USERS OF THREE PSYCHIATRIC SERVICES: PROFILE AND OPINION¹

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This study aimed to characterize mental patients and their companions at three psychiatric services; to identify diseases, diagnoses and treatments; to learn about their expectations and opinions about mental illness and psychiatric care. Methodology: Patients with mental disorders and their companions (750) at three care services (Emergency Unit, Psychosocial Care Center and Mental Health Clinic) answered the Clinical-Social Characterization Questionnaire and the Opinion Measurement Scale on concepts and psychiatric care. Results: Single patients with unstable relations with their partners, low educational level, unemployed, with little information about their diagnoses and treatments. Medication treatments and low commitment levels were predominant. Many patients had acquired the illness over the last five years. Subjects at the three services revealed diverging opinions regarding concepts and care.

DESCRITORS: psychiatry; mental health; nursing

USUARIOS DE SERVICIOS PSIQUIÁTRICOS: PERFIL Y OPINIÓN

El objetivo de este estudio fue caracterizar el portador de enfermedad mental y su acompañante en el atendimiento en tres servicios psiquiátricos; identificar la enfermedad, diagnósticos y tratamientos; conocer expectativas y opiniones a cerca de la enfermedad mental y asistencia psiquiátrica. Metodología - Portadores de trastorno mental y sus acompañantes (750) en tres servicios (Unidad de Emergencia, CAPS y Ambulatorio de Salud Mental) respondieron al Cuestionario de Caracterización Clínico-Social y a la Escala de Medida de Opinión sobre conceptos y atención psiquiátrica. Resultados: pacientes solteros, con uniones inestables, bajo nivel de escolaridad, sin trabajo, poco informados sobre sus diagnósticos y tratamientos. Predominaron tratamientos medicamentosos y bajos índices de internación. Muchos se enfermaron en los últimos cinco anos. Se observó convergencia de opiniones sobre conceptos y sobre la atención entre los sujetos en los 3 servicios.

DESCRIPTORES: psiquiatría; salud mental; enfermería

USUÁRIOS DE TRÊS SERVIÇOS PSIQUIÁTRICOS: PERFIL E OPINIÃO

Objetivou-se caracterizar o portador de doença mental e seu acompanhante em atendimento nos três serviços psiquiátricos; identificar doença, diagnósticos e tratamentos; conhecer expectativas e opiniões sobre doença mental e assistência psiquiátrica. Metodologia- Portadores de transtorno mental e seus acompanhantes (750) em 3 serviços (Unidade de Emergência, CAPS e Ambulatório de Saúde Mental) responderam ao Questionário de Caracterização Clínico-Social e a Escala de Medida de Opinião sobre conceitos e assistência psiquiátrica. Resultados: pacientes solteiros, com uniões instáveis, baixo nível de escolaridade, sem trabalho, pouco informados sobre seus diagnósticos e tratamentos. Predominam tratamentos medicamentosos e baixos índices de internação. Muitos adoeceram nos últimos 5 anos. Observou-se divergência de opiniões sobre conceitos e sobre a assistência entre os sujeitos, nos 3 serviços.

DESCRITORES: psiquiatria; saúde mental; enfermagem

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INTRODUCTION

Why revisit concepts about health and mental illness and about care based on the opinions of mental patients and their relatives?

There are 500 million people all over the world suffering from some kind of mental disorder, leading to a work incapacity rate of 40% and other consequences for patients, families and society⁽¹⁾.

These rates are related to increased life expectancy and aging, increased stress, family crises and lack of social support. The presence of a disease and its complications affect the family group, conditioning different levels of anxiety and psychodynamic disequilibrium.

A study involving relatives of schizophrenics examined the burden the presence of a mental patient represents for family members. In literature, the importance of the caregiver's role is observed, in mental illnesses as well as in other chronic diseases. These studies demonstrate concern with the different types of overload the family group is exposed to and the consequences for these people's health⁽²⁻³⁾.

On the other hand, the last three decades have witnessed a movement that has motivated profound changes in psychiatric care. Teamwork (multiprofessional and interdisciplinary), knowledge plurality and the complexity of actions and care services start to dominate the academic and professional area as fundamental requisites for the psychiatric care reform process⁽⁴⁻⁷⁾.

Thus, concepts like *dehospitalization* and *deinstitutionalization* guide the change process in the dominant focus of psychiatric actions from the specialized intrahospital area to outside the hospital, where outpatient services and day care centers gradually start to assume mental health care.

It is increasingly necessary to assess care quality from the users' perspective. This makes it possible to discover attitudes associated with the received care. This information benefits mental health service organization, workers and users.

This gives rise to the interest in getting to know not only patients' but also their companions' opinions, attempting to make nurses aware of the importance of care delivery to patients according to their needs, in order to improve service quality and take this population's family and social relationship network into account.

OBJECTIVES

- To characterize mental patients and their companions, identifying the disease motivating the search for care at three psychiatric services, their diagnoses and treatment.
- Getting to know their expectations about treatment, cure and care.
- Getting to know their opinion about mental illness and psychiatric care.

METHODOLOGY

We carried out a quantitative study with a descriptive approach.

Places

Data were collected at three mental health care services in Ribeirão Preto/SP, Brazil:

- Emergency Unit (EU), of the University of São Paulo at Ribeirão Preto Hospital das Clínicas (HCRP/USP) Covers 23 cities in the region and offers six beds for observation of acute or decompensation cases. Care is delivered 24 hours per day, with an average monthly flow of 180 cases. Care is agile, with patients being discharged or referred to other services in up to 72 hours⁽⁶⁾.
- Psychosocial Care Center (PCC), of the Ribeirão Preto Municipal Health Secretary. Municipally managed, this center covers 45 neighborhoods and is linked up with the health network, attending five Basic Health Units, with an average monthly flow of 430 cases. The PCC delivers care from Monday to Friday, between 7:30 and 17:30, including psychological, social, pharmacological, group activities, with nurses offering welcoming, occupational and recreational therapies.
- Regional Mental Health Outpatient Clinic (RMHOC), of the Ribeirão Preto Municipal Health Secretary. Covers 51% of the city population and some regional patients, and aims to diagnose, treat, deliver care and reinsert mental patients into society. The Clinic mostly attends chronic patients under therapeutic follow-up, with an average monthly flow of 2,065 cases, from Monday to Friday, between 7:00 and 18:00.

Population/sample

All patients with mental disorders and companions who attended the three sites during the

six-month data collection period were invited to participate.

This sample represents the group of non-hospitalized patients who needed psychiatric care at that moment. Subjects were included until reaching 250 patients and their respective 250 companions at each institution. This figure was reached after more or less two months of data collection at each service (N=750).

Alcohol and drugs users were excluded from this sample, as well as companions under 15 years of age.

Ethics

The project was approved by the Research Ethics Committee at HCRP/USP, and authorized by the responsibles for the local teams. All subjects received the necessary information and signed the Free and Informed Consent Term.

Data collection

Interviews with patients and their companions were held individually at the consultation rooms and took about 50 minutes, as many participants made comments and demonstrated the need for attention. Ten subjects refused to participate. At the EU, some contacts occurred after an episode had been controlled.

Instruments

- 1 Identification
- Mental Patient Characterization Questionnaire (MPCQ)
- Family Member/Companion Characterization Questionnaire (FCQ).

The two questionnaires were used to group data about: subject (patient and companion) identification; reason they attended the service; information about the disease, patient, diagnoses and treatments; expectations about cure and care.

2 - Opinion Measurement Scale - OMS

This scale was constructed on the basis of a large number of statements taken from scientific literature and the researchers' professional

experience. Its initial form contained 56 statements about health, mental illness and care and was applied to a population of 250 subjects (patients, relatives and professionals), as well as to other subjects (nursing students). Results were analyzed statistically⁽⁸⁻⁹⁾. A critical study of this instrument allowed us to reform it, with the help of correlation and significance tests, with a view to improving its efficiency. New studies, which critically analyzed the instrument's formulations, as well as a critical analysis that involved ten experts and a new correlation study of questions related to concepts, family, nursing and care allowed us to reconsider overlaps and reach the final form of the scale, with 34 questions⁽¹⁰⁾.

A pilot study was carried out at a psychiatric hospital in Pelotas/RS, involving 206 subjects (patients and relatives). This study made it possible to perform new statistical tests and compare both groups (patients and relatives) and areas of interest (concept and care). Results evidenced a well-balanced instrument, in view of its homogeneous score distribution and statements about concepts and care⁽¹¹⁾.

This instrument (Opinion Measurement Scale - OMS on Concepts and Psychiatric Care).

Data analysis

Next, we present the characterization of the two study groups at the three services, identification of their disease, diagnoses and treatments, as well as their expectations, so as to allow for analysis. The results of subjects' opinions about health and mental illness concepts and care were subject to statistical and qualitative analysis, based on literature references.

RESULTS AND ANALYSIS

The sample of 750 participants included 250 subjects (125 patients and their 125 companions) at each of the three psychiatric care services in Ribeirão Preto: (Emergency Unit - EU, Psychosocial Care Center - PCC and Regional Mental Health Outpatient Clinic - RMHOC).

Subject profile

According to data presented in detail in a comparative study of health and mental illness

concepts at three psychiatric services, the percentage of female mental patients was higher. Likewise, about 60% of companions were female caregivers⁽¹²⁾.

Almost $^2/_3$ of patients were single or divorced and less than 10% widowed, while a little more than $^1/_3$ lived in some kind of union. Among companions, almost $^2/_3$ had some kind of union, less than $^1/_3$ was single or divorced and about 10% widowed.

These data are in line with the concentration (around 90%) of companions' degree of kinship in wives and mothers. At the PCC, 11% of companions were over 70 years of age, mainly women. At the Clinic, 21% was older than 60.

Patients' age ranged from 15 to 90 years. A younger population attended the EU, with 13.6% under 19 and another 40% up to 29 years old. At the PCC, 43.2% of patients were between 40 and 59 years old and, at the Clinic, 55% between 30 and 59 years old.

The association between the onset of severe diseases like schizophrenia, mood and personality disorders and adolescence and young adult age is quite well-known, accompanied by worse evolution and low expectations. Moreover, the early phase of these diseases is associated with study, work, constitution of new family groups and other social commitments^(1,3-4).

Psychoses and schizophrenias are public health problems, as they start before the age of 25, breaking up the life projects of many young people and their families⁽¹³⁾. Hence, early identification and adequate treatment are very important, as well as increased information delivery to patients, relatives, health professionals and the general population about disorders, treatments and ways of welcoming patients.

Difficulties to distinguish between some behaviors and the prodromic symptoms of a psychotic episode are associated with the phase of great transformations in young people's lives and the new roles they assume in society. Generally treacherous manifestations of the disease at an early age are responsible for high levels of single persons, who interrupt their education and/or work.

We found low education levels among patients, 10% of whom were illiterate and between 65 and 73% had only finished basic education at the three services. These subjects' occupation was also concentrated in simple activities, such as housework and general maintenance (about 50% at the EU and PPC and 76% at the Clinic), while 30% of patients at

the EU and PPC had never worked or were retired. About two to four percent of patients possessed a higher education degree.

The situation was not very different among companions, with a concentration in simple activities (57-61%), between two and six % of self-employed professionals, between six and 18% retired and around 15% of students, unemployed or merchants.

In sum, this sample of the population that attends public psychiatric care services is characterized by low education level, unemployment or active in professionals with low qualification levels, and difficulties to assume social commitments. Moreover, especially at the EU, we found many young patients who were experiencing their first acute disease episode, which explains the data analyzed above.

The disease, diagnoses and treatments.

In the category *complaint*/reason to attend the service, we found a significant percentage (64.8%) of imprecise information at the EU, i.e. 24% could not inform why they were there, 19.2% alleged they were having a crisis, 17.6% that they were nervous and 4% for an appointment. Patients at the PCC (68.8%) and Clinic (70.4%) alleged they visited the service for a doctor's appointment and return; between four and five percent of them could not tell why they were there. They made little mention of their disease or symptoms. At the EU, 12% indicated a suicide attempt, 9.6% depression, 5.6% panic/anxiety and 4.8% hallucinations and lack of control, which is expected as the EU is an emergency care service.

As to the companions, the reason why they visit the service is not very different, but the following should be highlighted: at the EU, only 6% acknowledge the suicide attempts, against 12% according to patients; 5% alleged somatic problems; at the PCC, 39% came to pick up drugs from the pharmacy; at the Clinic, 18% simply came to accompany a patient and few companions knew about the patient's disease.

These results reveal denial of the disease, among patients as well as, mainly, among their relatives and companions. More than $^2/_3$ of people attending the PCC alleged that they did not know and that they visited the service for a mere appointment, while 39% of companions had come to pick up medication.

It is noticeable that the PCC should resist to chronification, moving beyond symptom control, stimulating users' participation in autonomous community spaces and valuing relatives' involvement.

In theory, this service's goal is in line with the idealizers of deinstitutionalization, psychosocial rehabilitation and the patients' reinsertion into their community, including active family participation and improving their quality of life^(4-5,14-15).

However, data informed by patients and companions attract attention to the need to assess whether this service is actually achieving its intended goals.

In the *diagnosis* category (informed by patients, informed by companions and recorded in the medical file), results point towards disinformation and information misalignment (Table 1). At the EU,

38% of patients neither knew their diagnosis nor the name of their disease; the same happened at the PCC (22% did not know and 15% used craziness, crazy, disoriented as designations); at the Clinic, 32% did not know and 19% had other designations. We found similar percentages of companions who did not know the diagnosis.

Among patients who knew the diagnosis at the EU, higher coincidence about depression and bipolar disorder stood out, as well as a larger number of medical references to psychotic episodes and schizophrenia. At the PCC, we found closer proximity between patients' and relatives' information. At the three services, disagreement levels were higher for schizophrenia, with higher records than cases informed by subjects. We also found 7.2% and 19.2% of dementia cases in medical file records.

Table 1 - Percentage distribution of diagnoses informed by mentally ill patients and recorded in the patient file, at the three services under study (Emergency Unit, Psychosocial Care Center and Clinic)

	Diagnosis																																
Institution	Does not know		Depression		Bipolar Disorder			Schizophrenia			Anxiety Disorder			Somatic Disorder		Personality Disorder		Psychotic Episode		Dementia		ıtia	Others		Total								
	Р	Α	M	P	Α	M	Р	Α	M	Р	Α	M	Р	Α	M	Р	Α	M	Р	Α	M	Р	Α	M	P	Α	M	Р	Α	M	Р	Α	M
Emergency Unit	37.6	33	-	26.4	26	24	5.6	8	9.6	8	11	19.2	3.2	1	-	6.4	10	3.2	1.6	1	16	2.4	8	20	0.8	2	4	7.2	-	-	100	100	100
Psychosocial Care Center	22.4	32	-	23.2	22	25.6	6.4	8	11.2	10.4	16	25.6	10.4	6	12	5.6	5	3.2	1.6	3	11.2	1.6	2	0.8	3.2	6	9.6	15.2	-	0.8	100	100	100
Mental Health Clinic	25.6	40	-	34.4	30	28.8	3.2	5	7.2	11.2	21	40	3.2	2	3.2	1.6	-	1.6	-	-	8.8	8.0	-	3.2	0.8	2	6.4	19.2	-	0.8	100	100	100

^{*} P - Diagnosis informed by patient, C - Diagnosis informed by companion, M - Medical diagnosis as informed in patient file

Medical diagnoses registered in patient files were more concentrated in schizophrenias, depression and personality disorders. We found more balanced and consensual diagnoses for depression cases at the three services and according to the three information sources.

Disease time: according to patients, a large number of people got ill over the last four years (66% at EU, 47% at PCC and 54% at the Clinic). Relatives reported lower levels at the three services. This imprecise information can be due to distance from the fact as well as to denial of the disease and suffering. Moreover, the duration of the period between the appearance of symptoms and their "acknowledgement" as part of the disease is variable.

We also observed that 19.2% of patients at the Clinic had been living with their mental disease for more than 20 years, and 24% between 10 and 20 years.

Some studies focus on the stigmatization of psychiatric patients and the importance of knowledge

about the disease and its treatments⁽¹⁵⁾. The authors affirm that knowledge is related with positive attitudes towards the patient.

As for *treatments*, a large majority (more than 80% at the three services) was treated with psychoactive drugs, less than half of which was associated with psychotherapeutic treatments. The highest levels were found at the Clinic, with 72% receiving only medication and 22% medication in combination with psychotherapeutic treatment. At the PCC, where the two treatment modes were offered, 33% mentioned receiving only medication treatment and 61% both modalities.

Another therapeutic conduct examined in this study was the number of hospitalizations among patients interviewed at the three services. Table 2 shows that patients and companions provide similar information; many patients had never been hospitalized (39% at EU; 54% at PCC; 40% at the Clinic); hospitalization times for those who had already been hospitalized ranged from 1 to 5 times.

Table 2 - Percentage distribution of mental patient hospitalization times as informed by subjects at the three services under analysis (Emergency Unit, Psychosocial Care Center and Regional Mental Health Outpatient Clinic)

Llacuitalizations	()	1 t	o 5	5 to	10	11 t	o 20	+ tha	n 20	Total	
Hospitalizations	Р	С	Р	С	Р	С	Р	С	Р	С	Р	С
Emergency Unit	39	36	48	49	5	7	6	6	2	2	100	100
Psychosocial Care Center	54	51	39	39	3	6	2	2	2	2	100	100
Outpatient Clinic	40	40	46	43	6	8	4	4	4	5	100	100

P = Patients, C = Companions

Other reported care included Emergency Care, Basic Health Unit and Outpatient Clinic. The frequency of these resources was high in care without hospitalization.

The psychosocial model is the paradigm of practices that replace the asylum model. In this paradigm, the patient should be the main participant in the entire therapeutic process, as well as member of a family and a social group⁽⁷⁾.

In an increasingly specialized way, mental health professionals are inserted in advances that not only foresee (adequate and necessary) medication treatment, but the individual project that includes other psychosocial therapies, activities to value individual capacities, self-care activities, holding patients accountable for their active participation in this process, relatives' joint experience and participation and valuation of patients' relationship network with their environment.

Expectations about treatment and cure

Nowadays and thanks to scientific advances, some treatments can alleviate many symptoms of mental illness. However, none of these provide a permanent cure.

In this study, we found different opinions about improvement and cure among subjects at the three services:

- At the EU, 38% of patients' expected their disease to improve, against 61% of companions. Moreover, 39% of patients and 18% of companions expected cure.
- At the PCC, relatives displayed low expectations about improvement (4%), but better expectations about receiving help (24%); as for patients, 50% expected improvement, 33% cure and 21% some help.

- At the Clinic, 68% of patients and 63% of companions revealed good expectation levels for improvement and cure, with 22% and 16% respectively.

Opinions about mental illness and psychiatric care among users at the three services and their companions

Let us start from the premise that mental patients are people whose subjectivity is in conflict, going through intense suffering, and who are part of a social group inserted in a social relationship network that both rejects and welcomes them.

The 34 statements examined through the Opinion Measurement Scale - OMS attempted to cover the main mental health issues, both in conceptual terms and considering subjects' perception of this care.

The recorded data were verified in STATA, calculating patients' and companions' mean opinion scores at the three services. We found differences between the two domains (Concept and Care) at the three services, with 2.36 as the mean score for PCC patients and 2.20 for their companions.

In order to assess the significance of the differences, the following statistical tests were performed: Kruskall Wallis verified whether subjects' opinion about the concepts significantly differed among the three sites; Wilcoxon checked for significant differences among subjects at the three services, with higher agreement levels in the Concept domain at the EU (P=0.55) than at the other services.

When looking at subjects' opinions at the three services, we found that, for some concepts, patients and companions attending the EU displayed different opinions, which was not the case among subjects from the two other services. To give an example, participants from the EU agreed that mental patients are aggressive. Subjects from the other two services did not share this concept.

Participants agreed that living with mental patients provokes tension and conflicts, generating diseases and disequilibria within the family.

Patients and companions also agreed that hospitalization has been indicated and facilitated in cases of aggression and lack of control, and that good care at outpatient clinics, health units and emergency services decreased the need for hospitalization.

Nurses' relations with mental patients and their relatives were valued in this study.

The madness/mental illness binomial has been strongly questioned over the last 30 years. What are the criteria to classify someone as ill? What is the psychiatric institution's function in this process? This kind of reflections became central, that is, the obvious became a source of doubts and concerns.

FINAL REFLECTIONS

This descriptive study was based on two questionnaires and a scale, which gathered information about patients at three psychiatric care services and their opinions on health, mental illness and care in this area. Some points deserve to be highlighted.

In terms of general characteristics, results from each of the three services (Emergency Unit, PCC and Mental Health Clinic) composed a sample of 750 subjects, evidencing higher concentrations of female patients and caregivers. Many mental disorder patients were single or involved in unstable relations, with low education levels and high unemployment rates. Specifically at the EU, subjects were younger, experiencing their first episodes and with little hospitalization experience. At the Clinic and the PCC, we found a more chronic population, but with similar characteristics for education, civil status and occupation.

At the three services, both patients and relatives had little information about their diagnoses and treatments. Medication treatment and low hospitalization levels were predominant. A large number of patients got ill during the last five years.

Expectations of cure were more present among patients at the EU than at the other two services, where subjects simply conformed to a possible improvement. Patients experiencing their first episode do not always have a very clear view on their diagnosis and its consequences. Both patients and relatives at the Clinic and the PCC have better knowledge about the disease, symptoms and treatments, as they have lived with the disease for many years. When they are aware of the prognosis, any possibility to relieve their suffering makes them happy.

We found diverging opinions among subjects at the three services, especially on some issues like aggressiveness, which is more present among participants from the EU.

Knowledge about the social and cultural dimension of the disease, in terms of cure, improvement, treatments and community resources can be of great help for patients with mental disorders and their relatives to live with the disease, burdens deriving from this process, health system resources and environments, thus granting a better quality of life to all people involved.

It is interesting that culture, beliefs and values can interfere in the perception and interpretation of disease symptoms, as well as in behaviors to seek help and participate actively in this experience.

Within the system, people using mental health services were traditionally seen as passive receivers, who were incapable of expressing their own ideas and desires, and were subject to care and treatment forms which other people had to formulate and decide on. However, in recent years, due to the whole reform movement and the development of state-of-the-art medication, conditions have increased for patients as well as relatives and health professionals themselves to start living with this situation in a more humanized way.

In this study, the ill expressed their personal view about their needs as patients and about the care they received, evidencing their active participation and accountability in this process.

Themes that deserve special attention on the basis of this study include: right to self-determination; need for information about the disease, medication and other forms of treatment; patients' active participation in their treatment and other activities in their community; need for alternative services; end of commitments in large institutions; importance of effective and adequate treatments.

These results are important for service organization as well as for professionals working there, in view of everybody's commitment to offer quality care, which influences conducts and practices. This is especially important for nursing, as these professionals are responsible 24 hours per day for direct care in closed services (Emergency Unit and hospitalization units), as well as for care delivery during opening hours in open services (Clinic, Psychosocial Care Nucleus and Psychosocial Care Center).

These data give rise to opportunities for reflection, discussion, production and reproduction of knowledge and practices, as well as to the need to humanize interpersonal relations between nurses and people attending each of these psychiatric care services.

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