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# CONCEPTS OF MENTAL HEALTH AND CARE ACCORDING TO MENTALLY-ILL PATIENTS AND THEIR RELATIVES

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This study aimed at 1) identifying social, demographic and clinical characteristics of mentally-ill patients and their relatives and 2) analyzing their conceptions concerning mental illness and psychiatric care. The Attitude Measurement Scale (AMS) was used. Quantitative and qualitative analyses of the data were carried out. The 104 study subjects comprised 35 patients and 69 relatives (n=104). The Mann-Whitney Test was used for comparing the opinions of patients X relatives and the Wilcoxon Test for comparing Concept and Care. There was homogeneity in the distribution of the subjects' scores for both Concept and Care. No questions stood out or were concentrated in either group. The subjects' profile shows the transition from asylum care to innovative experiences, although there is still a concentration of drug treatments and dependence on the psychiatric institution.

DESCRIPTORS: mental health; psychiatry; nursing care

## CONCEPCIONES SOBRE ENFERMEDAD MENTAL Y ATENCIÓN SEGÚN ENFERMOS MENTALES Y SUS FAMILIARES

Este estudio tuvo como objetivo: 1) identificar las características socio-demográficas y clínicas de los enfermos mentales y sus familiares y 2) analizar sus concepciones sobre enfermedad mental y asistencia psiquiátrica. Se aplicó la Escala de Medida de Opinión (EMO). Fueron realizadas análisis cuantitativos y cualitativos de los datos. Los 104 sujetos incluyen 35 portadores y 69 familiares (n=104). Las pruebas estadísticas fueron el Test de Mann-Whitney comparando dos poblaciones independientes (Portadores X Familiares), y el Test de Wilcoxon, comparando dos poblaciones relacionadas (Concepto y Asistencia). Hubo homogeneidad en la distribución de los escores de los sujetos tanto para Concepto como para Atención. Por lo tanto, no hubo cuestiones sobresalientes o concentradas en ninguno de los dos grupos estudiados. El perfil de los sujetos retrata la transición de la atención manicomial para experiencias innovadoras, aún todavía hay la concentración de los tratamientos medicamentosos y la dependencia de la institución psiquiátrica.

DESCRIPTORES: salud mental; psiquiatría; atención de enfermería

# CONCEPCÕES SOBRE DOENCA MENTAL E ASSISTÊNCIA SEGUNDO DOENTES MENTAIS E SEUS FAMILIARES

Este estudo objetivou: 1) identificar as características sociodemográficas e clínicas de doentes mentais e seus familiares; 2) analisar suas concepções sobre doença mental e assistência psiguiátrica. Aplicou-se a Escala de Medida de Opinião (EMO). Foram realizadas análises quantitativas e qualitativas dos dados. Os 104 sujeitos constituem-se em 35 portadores e 69 familiares (n=104). As provas estatísticas foram o teste de Mann-Whitney, comparando duas populações independentes (Portadores x Familiares), e o Teste de Wilcoxon, comparando duas populações relacionadas (Conceito e Assistência). Houve homogeneidade na distribuição dos escores dos sujeitos tanto para Conceito como para Assistência. Portanto, não houve questões que se sobressaíssem ou que se concentrassem em nenhum dos dois grupos. O perfil dos sujeitos retrata a transição da assistência manicomial para experiências inovadoras, embora haja a concentração dos tratamentos medicamentosos e a dependência da instituição psiquiátrica.

DESCRITORES: saúde mental; psiquiatria; cuidados de enfermagem

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#### INTRODUCTION

**T**he Brazilian advances in mental health care, which result from the global tendency to overcome the asylum model, are slowly moving ahead<sup>(1-3)</sup>. The institution on which this study was based is no different from the general picture of mental health care in Brazil and many other countries.

The mentally-ill patients report difficulties in relation to mental health services and their social relationships. They report their contact with grief, prejudices, revolt, hatred and guilt as well as critical moments such as the search for the causes of the problem they are faced with<sup>(4-5)</sup>.

These accounts reinforce the need to re-think the relationship between professionals and patients and their relatives, setting aside power relations to make room for relations among citizens.

There is an agreement that the psychiatric care process must move away from healing to daily assistance, providing the possibility of transformation in their lives<sup>(6-7)</sup>.

Therefore, it was investigated what mentallyill people and their relatives think about the disease and the care offered in this area $^{(8-10)}$ .

In analyzing the results of the application of an Attitude Measurement Scale with patients, relatives and professionals<sup>(11)</sup> and its reapplication with nurses students<sup>(9)</sup>, they observed the need to carry out studies in order to improve the efficiency of the instrument that measured their knowledge about the illness and mental health care.

The critical analysis of the statements as well as of the relevance of each question with a view to reformulating the Attitude Measurement Scale allowed for the exclusion or reformulation of various statements from the original scale. On the basis of the theoretical framework, the result of this critical analysis, as well as the correlation analyses, significance tests, validation and reliability tests led to the definition of an Attitude Measurement Scale with 34 statements.

The statistical analyses of a new apply of this instrument with 206 subjects allowed for the last corrections in the scale. On the occasion of the data collection, all patients and relatives assisted in the institution answered questions regardless their diagnoses: 102 cases of chemical dependency and

104 psychiatric patients and their relatives.

The authors analyzed the concepts about mental health and care according to the 102 dependents and relatives<sup>(12)</sup> and now present the analysis of the concepts of mental health and care as displayed by the other group (104 subjects).

#### **OBJECTIVES**

The objectives of this study were: 1) to identify the social, demographic and clinical characteristics of mentally-ill individuals and their relatives attending a psychiatric institution and 2) to analyze the conceptions of mental illness and psychiatric care, comparing the opinion of patients and their relatives.

## **METHODOLOGY**

Site

The research was carried out at the Hospital Espírita de Pelotas (HEP) - Rio Grande do Sul, Brazil. This is a philanthropical institution, which assists the Brazilian population as well as that from neighboring countries. It is located in the eastern part of Pelotas, at 230 Km from the state capital Porto Alegre.

This hospital covers the field of mental health, applies all conventional types of therapy and adopts, under a new perspective, a holistic focus on care. It receives patients of all social classes, regardless of their ethnical, political or religious origins.

#### Instruments

During the revision process of the Attitude Measurement Scale-AMS, which was reduced from 56 to 34 statements on mental illness and care, the Patient Profile Questionnaire-MDPPQ and Relative Profile Questionnaire-MDRPQ were included to get social, demographic and clinical data: a) identification of subjects, b) the complaint that made them consult the service, c) information concerning the disease, the patient and the treatment conducted as well as specifications regarding the diagnoses and treatments presently followed by the patient and d) the patient's

expectations in relation to the care to be given.

The AMS, consisting of 34 statements on Health, Mental Illness and Care, allows the subject to demonstrate his level of agreement or disagreement with the expressed content in accordance with a 5-point Likert scale.

Upon recording his opinion, the person indicates the extent of his agreement or disagreement according to a graded scale ranging from "I fully agree, I agree I neither agree nor disagree" to "I disagree or I fully disagree".

#### Sample

The 104 study subjects were selected among the 206 interviewees (psychiatric patients and their relatives) who were given some sort of care provided by the institution (HEP) in July 2002 (Pilot study).

As the main purpose of this study was to know individuals with psychiatric pathologies' concepts about health, mental illness and care, were exclude the 102 substance-dependents. Although this population is assisted in psychiatric institutions, this group's characteristics are more related to social problems than psychiatric disorders.

## Ethical procedures

This study was submitted to the evaluation of the Medical Ethics Committee of the Hospital Espírita at Pelotas (RS), which approved its realization. All patients and their relatives were previously informed about the objectives and procedures to be adopted and signed an informed consent document. Identification data did not show names or information that could individualize the subjects, thus ensuring their anonymity.

# Data collection

The subjects were approached by the researcher, who explained the objectives of the study. Those incapable of providing information (unconscious, confused or under medication effects which prevented their interaction) were excluded.

Social and demographic data (gender, age, marital status, address and profession) and clinical data were obtained through information provided by

patients and their relatives.

To apply the test, the researcher read each statement for the subject to choose one of the 5 options, thus expressing their opinion regarding mental health and care concepts in this field.

There was free interlocution between the researcher and the subjects with a view to detecting mistakes and imperfections in both test formulation and content.

Data analysis

Quantitative and qualitative analyses were carried out on the basis of the content expressed by the research subjects.

The AMS data provided information for the statistical analysis, in which the scores referring to the concepts were compared with those concerning care by applying the Mann-Whitney and Wilcoxon tests. The aim of the tests was to ascertain statically significant differences between the groups.

#### RESULTS AND DISCUSSION

The 104 study subjects comprised two groups: 35 mentally-ill people and 69 relatives (n=104).

Social and demographic characteristics of patients and relatives

Out of 35 interviewed patients, gender distribution was balanced with 17 males and 18 females, 40% of whom were up to 40 years old and 48.57% were between 41 and 60 years old. It was observed that 28.57% were single, 54.28% were married and 17.14% were separated.

Most of them (65.71%) lived in the city of Pelotas. It was also observed that one of them could not provide information concerning his place of residence and another was a street dweller.

The 35 mentally-ill patients did not have a profession which involved schooling or required a college degree. They were all classified as having simple occupations (housework - 8; agriculture - 3; general services - 7; technical jobs - 5; art - 3 and self-employment - 1). Eight were retired (Table 1).

Age

Table 1 - Social, demographic and clinical characteristics of the 35 psychiatric patients

%

F	18	Up to 40	40
M	17	41-60	48.6
Total	35	Over 60	1.4
Marital Status	%	Profession	No.
Marital Status Married	<b>%</b> 54.3	Profession Retired	<b>No.</b> 8

No.

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Married	54.3	Retired	8
Single	28.6	Housewife	8
Separated	17.1	General Services	7
		Technical Jobs	5
		Agriculture	3
Residence	%	Artist	3
In the city	65.7	Self-employed	1
Out of the city	28.6	Total	35
Out of the city	20.0	Total	33

Complaint	No.
No complaint	20
Depression/suicide	11
Nervousness	4
Total	35

Illnogg Dungtion (vocas)

Do not know Total

%
40
28.6
25.7
5.7
No.
33

No. of Hospitalizations	%
Up to 10	77
Over 10	8.6
Were never hospitalized	11.4
Do not know	2.8

Diagnoses (reported)	
Confused/Nervous/Anxious/Stress	15
Depression/Suicide attempt	15
Mental Disorder/Mad/Hallucinations	6
Do not know	3
Epilepsy/Spasm	2
Total	41

Among 69 relatives, there were 20 males and 49 females up to 40 (23), from 41 to 60 (30) and over 60 (16); 62.32% of these could be grouped in the age range between 30 and 60 years old.

It is important to emphasize that one of them was younger than 20 years old (son) and that there was a high percentage of relatives over 50 years old (40.98%), 14 (20.28%) of whom were widowed. All reports of having a partner were included in the

No.

49

married category.

Considering that 71% of these relatives were female, it is not surprising that 18 reported to work only as housewives (26.08%) and that 9 were maids. This group included a large number of pensioners (14.48%) and 34 people who performed simple activities, such as in agricultural work and general services, as well as technical jobs (31.88%) (Table 2).

Table 2 - Social and demographic characteristics of 69 relatives of psychiatric patients

M	20
Total	69
Reason to seek the service	No.
Companion	40
Visit	19
Medical prescription	4
Declaration	2
Change appointment	2
Hospitalization	1
Discharge	1

F

Total

Age	No.
Up to 40	23
41-60	30
Over 60	16
Total	69

Marital Status	No.
Married	42
Single	11
Separated	2
Widowed	14
Total	69

Relationship	No.
Parents	22
Spouses	16
Sibling	13
Child	5
Another relative	11
Others	2
Total	69

Residence	No.
In the city	52
Out of the city	16
Do not know	1
Total	69

Profession	No.
General services	18
Housewife	18
Techni. services	11
Retired	10
Self-employed	5
Student	3
Agriculture	2
Artist	1
Unemployed	1
Total	69

The patients' social and demographic characteristics informed by the 69 relatives did not differ much (proportionally), although the subjects were not paired (patient and relative).

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The 69 relatives did not exactly correspond to the 35 patients, since data collection was conducted independently, although it took place simultaneously in the same period of time.

The most frequently found relationships were that of parents (31.88%) and spouses (23.19%), which represented more than fifty per cent of these relatives. Children (7.24%) and siblings (18.84%) corresponded to 26.08%.

These relatives were accompanying the

patients during an appointment (57.97%), had come to collect a prescription or declaration or to change the date of an appointment (11.71%) or were visiting the patient (27.54%). One of them had come to pick up her son, who had been discharged.

The relatives reported that 63.77% of the patients were male. These subjects' ages were attributed as follows: 42.35% in the range of 20 to 40 years old, 46.38% in the range of 41 to 60, while only 11.9% were over 60 years old (Table 3).

Clinical characteristics

Among the 35 interviewed patients, the

clinical characteristics reported by the subjects themselves allowed for some reflections, based on Table 1.

With respect to clinical problems, it was observed that 20 subjects reported not to have any complaints. This represents 57.14% of the replies, whereas the others only informed depression, suicide or nervousness.

An analysis of this indicator showed that the question had not been well formulated, because the subject understood "complaint" as referring to the service and not as their clinical problem. Therefore, this result must be disregarded as a clinical indicator.

In relation to when the disorder had begun, it was observed that 40% of the subjects had had their first symptoms less than 10 years before and 28.57% had presented them between 10 and 20 years ago. One quarter of the 35 subjects (25.71%) had had the disorder for over 20 years.

These data correspond to the information that 77% had up to 10 hospitalizations and 8.57% had over 20.

It is relevant to notice that 11.42% had never been hospitalized. These patients informed that they did their best in order to avoid hospitalizations, thus keeping their social integration (work, school, family, etc).

Concerning the information given by 69 relatives about the patients, it was reported that 63.76% were males with a higher concentration in the age range from 41 to 60 years old (46.37%). Regarding the beginning of the disorder, the relatives also reported that 23.18% had been ill for over 20 years and that 59.42% had presented their first symptoms less than 10 years before. On the other hand, they informed that 77% had up to 10 hospitalizations and 15.94% had over 20 hospitalizations, as shown in Table 3.

Table 3 - Information from the 69 relatives concerning the psychiatric patient

Sex	No.
M	44
F	25
Total	69

Age	N°
Up to 40	29
41-60	32
+60	8
Total	69

Disease Duration (years)	No.
Less than 10	41
10-20	1
Over 20	16
Do not know	2

Treatments Conducted	No.
Drugs	41
Psychotherapy	3
Do not know	25
Total	69

No. of hospitalizations	96
Up to 10	77
10-20	7.1
Over 20	159

Diagnoses	No.
Mental Illness	22
Depression/breakdown	23
Psycho-organic	7
Problems in the head	10
Do not know	7
Total	69

Most of the patients (85.72%) classified their disease as mood disorders or confusion, nervousness, anxiety, stress, and problems in the head. Only 6 (17.14%) denominated themselves as mentally-ill or mad and reported to have hallucinations (Table 1).

Among the relatives, 10.14% did not know about the patient's diagnosis, whereas 31.88% classified it as mental illness, 20.28% as a problem in the head/ nervous breakdown, 10.14% as psychoorganic diseases and 27.53% as depression (Table 3).

Concerning the treatments applied, 94.28% of the patients only reported treatments with drugs, 2 of them did not know and none of them referred to psychotherapy (Table 1).

36.23% of the relatives could not provide any information about the treatments applied to the patients; the others reported that drugs were used

for 59.42% and psychotherapy for 4.34% (Table 3).

These subjects' profile reveals the movement of gradual transition from asylum care to innovative experiences, although the concentration of drugbased treatments and dependence on psychiatric institutions are still characteristic.

Statistical results of the Opinion Measurement Scale (AMS)

The comparisons between groups (Patients and Relatives) and between areas (Concepts and Care) were conducted through the mean score per individual in each area.

The statistical tests used were carried out with type-I error probability fixed at 5%.

In the Mann-Whitney statistical test for comparing two independent populations (Patients x Relatives), normal approximation was used for the

two-tail test<sup>(13)</sup>. In the Wilcoxon test for comparing two dependent populations, the alternative hypothesis

was that the scores related to concepts surpassed those related to care.

Table 4 - Results of Mann-Whitney and Wilcoxon Tests for groups of Patients and Relatives concerning Concepts and Psychiatric Care

Comparisons	Test	Observed Value	Result	Conclusion
Pat. x Rel. – Concept	Mann-Whitney	0.08	Non-signif.	Pat. = Re1.
Pat. x Rel. — Care	Mann-Whitney	0.11	Non-signif.	Pat. = Re1.
Conc. x Care (Patients)	Wilcoxon	4.88	Significant	Conc. > Care
Conc. x Care (Relatives)	Wilcoxon	7.12	Significant	Conc. > Care

Note: critical value for the tests: 1.64

In the Table 4, its possible to observe that significant differences between Patients and Relatives occurred neither in relation to mental health concepts nor in relation to care, according to the Mann-Whitney Test.

However, when comparing Concepts and Care according to the Wilcoxon Test, a significant difference was observed for both Patients and Relatives.

With respect to the mean Patient scores regarding Concepts, the result was 2.73 for patients and 2.71 for relatives, which configures a non-significant difference. Similarly, the mean scores regarding Care (1.73) for Patients do not differ very much from the result of the mean scores regarding Care for Relatives (1.65) (Table 5).

Table 5 - Mean scores of mentally-ill patients and relatives in relation to Mental health concepts and care

	Concept	Care
Relatives	2.71	1.65
Patients	2.73	1.73

In the individual analysis, 10 out of 35 subjects presented a mean value that varied over 3. In the other cases, the mean for Concepts varied from 2 to 3. In relation to care, one individual presented a mean over 3 and seven subjects displayed a mean between 2 and 3, whereas the others were below 2.

Regarding the relatives, 18 presented a mean over 3 for Concept and none had a mean over 3 for Care.

Standard deviation was 1.73 for patients and 1.73 for Relatives in questions related to Concept, and 1.37 for patients and 1.29 for Relatives related to Care, which indicated homogeneity in the

distribution of the subjects' scores for both Concept and Care. Therefore, no questions stood out or were concentrated in either group.

Note: critical value for the tests: 1.64

### **CONCLUSIONS**

To arrive at this analysis, an instrument was constructed in accordance with the methodological precepts indicated for these procedures.

In the elaboration of psychological scales, the researcher should follow 3 principles: theoretical, empirical and analytical<sup>(14)</sup>. Theoretical procedures focus on the subject to be examined; empirical procedures define the steps and techniques for applying the elaborated instrument; analytical procedures establish what statistical and qualitative analyses will be realized on the basis of the obtained data.

The analysis of the social and demographic characteristics of patients and relatives showed a population of users that was not different from those found in previous studies.

The statements related to mental health and psychiatric care that were presented in this study contain conceptual questions, which verify what is understood as mental health, characteristic behavior of mental patients, their insertion in society and beliefs and expectations about cure, therapeutic procedures and the care system.

The statistical results from the opinions of patients and their relatives on concepts regarding mental health care showed that there were no significant differences between the opinions of patients and relatives, except in the comparison of concept and care between the two groups of subjects.

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