Original Article

Need for caregivers among people living with mental disorders: an ecological study

Necessidade de cuidador entre pessoas que vivem com transtorno mental: estudo ecológico

Necesidad de cuidador en personas que viven con trastorno mental: estudio ecológico

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Abstract

Objective: To identify users of a Psychosocial Care Center who have caregiver dependence and their associated factors.

Method: This is an ecological study, with collection of secondary data from medical records of people living with mental disorders, which occurred in 2018 in a Psychosocial Care Center in the Brazilian Midwest. In the analysis, the dependent variable "need for caregiver" was used as a dependent variable.

Results: In the sample of 360 medical records, there was a prevalence of women (220; 61.1%), aged between 35 and 59 years (190; 52.8%), treatment time ≤5 years (164; 45.6%), care provided by family/friends (162; 45.0%), main diagnosis of psychotic disorders (128; 35.6%) and antipsychotic use (275; 76.4%). In the multiple analysis, the variables non-literacy/elementary school (p=0.041), having psychotic disorder (p=0.009) and antidepressant (p=0.026) remained associated.

Conclusion: The study pointed out that factors such as being men, non-literate/elementary school, having a psychotic disorder and using antidepressants have higher rates of dependence on care and should be considered and investigated by the Psychosocial Care Center team.

Resumo

Objetivo: Identificar os usuários de um Centro de Atenção Psicossocial que apresentam dependência de cuidador e seus fatores associados.

Método: Estudo ecológico, com coleta de dados secundários de prontuários de pessoas que vivem com transtorno mental, ocorrida no ano de 2018 em um Centro de Atenção Psicossocial no Centro-Oeste brasileiro. Na análise, usou-se como variável dependente "necessidade de cuidador".

Resultados: Na amostra de 360 prontuários, houve prevalência do sexo feminino (220; 61,1%), idade entre 35 a 59 anos (190; 52,8%), tempo de tratamento ≤5 anos (164; 45,6%), cuidado exercido por família/amigos (162; 45,0%), diagnóstico principal de transtornos psicóticos (128; 35,6%) e em uso de antipsicóticos (275; 76,4%). Na análise múltipla, permaneceram associadas as variáveis ter escolaridade não letrado/fundamental (p=0,041), possuir transtorno psicótico (p=0,009) e usar antidepressivo (p=0,026).

Conclusão: O estudo apontou que fatores como ser do sexo masculino, possuir escolaridade não letrado/fundamental, ter transtorno psicótico e fazer uso de antidepressivo possuem maiores índices para dependência de cuidados e devem ser considerados e investigados pela equipe dos Centros de Atenção Psicossocial.

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Resumen

Objetivo: Identificar los usuarios de un Centro de Atención Psicosocial que presentan dependencia de cuidador y los factores asociados.

Métodos: Estudio ecológico, con recopilación de datos secundarios de historias clínicas de personas que viven con trastorno mental, realizada en el año 2018 en un Centro de Atención Psicosocial en la región Centro-Oeste brasileña. En el análisis, se utilizó como variable dependiente "necesidad de cuidador".

Resultados: En la muestra de 360 historias clínicas, hubo prevalencia del sexo femenino (220; 61,1 %), edad entre 35 y 59 años (190; 52,8 %), tiempo de tratamiento ≤5 años (164; 45,6 %), cuidado ejercido por familia/amigos (162; 45,0 %), diagnóstico principal de trastornos psicóticos (128; 35,6 %) y en uso de antipsicóticos (275; 76,4 %). En el análisis múltiple, estuvieron asociadas las variables tener escolaridad no letrada/primaria (p=0,041), poseer trastorno psicótico (p=0,009) y tomar antidepresivos (p=0,026).

Conclusión: El estudio indicó que factores como ser de sexo masculino, tener escolaridad no letrada/primaria, tener trastorno psicótico y tomar antidepresivos poseen mayores índices para la dependencia de cuidados y deben ser considerados e investigados por el equipo de los Centros de Atención Psicosocial.

Introduction

Psychosocial Care Centers (CAPS) aim to offer care to people suffering from severe and persistent mental disorders, guaranteeing access to specialized care, without violating human rights. It represents the central device of the Psychosocial Care Network in Brazil, with a specific function in its regulation, opposing to treatment services based on isolation, prolonged hospitalizations and annulment of civil rights.(1) This space is characterized by monitoring and supporting not only users who live in it, but also their families.(2)

In line with psychosocial care, the look at people with mental disorders has become expanded, considering their connection and interaction with the family and the community. Thus, the responsibility for care is shared with family members and, in a two-way street, the family is the object of care of the multidisciplinary team, caregiver of their family member and supporter of the team. When the family manages to establish itself as a means of care, it makes it possible for its members to strengthen the sense of autonomy and establish bonds that respond positively to their demands.(3)

The deinstitutionalization process, implemented as one of the actions of Brazilian Psychosocial Care, assured the person undergoing psychiatric treatment the right to coexist in society, making the family co-responsible for the maintenance and care process, for treatment and rehabilitation.(4) In this sense, it is understood that, for rehabilitation, an extended interaction of knowledge is necessary, involving the pharmacological field and social, family and professional integration, aiming at improving the quality of life of people with mental disorders.(5)

Once a family member is affected by a certain mental disorder, different demands arise and the reorganization of functions and roles in the family dynamics.(2) Faced with a diagnosis involving mental health, family members are faced with negative emotions regarding acceptance, as it is understood that mental illness is disabling and may require lifelong treatment. (3)

In this context, the need for assistance to people who live and who live with a mental disorder is evident, especially caregivers of sick persons. This is because the high degree of limitation and fragility of mental illness generates dependence and demands support and help of the other in the Activities of Daily Living, requiring a caregiver.(6) Caregivers, or those who live with a mental disorder, need listening, welcoming, guidance and support, promoting the interaction of family members with health services.(5)

In this context, the present investigation was concerned with caregivers of people living with a mental disorder, understanding that, in most situations, the family member plays the role of caregivers. It also considers the family as a group with great potential for resocialization and reception of its members, being, therefore, essential for the effectiveness of Psychosocial Care, strengthening the actions of mental health care devices.(7)

The study is justified by the relevance of expanding Psychosocial Care beyond the sick person, with the following study question: Who are CAP users who need caregivers? What are your specific characteristics and demands? These issues are reinforced by the fact that, in the search for scientific evidence in the databases, several studies were found that investigated the profile of caregivers, their burden and their difficulties with care,(2,4) but the research did not present the factors associated with dependence on a caregiver, i.e., sociodemographic and specific variables of the illness itself and treatment.

In this regard, the objective was to identify CAPS users who are dependent on a caregiver and their associated factors.

Methods

This is an ecological study,(8) descriptive-exploratory, guided by the STROBE tool,(9) based on secondary data available in the medical records of people living with mental disorder of a type II CAPS, in the Central region of Brazil, collected between September and November of 2018. The sample considered medical records of people undergoing treatment at the time of the research, establishing as inclusion criteria open records in the CAPS referring to frequent individuals, regardless of the type of therapeutic approach.

Data collection took place by reading and extracting information of interest from the medical records in the CAPS environment itself, using an instrument formatted by the researchers guided by mental health references(10) about sociodemographic conditions (name, address, neighborhood, sex, age, education, religion, marital status, children and number of children, need for caregiver and year of reception), primary and secondary diagnoses (if present) and medications in use.

For the sample description, the following independent variables were used: sex (male versus female); age (≤ 35 versus > 35 to ≤ 59 versus ≥ 60); education (illiterate versus primary education versus high school versus higher education versus uninformed); marital status (single versus married/cohabiting versus divorced/separated versus widowed versus not informed); religion (evangelical versus catholic versus Spiritualism/*Umbanda* (African religion) versus none/nothing stated versus others); children (none versus ≥1 to <3 versus ≥3); treatment time (≤5 years versus ≥5 to ≤10 years versus >10 years); who cares for (self-care versus family/friends versus professionals); primary diagnosis (psychotic disorders versus anxiety disorders versus affective disorders versus neurological disorders versus substance abuse disorders) and antipsychotic use versus antidepressant use versus antihistamine and anticholinergic use. The diagnoses were: psychotic disorders (no versus yes); psychoactive substance use disorders (no versus yes); antipsychotic use (no versus yes); antidepressant use (no versus yes); and antihistamine/anticholinergic use (no versus yes).

In the analysis, "caregiver needs" was used as the dependent variable, information that was obtained from the notes of the medical records read, with family caregivers being the closest people or professionals, with a no versus yes answer.

The registration took place in an Excel® electronic spreadsheet, filled in with double checking. Statistical analysis was performed using the Stata Software Package (STATA), version 12.0. The description was presented in absolute numbers and prevalence, with a 95% Confidence Interval (95%CI). Bivariate and multiple analyzes were performed between dependent and independent variables, applying Poisson logistic regression, with the prevalence ratio (PR) effect measure. For the multiple model, the variables with p≤0.10, included by the forced entry method, were selected. Values of p<0.05 were considered associated with the dependent variable.

This study is part of a matrix project entitled "*Análise da atenção em saúde mental e constituição da rede no Sistema Único de Saúde no sudeste goiano*", approved by the Research Ethics Committee with Human Beings of the *Universidade Federal de Goiás*, Opinion 1,273,443, CAAE (*Certificado de Apresentação para Apreciação Ética* - Certificate of Presentation for Ethical Consideration) 25586013.2.0000.5083, and is in accordance with Resolutions 466/2012 and 510/2016.

Results

The study sample consisted of information from 360 people living with mental disorders, contained in their respective medical records. Among them, most were women (220; 61.1%; 95% Confidence Interval – 95%CI 56.1-66.4) and aged between 35 and 59 years (190; 52.8%; 95%CI 47.5-57.8). Sociodemographic and health-disease descriptions can be observed in table 1.

Table 1. Sociodemographic description and aspects of the health-disease process

Variables	n(%)	95%CI
Sex		
Male	140(38.9)	33.6-43.9
Female	220(61.1)	56.1-66.4
Age		
≤35	85(23.6)	19.2 -28.1
>35 to ≤ 59	190(52.8)	47.5-57.8
≥ 60	85(23.6)	19.4-28.1
Education		
Illiterate	32(8.9)	6.1-12.0
Elementary school	191(53.2)	47.9-58.2
High school	84(23.4)	19.5-27.9
Higher education	20(5.6)	3.6-8.1
Not reported	32(8.9)	5.8-12.0
Marital status		
Single	176(48.9)	43.6-53.6
Married/Common-law marriage	114(31.7)	26.9-36.4
Divorced/separated	19(5.3)	3.3-7.5
Widow	19(5.3)	3.1-7.8
Not reported	32(8.9)	6.1-11.9
Religion		
Evangelism	106(29.4)	24.5-34.7
Catholicism	134(37.2)	32.8-42.2
Spiritualism/Umbanda	13(3.6)	1.9-5.8
None/not reported	100(27.8)	23.3-32.8
Other	7(1.9)	0.6-3.6
Children		
None	141(39.2)	33.6-44.4
≥1-<3	131(36.4)	31.9-41.7
≥3	88(24.4)	20.0-28.9
Treatment time, years		
≤5	164(45.6)	40.3-50.6
>5-≤10	106(29.4)	25.0-34.7
>10	90(25.0)	20.8-29.7
Who cares for		
Self-care	191(53.1)	48.1-58.3
Family and friends	162(45.0)	40.0-50.0
Professionals	7(1.9)	0.6-3.6
Main diagnosis		
Psychotic disorders	128(35.6)	30.3-40.3
Anxiety disorders	23(6.4)	4.2-8.9
Affective disorders	126(35.0)	30.0-39.7
Neurological disorders	15(4.2)	2.2-6.1
Psychoactive substance abuse disorders	68(18.9)	15.3-23.1

95%CI - 95% Confidence Interval

Regarding the information collected on medication use, it is observed in table 2 that antipsychotic was the most used medication among the individuals involved in the research (76.4%; 95%CI 19.4-28.0), followed by benzodiazepine/barbiturate (55.3%; 95%CI 47.5-58.1).

Table 2. Most used medications, by class

Medication class	n(%)	95%CI
Antipsychotic	275(76.4)	19.4-28.0
Antidepressant	190(52.8)	47.5-58.1
Antihistamine/anticholinergic	81(22.5)	18.3-26.9
Benzodiazepine/barbiturate	199(55.3)	50.0-60.3

95%CI - 95% Confidence Interval

Among the information in the medical records, 169 (46.9%; 95%CI 41.7-51.9) showed the need for caregivers in their daily lives, whether this role was played by the family member or by a professional. The factors associated with this dependent variable can be observed in table 3.

Considering the results of bivariate analysis, independent variables sex, having a psychotic disorder (p=0.002), using antipsychotics (p=0.021), antidepressants (p=0.000) and antihistamines/anticholinergics (p=0.002). They remained associated in the multiple analysis after adjusting the model for forced entry, sex (p=0.022), non-literate/elementary school (p=0.041), having a psychotic disorder (p=0.009) and using antidepressants (p=0.026).

Discussion

The present investigation brought the estimate and description of demand or caregiver dependence of people living with mental disorders assisted by a CAPS. The findings corroborate a high prevalence of caregiver dependence and are related to sociodemographic and specific characteristics of the illness and treatment that the CAPS user experiences. They reinforce the disabling aspects of mental disorders and the need for professionals working in these spaces to focus on caring for caregivers and their families, with a view to treatment compliance, expansion of assertive actions, monitoring and psychosocial rehabilitation in mental health.

Most of the information presented in this study referred to women (220/61.1%), a result that is similar to that of other studies.(6,-11,12) Such an obser-

Table 3. Bivariate and multiple analysis of dependent variable need for caregiver and associated factors

Variables	Need for caregiver							
	n/total	%	Unadjusted PR*	95%CI	p-value	Adjusted PR†	95%CI	p-value
Sex								
Female	89/220	40.45	1	-	-	-	-	-
Male	80/140	57.14	1.412	1.044-1.910	0.025	1.447	1.055-1.987	0.022
Age, years								
≤35	46/85	54.12	1	-	-			
>35-≤59	80/190	42.11	0.175	0.541-1.118	0.7780	-	-	-
≥60	43/85	50.59	0.934	0.616-1.416	0.751	-	-	-
Education								
Higher education	1/20	5.00	1	-	-	-	-	-
High school	31/84	36.90	7.380	1.007-54.06	0.049	-	-	-
Non-literate/elementary school‡	117/223	52.47	10.493	1.465-75.117	0.019	7.906	1.089->10.0	0.041
Marital status								
Married/Common-law marriage	42/114	36.84	1	-	-	-	-	-
Widow	7/19	36.84	1.002	0.449-2.225	1.002	-	-	-
Single	95/176	53.98	1.465	1.018-2.106	0.039	1.151	0.705-1.878	0.573
Divorced/separated	11/19	57.89	1.571	0.809-3.052	0.182	-	-	-
Children								
Yes	89/219	40.64	1	-	-	-	-	-
No	80/141	56.74	1.396	1.032-1-.888	0.030	1.089	0.665-1.784	0.734
Religion								
Evangelism	48/106	45.28	1	-	-	-	-	-
Catholicism	63/134	47.01	1.038	0.713-1.511	0.845	-	-	-
Spiritualism/Umbanda	8/13	61.54	1.358	0.642-2.872	0.422	-	-	-
None/not reported	48/100	48.00	1.060	0.710-1.581	0.775	-	-	-
Psychotic disorders								
No	89/232	38.36	1	-	-	-	-	-
Yes	80/128	62.50	1.629	1.204-2.203	0.002	1.739	1.148-2.633	0.009
Psychoactive substance abuse disorders								
No	130/292	44.52	1	-	-	-	-	-
Yes	39/68	57.35	1.675	0.983-2.856	0.058	1.58	0.968-2.586	0.067
Antipsychotic use								
No	27/85	31.76	1	-	-	-	-	-
Yes	142/275	51.64	1.625	1.077-2.453	0.021	1.080	0.670-1.741	0.751
Antidepressant use								
No	105/170	61.76	1	-	-	-	-	-
Yes	64/190	33.68	0.545	0.399-0.744	0.000	0.668	0.468-0.953	0.026
Antihistamine/anticholinergic use								
No	114/279	40.86	1	-	-	-	-	-
Yes	55/81	67.90	1.661	1.204-2.292	0.002	1.232	0.832-1.824	0.297

In the multiple analysis, for the values of variable sex, the variables children and psychotic disorders were controlled. For the values of variables non-literate/elementary school and psychotic disorders, confounding variables regarding medication use were controlled. For the value of variable antidepressant use, the collinear variable psychotic disorders was controlled. *Bivariate analysis; † multivariate analysis; ‡ elementary school (complete/incomplete); PR - prevalence ratio; 95%CI: 95% Confidence Interval.

vation may be related to the fact that women seek more health services.(13) Moreover, disorders such as generalized anxiety and brief psychotic disorder are more prevalent in women.(10)

The 18% increase between 2005 and 2015 in cases of depression in the world population is mostly represented by women in all age groups. Women are the most prevalent in diagnoses of anxiety disorders.(14) Also, with regard to the prevalence of disorders in women, factors such as the way to face stressful events, sociocultural issues and hormonal and physiological distinctions are observed.(15)

Regarding the prevalence of the need for a caregiver, it was observed that 46.9%, i.e., almost half of the population assisted at the CAPS, are dependent on a caregiver. No studies were found that discuss this prevalence. Most studies that had caregivers as their object of study addressed issues such as the profile of caregivers or the burden experienced by these people.(2,4,16) The absence of evidence from other studies for the interlocution of the findings reinforced the relevance of this study with an innovative question, suggesting new investigations that better describe this reality.

Although most research participants were women, the multiple analysis showed that men had a greater need for caregivers (p=0.022). In the absence of scientific evidence from other studies with the present research object, it approaches discussions that may justify such a finding, such as the Brazilian historical-cultural context in which women, in greater proportion, become caregivers in the family environment,(2,17,18) which attributes to women a 'naturalness' or 'proximity' with the practice of caring. So, in addition to this proximity, such as caring for others, would women who suffer mentally be more skilled in self-care and, thus, depend less on caregivers?

Part of these answers can be found in the historical scenario, as well as in the development of humanity, as care for the home, the sick, older adults and children were given, above all, to women.(19) The difference in the care process between men and women may be the result of the social construction of care and has a bias genuinely attributed to the female figure.(16) In view of this cultural and historical discussion, the present investigation revealed greater dependence on caregivers when the mentally ill person is male. Another dimension of this condition can also be explained by the epidemiological characteristics of mental illness itself, which is more prevalent among men. In other words, in men, psychotic disorders are more prevalent and tend to manifest with an incidence of more lasting negative symptoms, with an impact on the worsening of prognosis.(10) These are certainly more serious symptoms that require more vigilance and attention.

The non-literate/elementary school level was also associated with the need for a caregiver (p=0.041). Furthermore, most of the information collected referred to the interruption of studies in elementary school (191; 53.2%), according to other studies, which pointed to the same occurrence.(12,20,21) Low education can bring with it the lack of a profession, which, in turn, leads to low income,(12) reflecting the need for care in several aspects.

People who have mental health impairment sometimes manifest problems in performing productive tasks and developing their potential. In addition to this, there are the barriers imposed by educational institutions, which often exclude these individuals from the education process and, consequently, from the job market.(22)

A low education level can complicate the treatment process, as the guidelines issued by health professionals may not be well understood, in addition to increasing the risk of possible errors in medication administration. Such findings corroborate the fact that a caregiver is required in order to meet the needs that these people have.(12,23)

There was also a relationship between people who have a psychotic disorder and the need for a caregiver (p=0.009). Such a need can be justified by the complexity of the disorder itself, as well as by the commitment it brings to the person's life, due to changes in thinking and perception.(24) It is noteworthy that people with psychotic disorders, such as schizophrenia, have greater impairment in socioeconomic life,(24) which ends up generating greater dependence on third parties.

Living with a psychotic disorder can result in deficits in processing speed and in greater damage to verbal memory, i.e., in important cognitive damage, which impacts on their daily life routine.(25) Such cognitive deficiencies limit individuals' social and leisure activity, their interpersonal communication and capacity for self-care and self-management, establishing a significant functional limitation.(26)

Psychotic disorders and schizophrenia are largely correlated with disability, causing impairment of educational and occupational tasks. They are also associated with a higher probability of early death compared to the general population.(27) Findings such as these reflect that people with psychotic disorders need a caregiver to assist them in carrying out daily tasks, as they cannot fully exercise autonomy.(6)

Regarding antidepressant use and its relationship with the need for a caregiver (p=0.026), it is known that depression causes several impacts, which reach different spheres of an individual's quality of life, such as psychological, physical and social, in addition to being considered a risk factor for other chronic health problems.(28) People affected by this disorder present with difficulty concentrating, mood depression, loss of desire to perform previously pleasurable tasks, easy irritation and somatic complaints. This set of symptoms impairs cognitive, work and interactional capacity, losing functionality for everyday life.(29)

In this sense, depression has been the main cause of health problems and disability worldwide, which highlights the need for care for people affected by this disorder. Treatment with antidepressant drugs is an alternative, although studies have shown the adverse effects caused by such medications, such as weight gain, anxiety, phobias, decreased libido, mental confusion, episodes of dizziness, motor agitation, tachycardia and even auditory hallucinations,(30) also becoming a factor of attention for those who care.

As for the limitations of this study, the data source is admitted, as it depends on aspects such as the quality and quantity of the information recorded in the medical records. Such a reality can result in the loss of a more accurate analysis of the reality studied, in this case, the dependence of caregivers.

Conclusion

Factors such as being men, non-literate/elementary school, having a psychotic disorder and using antidepressants were the main findings of this study and should be considered and investigated by the CAPS team, as they have higher rates of dependence on care. The prevalence of the need for caregivers, collected from the medical records of people living with mental disorders treated at the CAPS, pointed to an expressive vulnerability of this population for caregivers. In this sense, attention to this need of a person living with mental disorder will be fundamental to compose the therapeutic project in relation to their psychosocial rehabilitation. As a contribution to the multidisciplinary health team of mental health care, it is suggested that people cared for be the center of attention and, their caregivers, one of the strategies for the psychosocial model, i.e., a fundamental element of the social support network, which will be able to determine the assertiveness in its comprehensive follow-up. In the same way, nursing is pointed out as a professional category capable of making this interlocution of the CAPS device with caregivers, given their natural insertion in the community, and offer support, support and training to caregivers, whether a family member or close person.

Collaborations

Vera I, Oliveira JMB, Oliveira MV, Dias LS, Souza LMM and Lucchese R contributed to project design, data analysis and interpretation, article writing, critical review of relevant intellectual content and approval of the final version to be published.

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