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## Perfil dos familiares de usuários de Centros de Atenção Psicossocial: distribuição por tipo de serviço

Profile of the family of Psychosocial Care Center users: distribution by type of service

Perfil de los familiares de los usuarios de los Centros de Atención Psicossocial: distribución por tipo de servicio

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### ABSTRACT

**Objective:** To describe the socioeconomic and demographic profile of family caregivers of users of Psychosocial Care Centers type I, II and III. **Methods:** It is a quantitative, descriptive study, part of the evaluation research of Psychosocial Care Centers in Southern Brazil II in 2011. The participants of this study were 1242 family of users of CAPS. **Results:** The majority of family are women, whites, aged between 40 to 60 years, with low education and income, married, parents or mothers of users. One can see that socioeconomic and demographic characteristics of family caregivers are distributed similarly between the three modality of rated service (CAPS I, CAPS II and CAPS III). **Conclusion:** From the family caregivers profile knowledge, it is allowed to propose assistance and more focused support on the characteristics of each group.

**Descriptors:** Mental health; Mental health services; Family; Caregivers; Health Services Evaluation.

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## RESUMO

**Objetivo:** Descrever o perfil socioeconômico e demográfico dos familiares cuidadores de usuários de Centros de Atenção Psicossocial do tipo I, II e III. **Métodos:** Trata-se de um estudo quantitativo, transversal e descritivo, que integra a pesquisa de Avaliação dos Centros de Atenção Psicossocial da Região Sul do Brasil II em 2011. Os participantes do estudo foram os 1242 familiares de usuários dos CAPS. **Resultados:** A maioria dos familiares são do gênero feminino, brancos, com idades entre 40 a 60 anos, com baixa escolaridade e renda, casados, e pais ou mães dos usuários. Pode-se perceber que as características sociodemográficas dos familiares cuidadores se distribuem de forma semelhante entre as três modalidades de serviço avaliado (CAPS I, CAPS II e CAPS III). **Conclusão:** A partir do conhecimento do perfil dos familiares, permite-se propor uma assistência e suporte mais focado nas particularidades de cada grupo.

**Descritores:** Saúde mental; Serviços de saúde mental; Família; Cuidadores; Avaliação de serviços de saúde.

## RESUMEN

**Objetivo:** Describir el perfil socioeconómico y demográfico de los familiares cuidadores de los usuarios de los Centros de Atención Psicossocial de tipo I, II y III. **Métodos:** El tratamiento es una cuantitativa, transversal, descriptivo, parte de la investigación de la evaluación de los Centros de Atención Psicossocial en el sur de Brasil II en 2011. Los participantes del estudio fueron 1242 familiares de los usuarios de los CAPS. **Resultados:** La mayoría de los miembros de la familia son mujeres, blanco, de 40 a 60 años de edad con bajo nivel de educación e ingresos, casadas, padres o madres de los usuarios. Se puede observar que las características sociodemográficas de los cuidadores familiares se distribuyen de manera similar entre los tres tipos de servicio nominal (CAPS I, CAPS II y CAPS III). **Conclusión:** A partir del conocimiento de lo perfil de los familiares nos permite proponer un servicio más centrado y apoyo en las particularidades de cada grupo.

**Descriptor:** Salud mental, Servicios de salud mental, Familia, Cuidadores, Evaluación de Servicios de Salud.

## INTRODUCTION

The deinstitutionalization proposal of people with mental disorder brought the possibility of establishing new relations between society and madness, without denying that there is anything that can produce pain and suffering. In this perspective, it was created mental health services that seek not the exclusion of persons with disorder and allow the involvement of other actors in the provision of care, such as family.<sup>1-2</sup> The changes resulting from the psychiatric reform process have been and continue to be implemented, reviewed and rethought, to be understood as a process in constant transformation.

The family tightens the link between mental patients and society, it is essential to their participation in the treatment and adherence to these people Psychosocial Care Center (CAPS). So, it is important to the CAPS, which share responsibility for the care, through the co-responsibility and acting in various care settings.<sup>3</sup>

Psychosocial Care Centers are categorized by size and clientele it serves, getting the names of CAPS I, CAPS II, CAPS III, CAPSi (infant juvenile) e CAPSad (alcohol and

drugs), e the types of services as CAPS I (municipalities of 20,000 to 70,000 inhabitants), CAPS II (municipalities of 70,000 to 200,000 inhabitants) and CAPS III (municipalities with more than 200,000 inhabitants), defined in order of increasing size, complexity and population coverage. CAPS types I and II are intended for daily care of adults in their local population, with severe and persistent mental disorders. CAPS III are services for daily and night care of adults, given the population with severe and persistent mental disorders, 24 hours a day for seven days a week.<sup>4-5</sup>

To the Ministry of Health, family is an open system that interconnects with other systems and structures of society, consists of groups of people with emotional ties, of living together, with or without blood relationship, are people who share socialization relations and care linked by cultural, socioeconomic values that predominate in a particular geographical, historical and cultural context.<sup>6</sup>

If the care to mental patients is shared between the family and the CAPS, and the family is a care protagonist in freedom with participation in health activities of their family suffering, the realization of this study is already justifies teams health and managers need to know the family, its characteristics, identifying important aspects and supporting so that they do not overburden to exercise their caring role.

This study aimed to describe the socioeconomic and demographic profile of family caregivers of mental health services users type I, II and III.

## METHOD

This study is part of the Psychosocial Care Centers of evaluation research in the South of Brazil II (CAPSUL II), held in the three states of southern Brazil, Rio Grande do Sul, Santa Catarina and Parana, in 40 CAPS type I, II and III. The CAPSUL II research was divided into a qualitative study and other quantitative. In this study we used the quantitative database of family research CAPSUL II. Through a quantitative, descriptive study, with family caregivers of CAPS users. Data collection occurred from July to December 2011. Most of the relatives were interviewed in CAPS, in some cases the interview took place at home.

The sample selection was done through random draw respecting the proportionality of each state services. 40 CAPS, 18 were in Rio Grande do Sul, 10 in Santa Catarina and 12 in Parana. The sample included the collection of data from 40 families of each of the forty services, but were interviewed 1242 families. The losses are related to denials and the difficulty in finding the family. The criteria for selection of participants were: family of type I CAPS users, II or III, and sign the free and informed consent.

The 20 pairs of interviewers who conducted the interview received a training course with a workload of 40 hours. During the training the interviewers developed activities as a pilot study for final adjustment of the instruments and performance evaluation as an interviewer

in different services that made up the sample. In addition, during fieldwork interviewers they counted on the support of two field supervisors. Quality control was performed by replication of 5% of the interviews and correction coding. Data were entered in the software EPI-INFO 6.04, and made double entry for independent digitizers and with subsequent cleaning of the data, the analysis was performed in STATA software with univariate and bivariate analysis.

It was used instrumental data from the family, specifically used demographic and socioeconomic issues. The independent variables were gender (male, female), skin color (white, brown/mestizo, black, other), age (14-18 years, 19-39 years, 40-60 years, 61 years or more) education (no education/incomplete primary education, complete Elementary, Incomplete Elementary/high school degree/technical course, incomplete higher education/university degree/postgraduate), family income (0 to 1 minimum wage, more than 1 to 3 minimum wages, more than 3 times the minimum wage), civil status (single, married/with partner, separated/divorced, widowed), type of relationship with user (father/mother, brother/sister, spouse/partner, son/daughter, other family members). Research CAPSUL II was approved by the Ethics Committee of the Nursing School of the Federal University of Pelotas (UFPel) under Opinion No 176/2011. All participants signed an informed consent to participate in research.

## RESULTS

Among the 1,242 families surveyed, most were from Rio Grande do Sul representing 46% of the sample, followed by Paraná with 32% and Santa Catarina 22%. Regarding the type of service, 64% of family members accompanying the user in type I CAPS, 27% CAPS II and 9% in CAPS type III (Table 1).

**Table 1** - Distribution of families by type of CAPS, Brazil, 2011 (n = 1242)

Type of service	Frequency (n)	Percentage (%)
CAPS I	795	64%
CAPS II	330	27%
CAPS III	117	9%
Total	1242	100%

Most family caregivers were women, white skin color, parents or mothers of users, married or living with a partner with a mean age of 52 years (SD = 15.2). With regard to education, the highest frequency was of those with low level of education. In relation to income, the majority of participants had low family income condition. The sociodemographic characteristics of the family caregivers distributed by type of service are shown in Table 2.

**Table 2** - Profile of CAPS users of family type I, II and III, Brazil, 2011 (n = 1242)

Characteristics	Type of service					
	CAPS I		CAPS II		CAPS III	
	n	%	n	%	n	%
<b>Gender</b>						
Female	536	67.4%	230	69.7%	76	65%
Male	259	32.6%	100	30.3%	41	35%
<b>Skin color *</b>						
White	579	72.9%	227	69%	82	70.1%
Brown/mestizo	129	16.2%	59	17.9%	18	15.4%
Black	54	6.8%	25	7.6%	2	1.7%
Other	33	4.1%	18	5.5%	15	12.8%
<b>Age*</b>						
14-18 years	13	1.6%	3	0.9%	-	-
19-39 years	194	24.5%	67	20.3%	22	18.8%
40-60 years	383	48.3%	158	47.9%	54	46.2%
61 years or more	203	25.6%	102	30.9%	41	35%
<b>Education*</b>						
Incomplete Elementary	408	56.7%	149	49.7%	49	44.5%
Complete Elementary	84	11.7%	39	13%	16	14.6%
High School/Technical	181	25.2%	89	29.6%	25	22.7%
Higher/Graduate	46	6.4%	23	7.7%	20	18.2%
<b>Family income **</b>						
0 to 1 minimum wage	131	18.3%	54	17.1%	15	13.6%
1 to 3 minimum wages	435	60.7%	176	55.9%	55	50%
More than 3 minimum wages	150	21%	85	27%	40	36.4%

(To be continued)

(Continuation)

Characteristics	Type of service					
	CAPS I		CAPS II		CAPS III	
	n	%	n	%	n	%
<b>Marital status *</b>						
Single	137	17.3%	51	15.5%	17	14.5%
Married/with partner	499	62.9%	188	57.1%	68	58.1%
Separated/divorced	61	7.7%	39	11.9%	13	11.1%
Widower	96	12.1%	51	15.5%	19	16.2%
<b>Type of bond</b>						
father/mother	253	31.8%	114	34.5%	54	46.2%
Sister/brother	129	16.2%	54	16.4%	17	14.5%
Spouse	207	26%	74	22.4%	22	18.8%
Son/daughter	122	15.4%	53	16.1%	15	12.8%
other Family member	84	10.6%	35	10.6%	9	7.7%

\* Numbers differ because of the number of ignored people.

† National minimum wage at the time of data collection in 2011: R\$545.00

Based on the results shown in Table 2, one can see that socioeconomic and demographic characteristics of family caregivers are distributed similarly between the three types of rated service (CAPS I, CAPS II and CAPS III), ie in relation to gender, among those interviewed relatives in CAPS type I, 67.4% are women and 32.6% of men in CAPS II the prevalence of women was even higher, representing 69.7% of families interviewed in this modality service, already in CAPS III distribution was 65% for female and 35% male. Regardless of the type of service, CAPS I, II, III, women were the majority.

As for color, the prevalence was higher among respondents who reported white skin color regardless of the type of service, with higher percentages in CAPS type I, type II and III, respectively.

Regarding the age of the relatives interviewed, the prevalence was the age group between 40 and 60 years in the three forms of CAPS, representing 48.3% CAPS I, 47.9% and 46.2% II CAPS CAPS III. CAPS III were in the service mode with the highest percentage of elderly, or people over 60, which corresponds to 35% of total family accompanied this service already in CAPS II 30.9% reported having 61 years or more and CAPS I were 25.6%.

Regarding education of family members, 56.7% have not completed elementary school and only 6.4% college or graduate among respondents in CAPS I. As for families with higher education/graduate, the prevalence of families with this level of education was higher in CAPS mode III.

Family members interviewed in the three service modalities had low family income (between one and three minimum wages). Familiar with the best conditions of income earning more than three minimum wages correspond to 36.4% in the form of CAPS III, 27% CAPS II and 21% CAPS I.

The marital status of family caregivers showed higher prevalence among married with the highest percentage in CAPS I - 62.9%. Regarding the relationship with the user, most families were fathers or mothers with the highest

percentage in CAPS III - 46.2%, followed by CAPS II - 34.5% and CAPS type I 31.8%.

## DISCUSSION

With regard to socio-demographic characterization of family caregivers of people with mental disorders was evidenced predominance of women, white skin color. These results corroborate findings from other studies with family caregivers of people with mental disorder.<sup>7-11</sup> Also resembles results were found in studies with elderly caregivers that most caregivers were female.<sup>12-4</sup>

The gender issue that the study found is a common fact, who performs the tasks of caring for the family is usually the woman, obeying cultural norms according to which it is required to the organization of family life, child care and care for the sick. Therefore, the woman is shown as the primary caregiver, including in situations where it is responsible for income.<sup>8</sup>

Regarding age, it was shown that the highest frequency of respondents families are concentrated in the age group of 40 to 60 years with an average of 52 years. These results are in four studies with family caregivers of people with disorder in which the mean age were similar.<sup>7,9,15-7</sup> Still on the age of family caregivers, the findings of this study also corroborate studies conducted with caregivers of the elderly, where the mean age were similar to those found in this study.<sup>12,18</sup>

With regard to the education of the family, most have not completed elementary school. The low education level was also found in other studies with family caregivers of people with mental disorder<sup>7,9,19-20</sup> and family caregivers of seniors.<sup>12,14,18</sup>

Low education can also result in some issues such as the possibility of getting formal work, the difficulty in understanding some past guidance to the family by professionals, such as those related to medication use by people with disorder, or understanding in the diagnosis of the user.

As for the income of family caregivers of people with mental disorder, most often distribution concentrated on more than one to three minimum wages. These results corroborate the findings of other studies on the same population, where the income conditions were similar,<sup>7,9,20-1</sup> also resembles study with a population of elderly caregivers.<sup>12</sup>

The low family income conditions may be related to the difficulties of reconciling care activities with extra domiciliary activities because often the caregiver leaves the job to devote himself only to the person's care with mental disorders and domestic tasks, resulting in financial difficulty for the whole family. In addition, the low educational level can further hamper the family at the time of getting a job, reflecting again on the finances of these people.

It was found in this study that the marital status of family caregivers were mostly married, since as the link most of the family was parents or mothers of users. These findings corroborate other studies with relatives of users of mental health,<sup>7-11,15-6,20</sup> and with caregivers of patients the results were similar.<sup>12,18</sup>

Studies describing the family's mental health users caregivers profile found similar results especially regarding the predominance of women, highlighting the issue of gender, low income and education, can be a sign of difficulties with work, achieve or maintain employment. The provision of care may be implying that question and also prejudice and stigma that people face, it is also worth considering the fact that parents are the primary family caregivers, which can bring excessive costs in providing care.

Living with a person with mental disorder has implications that go beyond the restrictions on employment opportunities, leisure and rest of people who provide the care, the accumulation occurring roles of caregivers in family composition, which can cause overload.<sup>10</sup>

Furthermore, the predominance of women in the care users demonstrates the hegemony of the traditional notion of the female as a place of care, because the distribution of family care is very unequal, in which, most often, it is the female figures that charge.<sup>8</sup>

However, it is important to always highlight the important role that the family plays, regardless of the issues involved, highlighting that this is key player for the care of freedom of the person with mental disorder.

For its capacity to adapt and the recognition of society, the family is maintained throughout the history of mankind as an important social institution and that endures.<sup>22</sup>

There is need of health teams offer more support to families in the context of changes, both in their life and in the care they provide and care services. Thus, the co-responsibility for the mental health care that occurs between family and work needs to happen with the advancement of psychosocial rehabilitation policy, support families and empower them in order to advance the process of deinstitutionalization in mental health.<sup>23</sup>

## CONCLUSION

The results presented regarding family caregivers may provide support to the mental health teams and can plan and program their actions consistent with the real needs of this population, thus minimizing the impact suffered by the family in exercising their caring role.

Currently, family participation in the health context as a whole gains strength, it is necessary that professionals who are daily in health services pay attention to the strengths and weaknesses of this group in order to establish partnerships and co-responsibility for the care.

The CAPS modalities differed in relation to the size of the municipality, as there are also differences in relation to human resources that make up each service. Thus, it is important to consider each assessed mode serves its users and families with different characteristics, so it was important to present the differences regarding the modalities of evaluated services, although the results are similar.

Thus, from the family caregivers profile of knowledge, it is fair to propose an assistance and more focused support on the characteristics of each group.

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