

Psychosocial care center users and their experience of living with a mental illness*

USUÁRIOS DE UM CENTRO DE ATENÇÃO PSICOSSOCIAL E SUA VIVÊNCIA COM A DOENÇA MENTAL

USUARIOS DE UN CENTRO DE ATENCIÓN PSICOSOCIAL Y SU VIVENCIA CON LA ENFERMEDAD MENTAL

Ana Paula Nagaoka¹, Antonia Regina Ferreira Furegato², Jair Licio Ferreira Santos³

ABSTRACT

With a view to the changes in psychiatric care, the objective of this study was to learn about the opinion of patients, users of a Psychosocial Care Center, about their treatment, their experience of living with a mental illness and its psychosocial implications. The results were then matched with their social-demographic and clinic profile. A descriptive exploratory study was performed, where 65 patients with mental illnesses being treated in a center in Pindamonhangaba-SP and 53 of their relatives answered a semi-structured questionnaire. The results showed that patients with mental illnesses and family problems recognize that the disease has changed their lives, but their opinion differ about the degree of difficulties they have in doing their everyday activities. Although they have been treated for years through this extra-hospital individualized system, they know little about their disease. It was observed that 62% of them have severe diseases, but both groups showed a special ability of dealing their adversities. This study contributes with important information for mental health nursing practitioners.

DESCRIPTORS

Mental disorders
Mental Health Services
Psychiatric nursing
Family

RESUMO

Tendo em vista as mudanças na atenção psiquiátrica, este estudo teve por objetivo conhecer a opinião da população atendida em um CAPS sobre o tratamento, a convivência com a doença mental e suas implicações psicossociais, relacionando estes indicadores com seu perfil sociodemográfico e clínico. Realizou-se um estudo exploratório descritivo, onde 65 portadores de transtornos mentais em tratamento no CAPS de Pindamonhangaba-SP e 53 familiares responderam a um questionário semi-estruturado. Os resultados mostraram que portadores de transtornos mentais e familiares reconhecem o quanto a doença mudou suas vidas, mas as opiniões divergem quanto ao grau de dificuldade na realização das atividades diárias. Apesar dos anos de tratamento desta atenção individualizada extra hospitalar, os usuários conhecem pouco sobre sua doença. Observou-se que 62% têm doenças severas, porém, ambos os grupos manifestam uma capacidade especial para enfrentar as adversidades. O estudo contribui com informações importantes para a prática da enfermagem em saúde mental.

DESCRITORES

Transtornos mentais
Serviços de Saúde Mental
Enfermagem psiquiátrica
Família

RESUMEN

Tomando nota de los cambios en la atención psiquiátrica, este estudio objetivó conocer la opinión de la población atendida en un CAPs respecto a tratamiento, convivencia con la enfermedad mental y sus implicaciones psicossociales, relacionando estos indicadores con su perfil sociodemográfico y clínico. Se realizó un estudio exploratorio descriptivo, donde 65 enfermos mentales en tratamiento en el CAPs de Pindamonhangaba-SP y 53 familiares respondieron a un cuestionario semiestructurado. Los resultados mostraron que portadores de transtorno mental y familiares reconocen cuánto cambió sus vidas la enfermedad mental, las opiniones divergen en cuanto al grado de dificultad de realización de las actividades diarias. A pesar del tiempo de tratamiento de atención individual extrahospitalaria, los usuarios conocen poco sobre su enfermedad. Se observó que 62% tiene enfermedades severas, sin embargo ambos grupos manifiestan especial capacidad para enfrentar la adversidad. El estudio contribuye con informaciones importantes para la práctica de enfermería en salud mental.

DESCRIPTORES

Trastornos mentales
Servicios de Salud Mental
Enfermería psiquiátrica
Familia

¹ M.Sc. in Psychiatric Nursing, University of São Paulo at Ribeirão Preto College of Nursing. Ribeirão Preto, SP, Brazil. anapaulangk@yahoo.com.br ² Full Professor, Psychiatric Nursing and Human Sciences Department, University of São Paulo at Ribeirão Preto College of Nursing. Ribeirão Preto, SP, Brazil. furegato@eerp.usp.br ³ Full Professor, Department of Social Medicine, University of São Paulo Medical School. Ribeirão Preto, SP, Brazil. jalifesa@usp.br

INTRODUCTION

Psychiatric disorders entail a range of prejudices and discredits that end up affecting everyone. Therefore, for a long time, mental disorder patients were locked up in asylums, where their identity, family contact, social and civil rights were lost, together with the right to express their needs and desires. They were exposed to care and treatment forms that other people were in charge of formulating and deciding on.

The Brazilian Psychiatric Reform Movement, resulting from criticism against psychiatric care systems in England, France, the United States and Italy in the last 60 years, questioned knowledge, psychiatric institutions and asylums, affecting current health systems all over the world. The term deinstitutionalization is emphasized, not only as dehospitalization, but also as deconstruction, i.e. overcoming the asylum model. The new perspective considers subjects in their existence and in relation with their concrete living conditions, constructing possibilities⁽¹⁻³⁾.

The changes produced in the Brazilian Mental Health care model in Brazil and in many countries around the world increasingly value community-based treatments, seeking, besides symptom remission, social reinsertion and improved living conditions for victims. This has resulted in services like Psychosocial Care Centers (CAPS), semi-hospitalizations, outpatient clinics, therapeutic residences, community centers integrated into the healthcare network⁽⁴⁻⁶⁾.

Mental disorder patients turn into the subjects of their existence, active with regard to their treatment and assume co-responsibility for maintaining and managing care spaces. The family becomes an important resources in the rehabilitation of mental disorder patients. In view of these changes, partnerships should be established between the patient, family, community resources and the entire health service network⁽⁷⁾.

Studies have been accomplished to get to know these new services' efficacy, considering both professionals' clinical perspective and user satisfaction⁽⁸⁻¹²⁾.

Care delivery to individuals and their families is inherent in the nursing profession, so as guarantee good physical and mental conditions, with a view to valuing mechanisms to cope with adversities, pain and suffering. Therefore, nursing should be privy to new concepts, be open to new inquiries, discoveries and action proposals⁽¹³⁻¹⁴⁾.

With a view to furthering knowledge for nursing care to achieve mental disorder patients' actual adherence to their therapeutic project, this study aims to identify the socio-demographic and clinical profile of users at a CAPS

and their opinion on the disease, treatments and psychosocial implications, correlating these indicators.

METHOD

An exploratory and descriptive research was carried out at the CAPS in Pindamonhangaba-SP, which welcomes individuals with mental disorders and stimulates their social and family integrations through individual psychiatric care, expression workshops, handicraft, painting, videos, literacy, psychodrama, dancing, resocialization, hygiene and celebration of special dates. All of these serve as spaces for creation, expression and communication, contributing to the construction and/or recovery of their history and identity.

This CAPS offers 3 treatment modes: Intensive (daily and full time); Semi-intensive (3 times per week); Non-intensive (up to 3 times per month, including a psychiatric consultation), in compliance with Ministry of Health orientations⁽⁶⁾.

The team includes two psychiatrists, three nursing technicians, one cleaning aid, one occupational therapist, one social worker and three psychologists.

Mental disorder patients turn into the subjects of their existence, active with regard to their treatment and assume co-responsibility for maintaining and managing care spaces.

The sample included mental disorder patients treated at the CAPS for more than one month, under intensive and semi-intensive treatment, older than 18 years, able to answer the questionnaire. Subjects under non-intensive treatment were excluded due to their distancing from service routine, as their disease was better controlled and did not demand daily care.

Relatives were considered who, at the time of data collection, attended the service together with the patient, during the medical appointment or for a group activity.

Two questionnaires were constructed and tested (one for the patient and another for the relative), containing paired structured questions, according to the study variables (identification of all subjects, socio-demographic and clinical data of mental patient, as well as both groups' views on the disease, treatment and their psychosocial implications).

In compliance with ethical and legal research premises, approval for this project was obtained from an Institutional Review Board (Process No 0942/2008).

The researcher applied the questionnaires at the CAPS according to the functioning hours and workshops, without hampering the service routine.

Data were processed and results were submitted to statistical analysis, comparing the patients and their relatives' positions towards care, regarding clinical, demographic and psychosocial implications. Fisher's and Chi-square tests were applied to compare both subject

groups. The discussion was based on literature about de-institutionalization and psychiatric care.

RESULTS AND DISCUSSION

Identification

At the time of data collection, 137 patients with mental disorders were registered at the CAPS, 31 under intensive care, 50 under semi-intensive and 56 under non-intensive care. Hence, the 56 non-intensive patients were excluded from the sample. Out of 81 eligible patients, 3 had been treated for less than one month and 6 were suffering an episode, making them unable to answering the questionnaire. In addition, 7 patients could not be contacted.

Among the 81 relatives, 3 refused to answer the questionnaire, 13 refused to participate or did not attend the service on the scheduled date and 12 could not be contacted.

Thus, 65 mental disorder patients and 53 relatives participated in the study, in compliance with pre-established criteria. One neighbor's answers were processed as he was considered a relative and the subject acknowledged him as such. This kind of subject is accepted when the person interacts, experiences daily situations, has perspectives and develops skills to assume the caregiver role.

Patients (50% men) were between 19 and 61 years old. The majority (80%) was between 31 and 60 years old. Among the relatives, most were women (77%). Ages ranged from 21 to 79 years, with a majority (75%) over 46 years of age.

Two groups stood out regarding the type of illness registered in the file, schizophrenia (37%) and bipolar disorder (25%) patients, totaling 62% of the sample. It should be highlighted that 32% of the mental disorder patients said they did not know their own diagnosis.

When comparing the patients and relatives' answers regarding their knowledge level on the disease, the results of Fisher's test were positive (0.013). Among family members, 43% said they knew a lot or everything about the disease. Among patients, on the other hand, 49% said they knew little or nothing about their own disease, independently of their education level.

The mental disorder entails relationship and memorization difficulties, mood swings, signs and symptoms that hamper getting or keeping a fixed job. They also carry prejudice and discredit, besides medication side effects, such as sleepiness, shivering, intestinal discomfort, excessive salivation and others.

In view of these limitations, job losses, deriving from the diagnosis treatment and the number of hospitalizations, it is observed that 46% of the subjects receive some kind of benefit, considering disability retirement or disease aid. In the schizophrenic population, that rate increases to

54%. This group shows the highest hospitalization frequencies (25% were hospitalized more than 10 times). Age also influences the receipt of benefits, that is, 60% of patients receiving benefits are over 46 years of age (χ^2 test=0.017).

Table 1 - Characterization of mental disorder patients – Pindamonhangaba, SP - 2008

Characteristics	N	%
Diagnosis		
Schizophrenia	24	37.0
Bipolar Disorder	16	24.6
Borderline	2	3.1
Depression	1	1.5
Delusional disorder	1	1.5
Does not know	21	32.3
Start age of the disease		
18 to 30 years	6	9.2
31 to 45 years	32	49.2
46 to 60 years	14	21.6
61 and older	7	10.8
Could not inform	6	9.2
Treatment time at CAPS		
Less than 1 year	11	16.9
1 to 2 years	8	12.3
2 to 3 years	17	26.2
3 and more	29	44.6
Therapeutic mode		
Intensive	23	35.4
Semi-intensive	42	64.6
Number of hospitalizations		
None	21	32.3
One	11	17.0
Two	6	9.2
Three	6	9.2
Four	8	12.3
Five	1	1.5
Eight	1	1.5
More than ten	11	17.0
Benefit (Retirement/disease aid)		
Yes	30	46.1
No	35	53.9
Total	65	100

Only 6% of patients work, a fact appointed as a heavy burden of frustration for them and the family.

Disease and treatment

The CAPS offers individual therapeutic projects, aiming to attend to each patient's particular needs. Nevertheless, despite years of treatment (70.8% have been under treatment for more than two years) and individualized care, almost half of the patients (49%) answered knowledge little or nothing about their disease.

Psychiatric nursing care should involve not only the patient as a person, but everything around him/her. Professionals should help the family to find meaning in this

experience, that is, should help them gain knowledge on their disease and treatments and to find ways to cope with them⁽¹³⁻¹⁴⁾.

Both relatives and patients agree that, when patients agree that, the more the treatment helps the patient, the more it helps the family (χ^2 test = 0.000). Likewise, the more supported the family feels, the more the patient feels satisfied with the received care (χ^2 test = 0.000).

Psychosocial care is part of a new care model, which is hence under construction, and supports patients and relatives to recover their self-esteem and autonomy, reinforcing their condition as citizens⁽¹²⁾.

Table 2 - Mental disorder patients attended at CAPS II – Pinda-monhangaba, SP - 2008

Characteristics	Patients		Family	
	N	%	N	%
Treatment helps the patient				
Nothing	1	1.5	0	0.0
Little	2	3.1	1	1.9
More or less	9	13.9	6	11.3
A lot	39	60.0	31	58.5
Completely	14	21.5	15	28.3
Treatment helps the family				
Nothing	4	6.1	0	0.0
Little	3	4.6	4	7.5
More or less	6	9.2	3	5.7
A lot	43	66.2	31	58.5
Completely	9	13.9	15	28.3
Total	65	100	53	100

Bonding facilitates the partnership among team, patients and families. With a view to care delivery closer to the needs of mental disorder patients and their relatives, activities like workshops, home visits, events and celebrations improve the relations and permit the exchange of experiences and help. The attitude expected from the team is more sensitive to listening, understanding and the construction of individual therapeutic interventions, respecting each stakeholder's specific reality⁽⁸⁾.

When the household routine includes a mental disorder patient, the family gains new responsibilities, such as accompanying him/her to the health service, administering his medication, coordinating his daily activities, giving social support, dealing with his problematic behavior and crises, which can represent a huge burden for the family⁽¹⁵⁻¹⁸⁾.

When comparing data on family burden in relation to patient treatment needs, the χ^2 test also showed a positive result (0.013). In other words, the more the relatives feel overloaded, the more they believe that the patient needs treatment.

Both family members and patients agree that, the more treatment helps the patient, the more it helps the

family (χ^2 test = 0.000). Likewise, the more supported the family feels, the more satisfied the patient gets with the care received (χ^2 test = 0.000).

Only one third of the relatives work and, although most of them work as autonomous professionals, only 55% participate in some activity at the CAPS, especially in family meetings (with and without the patient's presence) and medical appointments. Despite acknowledging the benefits of treatment, the family still faces difficulties to interact with the service.

This is also the case due to the fact that, besides the difficulties the disease creates and the resulting economic burdens, the family still needs time to attend the service. Besides transportation difficulties, it should be taken into account that most of them (75%) are older than 46 years.

The large majority of subjects, both patients (86%) and relatives (91%), feel totally or very satisfied with the care they receive from CAPS professionals, which can entail improvements for their quality of life.

The χ^2 test (0.032) also showed that a treatment that helps the family influences the patient's satisfaction with life. Although most patients agree that the disease changes their daily life quite a lot, they indicate that they are satisfied with life.

When the family and patient feel members, participants and inserted in the service, satisfaction increases, in compliance with the premises of the Psychiatric Reform^(4,11).

Mental health professionals need to be ready to support both relatives and patients, for them to find meanings in their experiences, accept the disease and be able to cope with it⁽¹³⁾. Help, support and contact with CAPS professionals were mentioned as decisive factors for positive assessments of health services in a study accomplished in the states of Paraná, Santa Catarina and Rio Grande do Sul⁽¹⁰⁾.

Professionals also face difficulties in their practice, as they are assimilating new practices, in direct contact with the new and the unknown, constructing work more articulated with professionals from other areas and in need of a new meaning for their own knowledge⁽¹¹⁾.

Psychosocial implications

Disease is an unforeseen event that can disorganize family functioning.

Alterations in mental disorder patients' behavior interfere in their daily activities, relationships and leisure. These transformations alternate with needs that arouse stress and burden, mainly for relatives (62% feel very or totally overloaded). The family suffers from the powerlessness and fear towards inadequate and unforeseeable behavior, is physically and emotionally exhausted and may even get ill⁽¹⁶⁻¹⁸⁾.

Despite these changes, 41% of patients said they make the most or a lot of life and 68% affirm facing little or no difficulty to perform their daily activities, which differs from 51% of relatives' opinions, who affirm that patients face difficulties to accomplish daily activities, which entail dependences, concerns, insecurities towards the future. They feel frustrated due to the belief that patients make nothing of life (66%).

When the disease appeared, 59% of relatives started to believe that religion influenced their lives more. Religious involvement is associated with psychological wellbeing and this type of support is more relevant in stressed persons⁽¹⁸⁾.

Out of patients who declared believing in some religion, 57% affirmed satisfaction with life, against 43% among those who do not attend any religion.

Brazil is a country of religious people and knowledge on the impact of religious beliefs on disease etiology, diagnosis and the evolution of psychiatric disorders can help health professionals to understand their patients better. Professionals need to take into account when religious beliefs are used to deal with the mental illness better and when they may be exacerbating that disease⁽¹⁹⁾.

Most family members (62%) indicate being very or totally overloaded. Knowing the burden relatives experience allows the team to design interventions that can help to improve relationships, contribute to assess the weight of tasks, facilitate cooperation, decrease stressors, or even the manifestation of somatic or psychological disorders in family members⁽¹⁵⁻¹⁸⁾. A study in the South of Brazil found that teams achieve solid results in mental health care, but should attempt to interact more with the family⁽¹⁷⁾.

It is important to grant family members the opportunity to be heard regarding their anguish about mental disorder patients and service functioning, thus seeking better coping forms⁽¹¹⁾.

REFERENCES

1. Amarante P, coordenador. Loucos pela vida: a trajetória da reforma psiquiátrica no Brasil. Rio de Janeiro: FIOCRUZ; 1995.
2. Lúchmann LHH, Rodrigues J. O movimento antimanicomial no Brasil. *Ciênc Saúde Coletiva*. 2007;12(2):399-407.
3. Amarante P, coordenador. Archivos de saúde mental e atenção psicossocial. Rio de Janeiro: Nau; 2005.
4. Brasil. Ministério da Saúde. Secretaria de Atenção à Saúde. Saúde Mental no SUS: acesso ao tratamento e mudança do modelo de atenção: Relatório de Gestão 2003-2006. Brasília; 2007.
5. Organización Mundial de la Salud (OMS). Manual de recursos sobre salud mental, derechos humanos y legislación de La OMS. Geneva; 2006.
6. Brasil. Ministério da Saúde. Secretaria de Atenção à Saúde. Legislação em Saúde Mental: 1990-2004. Brasília; 2004.
7. Amarante P. Novos sujeitos, novos direitos: o debate em torno da reforma psiquiátrica. *Cad Saúde Pública*. 1995;11(3):491-4.
8. Schrank G, Olschowsky A. O Centro de Atenção Psicossocial e as estratégias para inserção da família. *Rev Esc Enferm USP*. 2008;42(1):127-34.
9. Leão A, Barros S. As representações sociais dos profissionais de saúde mental acerca do modelo de atenção e as possibilidades de inclusão social. *Saúde Soc*. 2008;17(1):95-106.
10. Kantorski LP, Jardim VR, Wetzel C, Olschowsky A, Schneider JF, Heck RM, et al. Satisfação dos usuários dos Centros de Atenção Psicossocial da região Sul do Brasil. *Rev Saúde Pública*. 2009;43 Supl.1:29-35.

It was observed among mental disorder patients as well as relatives, a special capacity to overcome adversities (resilience) was observed. This attitude should not be mixed up with invulnerability, because this is not about absolute resistance to adversities, but a construction and reconstruction process of a person's life history through multiple interpretations of daily life⁽²⁰⁾.

CONCLUSION

Mental disorders are accompanied by signs and symptoms that hamper these patients' performance, entail bottlenecks and prejudices in society and even inside the family.

This study evidences that families feel overloaded, not only due to the fact of having to see to patients' daily difficulties, but also due to the insecurity and unpredictability of their behaviors and reactions, besides the idea that patients make little or nothing of life.

The results showed that mental disorder patients and family members acknowledge the extent to which the disease changed their lives, but opinions diverge on the degree of difficulty to accomplish activities of daily living. Despite the severity of the diagnoses and years under treatment, users know little about the disease.

It was observed that, despite all changes and difficulties both patients and relatives face, both groups were satisfied with life and optimistic towards the future.

This study contributes through knowledge and conceptions on care delivery and mental health care that are important for nursing practice, with a view to greater treatment efficacy and mental disorder patients' effective social insertion, with quality of life.

11. Schneider JF, Camatta MW, Nasi C, Kantorski LP, Wetzel C. Utilização da avaliação de quarta geração em um centro de atenção psicossocial. *Rev Gaúcha Enferm.* 2009;30(1):54-61.
12. Teixeira JS, Kantorski LP, Olschowsky A. O Centro de Atenção Psicossocial a partir da vivência do portador de transtorno psíquico. *Rev Gaucha Enferm.* 2009;30(3):453-60.
13. Travelbee J. *Intervención em enfermeria psiquiátrica.* Carvajal: OPAS/OMS; 1982.
14. Waidman MAP, Elsen I, Marcon SS. Possibilidades e limites da teoria de Joyce Travelbee para a construção de uma metodologia de cuidado à família. *Rev Eletr Enferm [Internet].* 2006 [citado 2008 nov. 25];8(2):282-91. Disponível em: http://www.fen.ufg.br/revista/revista8_2/pdf/v8n2a13.pdf
15. Barroso SM, Bandeira M, Nascimento E. Fatores predisponentes da sobrecarga subjetiva de familiares de pacientes psiquiátricos atendidos na rede pública de Belo Horizonte, Minas Gerais, Brasil. *Cad Saúde Pública.* 2009;25(9):1957-68.
16. Borba LO, Schwartz E, Kantorski LP. A sobrecarga da família que convive com a realidade do transtorno mental. *Acta Paul Enferm.* 2008;21(4):588-94.
17. Bandeira M, Barroso SM. Sobrecarga das famílias de pacientes psiquiátricos. *J Bras Psiqu.* 2005;54(1):34-46.
18. Koga M, Furegato ARF. Convivência com a pessoa esquizofrênica: sobrecarga familiar. *Ciênc Cuidado Saúde.* 2002;1(1):69-73.
19. Koenig HG. Religião, espiritualidade e psiquiatria: uma nova era na atenção à saúde mental. *Rev Psiqu Clín.* 2007;34(1):5-7.
20. Pinheiro DPN. A resiliência em discussão. *Psicol Estudo.* 2004;9(1):67-75.

Support

National Council for Scientific and Technological Development - CNPq