>.

Still on mental health care, one of the main complaints presented in substitutive services is the deficit of psychiatrists<sup>24</sup>, but even in a hospital in this area of expertise, it was observed that there was no record of medical care for all users, for other professional categories. That is, the integrality of the care goes through the types of services available in mental health. Understanding that other services can assist individuals in a holistic way, aiming at psychosocial rehabilitation, through principles such as respect and recontextualization of their differences, preservation of their identity and citizenship through active participation in treatment<sup>27</sup>. However, it is observed that

[...] only a minority of the population has access to the care they need, and the hospital institutions that provide this care have been characterized, mostly, by the violation of the human rights of this population and the low rehabilitation effectiveness (Lima, 2011:

The analysis of studies about deinstitutionalization in developed countries has shown that, through a specialized or intensive rehabilitation process, it is possible to optimize social functioning, stabilize or improve psychiatric symptoms and, therefore, the quality of life of these users and its relationship with the environment<sup>28</sup>. In general, it is necessary to identify and act on the different areas that enable the recovery of mental health users, in this case, those with long-term care<sup>29</sup>.

#### CONCLUSION

After 152 years of the construction of the first psychiatric hospital in Pernambuco, barriers to changing care for users with mental disorders would not disappear with a law promulgated only 15 years ago. The long stay in the psychiatric hospital remains not justified by the clinical situation, but rather as a place of housing. Many social, political and cultural aspects are involved in this reality and need to be modified to serve a population marginalized by society and neglected by health care and social assistance.

As pointed out in other studies, although there is a gradual replacement of the beds in psychiatric hospitals by the network of integral attention to mental health, the demand for substitutive services needs a reconfiguration in the care provided, so that the deinstitutionalization of these users does not become just a dehospitalization. From the information in this study, it is assumed that the insufficiency of the substitutive network maintains the search for hospital care.

However, the use of secondary data was a limiting factor in this study, impeding the deepening and clarification of some issues analyzed. Therefore, it is suggested that research be done directed to the occupational history of these users, the articulation of psychiatric hospitals with the substitutive network and the follow-up of deinstitutionalization processes until the outcome.

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