

# Mental health care today

O CUIDADO EM SAÚDE MENTAL NA ATUALIDADE

EL CUIDADO EN SALUD MENTAL EN LA ACTUALIDAD

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## ABSTRACT

The objective of this study was to identify the sociodemographic characteristics of caregivers to people who have been discharged from psychiatric hospitalization. A quantitative exploratory study was performed at an out-patient clinic of a mental health service. The sample consisted of patients who had been discharged and their caregivers. A questionnaire was used, and the study was approved by the local research ethics committee. Of the 48 discharged patients, 21 had a caregiver. All the identified caregivers were relatives of the patients, and their average age was 46.6 years. In 38% of cases, the patient's mother was the caregiver. In terms of marital status, 61.9% of the caregivers were married or living in common-law relationships, and only one caregiver did not have children. The main source of income for 28.6% of the participants was temporary keeping eventual jobs. By knowing who is the caregiver of a patient discharged from psychiatric hospitalization it is possible to identify the characteristics that may help to determine the best treatment and professional support for that population.

## DESCRIPTORS

Mental health  
Psychiatric nursing  
Deinstitutionalization  
Caregivers  
Family

## RESUMO

O objetivo desse trabalho foi identificar as características sócio-demográficas dos cuidadores de pessoas que tiveram alta hospitalar de internação psiquiátrica. Foi realizado um estudo quantitativo exploratório em um serviço ambulatorial de saúde mental. A amostra foi composta por pacientes egressos de internação e seus cuidadores. Foi utilizado um questionário e a pesquisa foi aprovada pelo CEP. De 48 pacientes egressos 21 possuíam um cuidador. Todos os cuidadores identificados eram familiares dos pacientes e a idade média foi de 46,6 anos. As mães eram as principais cuidadoras em 38% dos casos. Casados ou amasiados representaram 61,9% dos cuidadores e apenas um cuidador não tinha filhos. A principal fonte de renda foi trabalho eventual para 28,6%. Conhecer quem são os cuidadores dos pacientes egressos de internação psiquiátrica, hoje, possibilita identificar características que podem fomentar a determinação do melhor tratamento e suporte profissional ao cuidado dessa clientela.

## DESCRITORES

Saúde mental  
Enfermagem psiquiátrica  
Desinstitucionalização  
Cuidadores  
Família

## RESUMEN

Este trabajo objetivó identificar las características sociodemográficas de cuidadores de personas que tuvieron alta hospitalaria de internación psiquiátrica. Estudio cuantitativo exploratorio, realizado en servicio ambulatorio de salud mental. Muestra constituida por pacientes egresados de internación y sus cuidadores. Se utilizó cuestionario, la investigación fue aprobada por el CEP. De 48 pacientes egresados, 21 poseían cuidador. Todos los cuidadores identificados eran familiares de los pacientes, con edad media de 46,6 años. Las madres eran las principales cuidadoras, en 38% de los casos. Casados o cónyuges representaron 61,9 de cuidadores y sólo un cuidador no tenía hijos. La principal fuente de ingresos fue el trabajo eventual para 28,6%. Conocer quiénes son los cuidadores de los pacientes egresados de internación psiquiátrica, actualmente, posibilita identificar características que pueden colaborar en la elección del mejor tratamiento y apoyo profesional para el cuidado de tales pacientes.

## DESCRIPTORES

Salud mental  
Enfermería psiquiátrica  
Desinstitucionalización  
Cuidadores  
Familia

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## INTRODUCTION

Since ancient times, humanity has faced difficulties to deal with differences and disagreements between common sense and experience. In psychiatrics, the treatment of madness has sometimes been based on intolerance towards the behavior of mental patients, with people's confinement as an option to drive off the different and *protect* society<sup>(1)</sup>.

In recent decades, psychiatric hospitals ceased to be the base of the care system, giving ground to a network of increasingly complex extra-hospital services, with a view to the deconstruction of the model in force. Psychiatric hospitalization became more discerning, with shorter hospitalization periods, enhancing the consolidation of a more integrated, dynamic, open and community-based mental health care model.

In this context, patients, families and community service professionals increasingly turn into the main mental health care providers. This demands articulation among different health network services at different care levels<sup>(2)</sup>.

In Brazil, however, like in many other countries, this service network is still developing and lacks further implantation of extra-hospital infrastructure closer to its clients' daily reality<sup>(3)</sup>. Despite these advances, mental health care is still marked by a process of successive hospitalization, characterizing a new phenomenon known as revolving door. That is, the patient alternates between acute episodes with hospitalization and periods of stability when in the community<sup>(4)</sup>.

Mental health care demand is not limited to the minimization of hospitalization risk or to symptom control. Today, care also involves personal, social, emotional and financial issues related to contact with mental illness. This care is daily and entails a demand for attention that is not always readily attended to, due to countless difficulties patients and their relatives, as well as professionals and society in general experience, such as: lack of resources, inadequacy of professional care, stigmatization, violation of patient right, difficult access to professionalization programs, etc.<sup>(5)</sup>.

Besides, the notorious complexity of mental health care should be highlighted. In many cases, multiple drug therapy is needed, accompanied by long-term therapeutic and occupational support. In this sense, these patients' care process should be enhanced with a view to rehabilitation and psychosocial interaction.

Hence, the search for mental health care adequacy has aroused countless inquiries on the deinstitutionalization proposal, as this proposal still has not been properly consolidated in the proposed care model, generating great demands for the insufficient number of characteristically communitarian substitutive services, mistaken care approaches and even lack of care in some cases<sup>(6-7)</sup>.

In Brazil, some of the National Mental Health Policy's proposals, based on law 10.216/02, focus on qualification, expansion and strengthening of the extra-hospital humanized care service network, such as: Psychosocial Care Centers (CAPS), Therapeutic Residential Services (SRTs) and Psychiatric Units in General Hospitals (UPHG): inclusion of mental health actions in primary health care and social reinsertion of long-term confined patients into the family and community, besides Psychosocial Rehabilitation<sup>(8)</sup>.

This Rehabilitation involves the use of multiple techniques aimed at enhancing this population's skills, improving mental patients' interaction with their social network, guaranteeing their rights as citizens, as well as their adaptation to the duties this condition demands, with a view to better mental health care management<sup>(9)</sup>.

In other words, care has been targeted through the training of all subjects involved in this process (patients, relatives, professionals and society), with a view to a better understanding of the mental illness, breaking the barriers for dignified care for these sick people, qualification of mental health care, restoring, according to available resources, their potential for *autonomous* life in society. This highlights the caregiver's fundamental role:

...mental health care derives from an intrinsic relation among health services, their professionals, patients and families, taking into account the particularities of each cultural, social and economic context....

... a person, whether a family member or not, who, with or without pay, takes care of the patient or dependent in practicing his/her daily activities, such as food, grooming, routine medication, accompaniment to health services and other services needed in daily life – such as going to banks or pharmacies, excluding techniques or procedures identified with legally established professions, particularly in nursing<sup>(10)</sup>.

Thus, mental health care derives from an intrinsic relation among health services, their professionals, patients and families, taking into account the particularities of each cultural, social and economic context.

As, in many cases, this caregiver is part of these patients' family core, it is extremely important to get better knowledge on whom these family caregivers are who are partners in mental health care. Despite the positive aspect of promoting family and social bonds, this responsibility is often marked by caregivers' overload, due to the lack of orientation and support needed to perform the role they assume in daily life<sup>(2)</sup>. Therefore, we believe that knowing these clients' personal and daily characteristics can provide important information for more humanized, shared and collective assistance planning in mental health care.

In this research, we investigate general characteristics of the people who help in care delivery to mental patients after psychiatric hospitalization in an extra-hospital mental health service. As nurses, we believe that this is an important resource to quality assistance and support to mental health care.

## OBJECTIVE

The goal of this research was to identify the socio-demographic characteristics of caregivers to mental patients discharged from psychiatric hospitalization.

## METHOD

An exploratory, descriptive and prospective research was carried out between December 2007 and April 2008. Approval for this study was obtained from the Institutional Review Board of the Teaching Health Center *Joel Domingos Machado*, affiliated with the University of São Paulo at Ribeirão Preto Medical School – USP – (protocol 254/CEP-CSE-FMRP-USP).

The *Place* of study was a Mental Health Center (NSM), an outpatient care unit in Ribeirão Preto.

The study *population* represents the universe of all patients and their caregivers, registered at the mental health service under analysis.

The *sample* comprised the caregivers of all patients after *recent* psychiatric hospitalization at a public mental health care service, as these patients acknowledged them. The definition of caregiver adopted in this study was based on the National Health Policy and mentioned above<sup>(10)</sup>.

In this service's routine, all clients who have gone through psychiatric hospitalization are seen in a medical appointment to re-establish extra-hospital care monitoring. Caregivers were contacted during the post-nursing consultation to invite them to participate in the research and fill out the informed consent term.

For *data collection*, we used a questionnaire with the following variables: *Diagnosis of discharged patient, having a caregiver, caregiver's bond with patient; caregiver's gender; caregiver's age; caregiver's education level; caregiver's marital status; caregiver's number of children; caregiver's work; caregiver's opinion on the importance of medication treatment.*

Central trend measures in SPSS software, version 10.0, were used for *data analysis*.

## RESULTS

During the study period, 54 mental patients were discharged from psychiatric hospitalization. This represented an average 13 hospitalization per month, excluding cases in which the same patient needed a new hospitalization during the same period. Six patients were excluded due to absence from the consultation or transfer to another service.

Among the 48 patients under analysis, only 21 affirmed having and presented a person who helps them to maintain their treatment, although most of them (93.8%) lived

with relatives. The 21 caregivers of the 48 patients discharged from psychiatric hospitalization who accepted to participate in the research were interviewed.

The caregivers' socio-demographic characteristics are presented in Table 1.

**Table 1** - Socio-demographic and economic characteristics of patient caregivers after recent hospitalization - Ribeirão Preto - 2008

| Variable                 | Characteristics                | N(%)     |
|--------------------------|--------------------------------|----------|
| Age (full years)         | Average age 46.6 years         |          |
|                          | Median: 52 years               | 11(52.4) |
|                          | Variation: 22-62               |          |
| Gender                   | Female                         | 16(76.2) |
|                          | Male                           | 5(23.8)  |
| Marital status           | Single                         | 1(4.8)   |
|                          | Married/Fixed partner          | 13(61.9) |
|                          | Divorced/Separated             | 3(14.3)  |
|                          | Widowed                        | 4(19.0)  |
| Children                 | None                           | 1(4.8)   |
|                          | One                            | 7(33.3)  |
|                          | Two                            | 7(33.3)  |
|                          | Three or more                  | 6(28.6)  |
| Family bond with patient | Mother                         | 8(38.0)  |
|                          | Sibling                        | 6(28.6)  |
|                          | Husband/wife                   | 5(23.8)  |
|                          | Son/daughter                   | 1(4.8)   |
|                          | Nephew/niece                   | 1(4.8)   |
| Occupation               | Unemployed                     | 3(14.4)  |
|                          | Temporary jobs                 | 6(28.6)  |
|                          | Informal regular job           | 4(19.0)  |
|                          | Formal regular job             | 4(19.0)  |
|                          | Retired                        | 4(19.0)  |
| Education                | Unfinished primary education   | 4(19.0)  |
|                          | Finished primary education     | 11(52.4) |
|                          | Unfinished secondary education | 4(19.0)  |
|                          | Finished secondary education   | 1(4.8)   |
|                          | Finished higher education      | 1(4.8)   |

Figures between parentheses correspond to the percentages of caregivers (N=21, with N = total number of caregivers of former patients under analysis)

Most (56.25%) of the patients did not have or did not acknowledge having a caregiver on the occasion of the research. All patients who presented caregivers had a severe and persistent mental illness diagnosis, with schizophrenia as the most prevalent diagnosis in the sample (52.4%).

Most caregivers were women (76.2%), married (61.9%), with children (95.2%) and who finished primary education (71.4%). Four caregivers (19.0%) did not finish and only one finished secondary education. One caregiver had a higher education degree.

The mean age was 46.6 years, ranging from 22 to 62 years. The caregivers' degree of kinship with the patients was distributed as follows: mothers in 38% of cases, siblings in 28.6%, husbands/wives in 23.8%. One caregiver was the patient's son and one was a nephew.

As for marital status, 61.9% of caregivers were married or lived with a fixed partner, 19.0% were widowed. Separated or divorced people represented 14.3% of the sample and single caregivers 4.8%. Regarding the number of children, 33.3% had a child and 33.3% two children. Patients with three children or more corresponded to 28.6% of the sample. Only one caregiver had no children.

The main source of revenues among caregivers was occasional work (28.6%). The caregivers' distribution among the other categories was regular, with four (19.0%) doing informal regular work (without a contract), four had a regular job contract and four were retired. Three caregivers were unemployed.

The 21 caregivers unanimously agreed that medication treatment in mental patients' treatment is important.

## DISCUSSION

Psychiatric care has been changing for some decades, directing its focus at community care and the deinstitutionalization of psychiatric patients. In Brazil, today, investments are made in service infrastructure and redefinitions in care delivery to mental health clients.

Thus, the deinstitutionalization of mental health care acclaims a direct partnership among health professionals, family members and patients, with a view to treatment maintenance in community services. This research revealed that all caregivers in the sample were relatives of mental patients, strengthening their perception as fundamental for care practice.

Studies demonstrate that families' daily structure is significantly disorganized because they have to face mental patients' constant mood swings and behavior<sup>(11-12)</sup>. Family members often face difficulties to understand a different behavior and try to *normalize* the strange as closely as possible to common sense, which can often hamper care maintenance.

In this respect, it is interesting to observe that, although 93.8% of patients affirmed living with relatives, only 43.7% of them affirmed having a caregiver. The other patients denied there was someone concerned to help them with their treatment. In these cases, the interviewed patients truly may be lacking or underestimating care.

It is known that, when the family participates in care for its members, it plays a determinant role in treatment success<sup>(13)</sup>. Home is a space where people with chronic conditions and other problems can have a good quality of life and maintain their disease stable<sup>(14)</sup>, provided that the family receives orientation and support from health services for this purpose.

It is highlighted that living with a mental patient entails an additional cost that goes beyond the limitations in terms of job, leisure and relaxation opportunities for caregivers<sup>(15)</sup>. The caregivers identified in this research were mainly mothers, mostly married and with more than one child. This condition appoints that these caregivers may be accumulating roles in the family composition, which may entail an overload.

Family overload can be defined as the emotional and economic stress families submit to when a relative is discharged from a psychiatric hospital and returns home, mainly when family bonds when broken by the chronicity pattern, in case of patients who spend long periods in psychiatric institutions. These changes often demand adaptations that can affect these family members' needs, can cause an accumulation of responsibilities and even postponement of personal plans<sup>(16)</sup>.

Mental health services need to offer assistance that includes care to identify and relieve the caregivers' overload, besides promoting skills training to stimulate mental patients' autonomy and psychosocial rehabilitation.

The efficacy of care the caregivers, in this case relatives, deliver was not the focus of this research. We do consider the full range of its relevance though. After psychiatric hospitalization, discharged patients and their families face the difficult reintegration process of their social relations. These clients' demand needs to be identified so that professionals, patients and family members structure and manage daily reality in the surround social, economic and cultural relations.

The presence of a family member with a mental disorder always entails some degree of overload for his/her relatives and provokes a constant need for family structure adaptations<sup>(17)</sup>. Treatment maintenance, education, ventilation and crisis relief interventions can attempt to respond to these people's care demand, not restricted to the mere guaranteed psychopharmacological treatment adherence, but also aiming to identify and minimize risks, addressing lacks and social, emotional and financial conflicts the chronic manifestation of mental illness generate.

## CONCLUSION

The innovations generated by the paradigm change in psychiatric care demand further research and adaptations of health professionals and services to enable them to respond to their patients and caregivers' demands. With discerning psychiatric hospitalizations marked by shorter confinement periods, patients and relatives have increasingly turned into the main mental health care providers.

In this context, the chronic nature of mental disorders makes these people live with the hospitalization-rehospitalization process and their daily activities are organized around the mental illness treatment possibilities. Therefore, knowing the caregivers of patients after psychiatric hospitalization today permits the identification of characteristics that can enhance the determination of the best treatment and professional support for these clients' care.

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