

Disruptions experienced by family caregivers of people with mental disorders: prevalence and related characteristics

Rupturas vivenciadas por familiares cuidadores de pessoas com transtornos mentais: prevalência e características relacionadas

Rupturas vividas por familiares cuidadores de personas con trastornos mentales: prevalencia y características relacionadas

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ABSTRACT

Objective: to identify the prevalence and characteristics of family caregivers of people with mental disorders who, based on their care history, experienced disruptions related to work, study, leisure, and interpersonal relationships. **Method:** a cross-sectional study was conducted with 537 family members of users of Psychosocial Care Centers in the 21st Health Region of the State of Rio Grande do Sul. **Results:** among the disruptions studied, the most prevalent related to leisure (38.7%), home visits by friends or family (34.3%) and work (33.9%). For disruptions in studies and romantic relationships, prevalence corresponded to 9.9% and 8.6% respectively. Among the characteristics related to these disruptions, there were lower education levels, lower income, and a greater degree of dependence of the assisted user. **Conclusion:** through this study, it was possible to deepen the investigations about some repercussions in the lives of family members of people with mental disorders.

Descriptors: Family; Caregivers; Mental health; Community mental health services

RESUMO

Objetivo: identificar a prevalência e as características de familiares de pessoas com transtornos mentais que, a partir da experiência do cuidado, vivenciaram rupturas relacionadas ao trabalho, estudo, lazer e relacionamentos interpessoais. **Método:** estudo transversal com 537 familiares de usuários de Centros de Atenção Psicossocial da 21ª Região de Saúde do Estado do Rio Grande do Sul. **Resultados:** entre as rupturas estudadas, as mais prevalentes foram relacionadas ao lazer (38,7%), frequência da casa de amigos ou familiares (34,3%) e trabalho (33,9%). Para as rupturas de estudos e relacionamentos amorosos, as prevalências corresponderam à 9,9% e 8,6% respectivamente. Entre as características relacionadas a essas rupturas, estiveram menor escolaridade, menor renda e

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maior grau de dependência do usuário assistido. **Conclusão:** por meio deste estudo, foi possível aprofundar as investigações sobre algumas repercussões na vida dos familiares de pessoas com transtorno mental.

Descritores: Família; Cuidadores; Saúde mental; Serviços comunitários de saúde mental

RESUMEN

Objetivo: identificar la prevalencia y las características de familiares de personas con trastornos mentales que, a partir de su papel como cuidadores, vivenciaron rupturas en el trabajo, estudio, actividades de ocio y relaciones interpersonales. **Método:** se realizó un estudio transversal con 537 familiares de usuarios de los Centros de Atención Psicosocial de la Región 21 de Salud del Estado de Rio Grande do Sul. **Resultados:** entre las rupturas estudiadas, las más frecuentes se relacionaron con actividades de ocio (38.7%), visitas a casa de amigos o familiares (34.3%) y trabajo (33.9%). La prevalencia de rupturas con estudios y relaciones amorosas fue 9.9% y 8.6% respectivamente. Entre las características relacionadas con esas rupturas están bajo nivel educativo, bajos ingresos económicos y mayor grado de dependencia del usuario asistido. **Conclusión:** a partir de este estudio se logró profundizar las investigaciones sobre algunas repercusiones en la vida de familiares de personas con trastornos mentales.

Descriptor: Familia; Cuidadores; Salud mental; Servicios comunitarios de salud mental

INTRODUCTION

Psychosocial Care Centers (CAPS), governed by Directive No. 3,088 of December 23, 2011, are the main facilities for mental health care in Brazil. They are responsible for assisting individuals with mental disorders and offering clinical and psychosocial rehabilitation.¹ Currently, these facilities correspond to more than 2,300 care centers, to which approximately 30,000 professionals are linked.²

CAPS operate in a community-based, outpatient-based, and regionalized manner, being classified into 5 forms: CAPS I (Municipalities with population over twenty thousand inhabitants), CAPS II (Municipalities with population over seventy thousand inhabitants) and CAPS III (Municipalities or regions with population over two hundred thousand inhabitants). In addition, there are the CAPS AD (Alcohol / Drugs) that support people with needs resulting from the problematic use of psychoactive substances; and CAPSI

(Children / Adolescents) focused on the psychosocial care of children and adolescents.¹

Within the work process of these facilities, one of the main premises is the incorporation of the user's relatives in treatment. In general, one of the family members is incorporated into the user's treatment plan and constitutes a point of reference for care going beyond that provided by the facilities.¹ However, this process is often a challenge, since the division of care between the facilities and families is marked by issues such as conflicts over responsibility for users and divergent opinions about treatment.³ Thus, increasingly, the user's family, in all its complexity, is understood as a fundamental part of the user's treatment, as well as an important study subject in the field of mental health care.¹

It is noteworthy that the inclusion of the family as a partner in treatment has been documented as a factor that

contributes to a better prognosis of users, especially regarding reintegration and psychosocial rehabilitation. However, it is necessary to consider that the need for care arising from the illness of a member of the family group demands a process of change and reorganization for which the family is often not prepared.⁴

In this regard, there are frequent studies in the literature that point to the perspective that family members of users with mental disorders, when they take on daily care tasks, report experiencing a high level of demand placed on them personally, resulting in considerable limitations to their daily life.⁵⁻⁷

From a subjective point of view, it was highlighted the feeling of fear and anguish related to the possibility of an acute onset, the experiencing of burden, and emotional and mental illness.^{4,6-9} Objectively, reports of changes in sleep routine, work-related and financial losses, disruption of significant bonds and discontinuance of leisure activities stand out.^{6-7,10}

However, although these changes in daily life are well documented in qualitative studies, and even pointed out in quantitative studies as factors associated with the use of psychotropic drugs¹¹ and suicidal ideation,¹² studies that illustrate the magnitude of occurrence of these phenomena are still lacking.

In this regard, based on a representative sample of relatives of Psychosocial Care Centers' users in the 21st Health Region of Rio Grande do Sul, this study aimed to identify the prevalence and characteristics of family

members of people with mental disorders who, based on their care history, have experienced disruptions related to work, study, leisure, and interpersonal relationships.

METHOD

This is a cross-sectional study conducted with relatives from Psychosocial Care Center users in the 21st Health Region of Rio Grande do Sul, Brazil, in 2016.

The 21st Health Region of Rio Grande do Sul is composed of 22 municipalities, as part of which 11 of them are home to 23 CAPS. Of these, four are intended for specific care for alcohol and other drugs users, 3 are intended for the care of the child population, in addition to the 16 CAPS type I and type II that treat adult patients with general mental health demands.

This study included all CAPS type I and type II of the region mentioned above. According to data collected from the coordinators of these facilities, during the research period, approximately 2,900 users were being attended to.

To define the number of participants, a sample calculation was performed considering an estimated frequency of 50% with a margin of 5 points and alpha (α) of 5%, resulting in a minimum n of 384 participants to estimate the prevalence of the event. For association, using a power of 80% with significance level of 5%, a ratio of unexposed to exposed group of 1, Relative Risk of 1.3 and considering a prevalence of 40% in the unexposed group, an indicative sample of $n= 536$ was obtained. Therefore, there was an

addition of 30% to the largest n indicated (n = 536) to consider losses. Thus, the intention was to apply the questionnaire to 697 family members of Psychosocial Care Center users.

Considering the disparity in the number of individuals assisted at the Psychosocial Care Centers, to make the sample representative of the population of studied family caregivers, to define the number of subjects to be investigated at each facility, the proportionality of individuals assisted by the Psychosocial Care Centers was considered.

The selection of participants was undertaken by simple random sampling. Based on the lists of users of the Psychosocial Care Centers, after a draw, the family members were identified and contacted. In the event they met the inclusion criteria, they were invited to participate in the study. The questionnaires were applied at the Psychosocial Care Centers. The inclusion criteria were being of age and being involved in the user's care activities. Being a formally hired caregiver was an exclusion criterion. The percentage of losses among the aimed sample corresponded to 22.95%, related to refusals and difficulties in answering the questionnaire. As such, the final population included under this study was 537 family members to whom the questionnaire was applied in a pre-structured form.

The questionnaires were applied at the Psychosocial Care Centers between February and October 2016 and were performed by 24 previously trained questionnaire surveyors. These surveyors were selected from among undergraduate students of nursing and

psychology courses. As there was no funding to pay for the transportation of the family members or reimburse them for their expenses, the application of the questionnaires was scheduled on the days that family members voluntarily came to the Psychosocial Care Center to accompany users or participate in some activity.

Data quality control was performed in the coding of questionnaires and in the review performed by supervisors when receiving the questionnaires. The supervisors were graduate students from a nursing school. Data entry into the database occurred in Stata 11.1 Statistical Package (Stata Corp., College Station, United States). Inconsistencies in the data were evaluated and corrected when necessary.

This study adopted an own-developed questionnaire, constructed based on literature review, and subsequently evaluated by 2 mental health specialists (20 years of research in the field), and tested in a pilot application with 2 family members of CAPS users.

The outcome of this study is the investigation of disruptions related to work, study, leisure, and interpersonal relationships. For the investigation of these disruptions, based on the statement "*As a result the illness of <name>, have you had to do some of the following things?*" the surveyed family members were asked whether they were required: to stop working; to stop studying; to stop visiting the home of friends or family; to stop engaging leisure activities; or to end a romantic relationship. The answer options were of the yes or no type.

Variables about sociodemographic data of the family caregiver, in addition to the characteristics of the assisted user, such as the degree of dependence, were also investigated. To characterize the degree of dependence of the assisted users, use was made of the of the Instrumental Activities of Daily Living (IADL) evaluation scale¹³ whose score varies from 0 to 16 points. To categorize the results, the cutoff points proposed by the validation study¹⁴ were used: 0 to 5 severe or total dependence; from 6 to 11 moderate dependence and from 12 to 16 slight dependence or independent.

Thus, the independent variables studied were: gender (male; female); age (18 to 40 years; 41 to 50 years; 51 to 60 years; 61 years or more); schooling (9 years of study or more; 5 to 8 years of study; 0 to 4 years of study); per capita income (1 minimum wage or more; 0.5 to 1 minimum wage; up to 0.5 minimum wage); division of care (shares care; does not share care); diagnosis of the user (anxiety; depression; bipolarity; schizophrenia; mental retardation; alcohol/drugs); degree of user dependence (independent; partially dependent; dependent).

In our study, division of care is understood as the sharing of activities related to care, whether instrumental, such as food preparation and monitoring in consultations, or involving more complex tasks, such as emotional support, identification of symptoms, and care in times of acute onset.

The analyses were conducted with the Stata 11 Statistical Package (Stata Corp., College Station, United States). Initially, descriptive statistics were used to calculate the means for numerical

variables as well as their respective standard deviations. It was also used for calculating prevalence concerning each of the strata of the studied variables.

To conduct hypothesis tests, in the case of categorical variables, the chi-square test was used to identify whether there was an association between the independent variables, arranged in line, and the outcome variable, arranged in the column in a contingency table constructed from sample data. The null hypothesis was that the variables were not associated, and the alternative hypothesis was that the variables were associated. Statistical significance was defined as $p\text{-value} < 0.05$. The calculations were performed based on valid data, while missing data were excluded from the analysis.

The study was submitted to and approved, under Case No. 51687715.0.0000.5316, by an accredited Ethics Committee and followed Brazilian regulatory standards and guidelines on research involving human beings - CNS Resolution 466/2012, in addition to the provisions of the Helsinki Declaration. Ethical principles were ensured by guaranteeing the right not to participate in the research from the first telephone contact; anonymity and informed consent, which was read aloud by the questionnaire surveyor in the presence of the subject who, after clarifying his or her doubts, signed the document.

The Guidelines for Strengthening the Reporting of Observational studies in Epidemiology (STROBE Statement) were followed in this study.

RESULTS

The respondents corresponded to 537 family caregivers, 63.3% being female. The mean age was 51.1 years (SD = 13.3), ranging from 18 to 92 years. Among the interviewees, 38.5% reported having up to 4 years of schooling, while 35.2% reported having studied between 5 and 8 years and 26.2%, 9 years of study or more. Regarding income, 37.7% reported per capita income of up to 0.5 minimum wage, 41.2% reported per capita income of 0.5 to 1 minimum wage and 21% per capita income higher than a minimum wage. 59.7% of the interviewees had a partner and 31% had paid work.

Among the studied population, the prevalence of family members who had to stop working after the user's illness was 33.9% (n=182). Those who had to stop studying corresponded to 9.9% (n=53). Regarding disruptions related to leisure activities and visiting the homes of friends or family, prevalence corresponded to 38.7% (n=208) and 34.3% (n=184) respectively. Regarding romantic relationships, 8.6% (n=46) of the subjects reported having ended a relationship due to the user's illness.

The prevalence found for the outcomes related to work disruptions, disruptions to studies, and disruptions to leisure activities according to the sociodemographic characteristics of family members, characteristics of the care provided, and concerning assisted users can be observed in Table 1.

The prevalence found for the outcomes related to disruptions to the visiting of the home of friends or family, and disruptions to romantic relationships according to the sociodemographic characteristics of

family members, characteristics of the care provided, and concerning assisted users can be observed in Table 2.

The disruptions of work activities were higher among individuals with a lower level of education: Family caregivers with 9 years of schooling or more had a prevalence of the outcome of 19.8%, while among those with up to 4 years of schooling, the prevalence was 45.7%. In the same regard, family members with lower income had the highest prevalence of work-related disruptions. Among family members in the lowest income stratum, up to half a minimum wage, the prevalence of the outcome was 40.7%.

Regarding disruption to study activities, the prevalence of the outcome was higher the younger the family caregiver was. While among interviewees aged 61 years or more, the prevalence found was 4.7%, among relatives aged 18 to 40 years, the prevalence of study-related disruptions was 15.4%. Regarding schooling, the prevalence of the outcome was higher the higher the level of education. While among family members with up to 4 years of study, the prevalence of the outcome was 6.3%, among the interviewees with 9 years of study or more prevalence was 14.2%.

There was an even higher prevalence of disruption to study activities when the assisted user had a higher degree of dependence. While among the relatives of independent users the prevalence of these disruptions was 7.1%, among relatives of users with a higher degree of dependence the prevalence was 17.7%.

Regarding disruptions to leisure activities, it can be observed that there was a higher prevalence among female relatives (42.3%), and the occurrence of these disruptions increased to the extent that family members had a lower level of education and income. In the lowest strata of education and income, the prevalence of the outcome was 40.1% and 53.6% respectively.

Regarding the division of care, a higher prevalence of disruptions to leisure activities was observed among family members who did not share care, 48.9%, compared to 30.1% among those who received help from other family members or friends.

Table 1: Prevalence of disruptions related to work disruptions, disruptions to studies, and disruptions to leisure activities according to each stratum of the variables selected for analysis (n=537). Rio Grande do Sul/Brazil, 2016

Variables	N	Work disruptions		Disruptions to studies		Disruptions to leisure activities	
		% (IC)	p	% (IC)	p	% (IC)	p
Gender							
Male	197	30.9 (24.9-37.7)	0.265	8.1 (5.1-12.7)	0.301	32.5 (26.3-39.3)	0.024
Female	340	35.7 (30.7-40.9)		10.9 (8.0-14.6)		42.3 (35.7-64.7)	
Age (years old)							
18 to 40	136	31.6 (24.4-39.8)	0.109	15.4 (10.3-22.4)	0.017	37.5 (29.8-45.8)	0.484
41 to 50	107	43.9 (34.8-53.3)		11.2 (6.5-18.5)		43.9 (34.8-53.3)	
51 to 60	123	32.5 (24.8-41.2)		9.8 (5.6-16.2)		40.6 (32.3-49.4)	
61 or older	171	30.6 (24.1-37.8)		4.7 (2.3-8.9)		35.1 (28.3-42.5)	
Education (years of study)							
9 years or more	141	19.8 (14.1-27.2)	0.001	14.2 (9.3-20.9)	0.048	30.5 (23.5-38.5)	0.001
5 to 8	189	32.3 (26.0-39.2)		10.6 (6.9-15.7)		43.4 (36.5-50.5)	
0 to 4	207	45.1 (38.5-51.9)		6.3 (3.7-10.4)		40.1 (33.6-46.8)	
Renda Per Capita* (minimum wage)							
1 or more	108	14.8 (9.3-22.7)	0.001	4.6 (1.9-10.3)	0.090	24.1 (16.9-32.9)	0.001
0.5 to 1	212	36.5 (30.2-43.1)		9.4 (6.1-14.1)		40.5 (34.2-47.2)	
Up to 0.5	194	40.7 (34.0-44.7)		12.4 (8.4-17.7)		53.6 (39.5-53.4)	
Care division							
Shares care	292	28.4 (23.5-33.8)	0.003	8.2 (5.5-11.9)	0.162	30.1 (25.1-35.6)	0.001
Does not share care	245	40.6 (34.6-46.8)		11.8 (8.3-16.4)		48.9 (42.7-55.2)	
User diagnosis**							
Anxiety	35	37.1 (23.1-53.6)	0.004	5.7 (1.5-18.6)	0.779	40.1 (25.5-56.4)	0.001
Depression	176	24.6 (18.7-31.4)		8.5 (5.2-13.5)		26.7 (20.7-33.6)	
Bipolarity	69	40.6 (29.7-52.3)		13.1 (7.1-22.9)		47.8 (36.4-59.4)	
Schizophrenia	169	41.4 (34.2-48.9)		11.2 (7.3-16.8)		48.5 (24.3-38.0)	
Intellectual Disability	38	47.4 (32.4-62.7)		13.2 (5.7-27.3)		39.5 (25.6-55.2)	
Alcohol/Drugs	21	19.1 (7.6-40.0)		9.5 (2.6-28.9)		28.6 (13.8-49.9)	
Degree of dependence***							
Independent	238	21.1 (16.3-26.6)	0.001	7.1 (4.4-11.0)	0.006	24.3 (19.2-30.0)	0.001
Partially dependent	185	40.1 (33.2-47.1)		8.6 (5.3-13.5)		43.7 (36.8-50.9)	
Dependent	113	51.3 (42.2-60.3)		17.7 (11.7-25.7)		61.6 (51.8-69.5)	

*N=514 / **N=506 / ***N=536

Source: research data, 2016.

Table 2: Prevalence of disruptions related to disruptions to the visiting of the home of friends or family, and disruptions to romantic relationships according to each stratum of the variables selected for analysis (n=537). Rio Grande do Sul/Brazil, 2016

Variables	N	Disruptions to the visiting of the home of friends or family		Disruptions to romantic relationships	
		% (IC)	p	% (IC)	p
Gender					
Male	197	31.5 (25.3-38.2)	0.299	7.6 (4.6-12.1)	0.549
Female	340	35.9 (30.9-41.1)		9.1 (6.5-12.6)	
Age (years old)					
18 to 40	136	29.4 (22.4-37.5)	0.474	4.4 (2.1-9.2)	0.068
41 to 50	107	38.3 (29.6-47.7)		14.2 (8.6-21.8)	
51 to 60	123	36.6 (28.6-45.3)		8.9 (5.1-13.3)	
61 or older	171	33.9 (27.2-41.3)		8.1 (4.9-13.2)	
Education (years of study)					
9 or more	141	25.5 (19.0-33.3)	0.024	2.8 (1.1-7.0)	0.014
5 to 8	189	34.9 (28.4-41.9)		11.6 (7.8-16.9)	
0 to 4	207	39.6 (33.2-46.4)		9.6 (6.3-14.4)	
Renda Per Capita* (minimum wage)					
1 or more	108	20.4 (13.8-28.9)	0.002	5.6 (2.5-11.5)	0.535
0.5 to 1	212	38.7 (32.3-45.3)		8.9 (5.8-13.5)	
Up to 0.5	194	38.1 (31.6-45.1)		8.8 (5.5-13.5)	
Care division					
Shares care	292	28.8 (23.2-33.5)	0.001	7.9 (5.3-11.5)	0.533
Does not share care	245	41.6 (35.6-47.8)		9.4 (6.3-15.6)	
User diagnosis**					
Anxiety	35	22.9 (12.1-39.0)	0.099	2.9 (0.5-14.5)	0.013
Depression	176	28.4 (22.2-35.4)		4.5 (2.3-8.7)	
Bipolarity	69	37.7 (27.2-49.5)		13.1 (7.0-22.9)	
Schizophrenia	169	40.8 (33.7-48.3)		13.6 (9.2-19.5)	
Intellectual Disability	38	42.1 (27.8-57.8)		2.6 (0.4-13.4)	
Alcohol/Drugs	21	33.3 (17.9-54.6)		14.3 (4.9-34.6)	
Degree of dependence***					
Independent	238	20.5 (15.8-26.1)	0.001	7.5 (4.8-11.5)	0.263
Partially dependent	185	43.8 (36.8-50.9)		7.6 (4.5-12.3)	
Dependent	113	47.8 (38.8-56.9)		12.4 (7.5-19.7)	

*N=514 / **N=506 / ***N=536

Source: research data, 2016.

A higher prevalence of disruptions to leisure activities was observed among family caregivers of users diagnosed with schizophrenia (48.5%) and bipolarity (47.8%). It is also noteworthy that the higher the degree of dependence of the assisted user, the higher the prevalence of this outcome. While among relatives of users identified as independent the prevalence was 24.3%, among relatives of users with a higher degree of dependence, the prevalence of

disruptions to leisure activities was 61.6%.

Regarding the disruptions related to the visiting of the homes of friends or family, a higher prevalence was observed in family caregivers who had a lower level of education and income. In the lowest strata of education and income, the prevalence of the outcome was 39.5% and 38.1% respectively.

There was also a higher prevalence disruption to the visiting of the home of friends or family among the interviewees

who did not share care activities (41.6%) and among those who assisted more dependent users. While family caregivers of independent users featured a prevalence of the outcome of 20.5%, among those who assisted users with a higher degree of dependence, the prevalence was 47.8%.

Finally, regarding disruptions to romantic relationships, it can be observed that a higher prevalence was found among family caregivers in the intermediate education stratum. Among family members who had studied between 5 and 8 years, the prevalence of the outcome was 11.6%, compared to 2.8% among family members with 9 years of schooling or more and 9.6% among users with up to 4 years of schooling.

It was also observed that the highest prevalence of disruption to romantic relationships occurred among family caregivers who assisted users diagnosed with alcohol or other drug abuse (14.3%), schizophrenia (13.6%) and bipolarity (13.1%).

DISCUSSION

The repercussions of care on the lives of family caregivers who take on the assistance of people with mental disorders have been the subject of several studies both in Brazil^{8,11,15} and abroad.^{9, 16} There are frequent reports that the routines of these people change as a result of illness and that they start to experience work and financial-related losses, discontinuance of leisure activities and visits to other family members, in addition to the feeling of a physical and psychological burden.^{6-7,10}

Regarding disruptions in the world of work, it is noteworthy that 33.9% (n= 182) of the surveyed family caregivers reported that they had stopped working after the illness of the assisted user. This finding corroborates that pointed to by previous studies^{5,10,17} in that, in many cases, a family caregiver needs to stop working to devote him or herself to the user's care.

It should be emphasized the fact that family caregivers leave the labor market to provide care represents *per se* a considerable impact in individual and social terms. However, it is important to consider that this phenomenon is possibly an aggravating factor of an already complex situation, in which the user has also stopped working. The result is that, due to illness, at least two people no longer contribute to family income, which becomes burdened with extra expenses such as the purchase of medicines and transportation for health services.

Thus, our results help in understanding the association found by previous studies between the absence of paid work and outcomes such as higher degree of burden¹⁷ and presence of minor psychiatric disorders.⁴ It is suggested that in addition to the perspective that people who do not work are prone to spending more time providing care, this association, in many cases, carries with it a history of considerable disruption to the life of caregivers.

Regarding the characteristics of family caregivers who experienced work disruptions and has a lower level of education and lower per capita income, non-division of care and higher

dependence degree of the assisted user stood out.

The higher prevalence of work disruptions among family members with a lower level of education may be related to a previous lower-paid position in the labor market, and, therefore, a lower contribution to family income. Thus, this factor could have led the subject to being elected by the family group as a potential caregiver. It is pointed out that subjects with a higher level of education are more likely to occupy higher-paid positions.¹⁸ However, it should be emphasized that this perspective was not investigated in this study, which is also cross-sectional, thus making it impossible to infer cause and effect.

In this regard, the relationship found between lower per capita income and history of work disruption may represent a product of disruption rather than an aspect that favored the outcome. It is noteworthy that loss to family income has already been pointed in previous studies as a complaint among family caregivers of people with mental disorders.¹⁰

There was higher prevalence of work disruption among family caregivers who assisted users with more severe diagnoses from the point of view of dependence, such as mental disability (47.4%), schizophrenia (41.4%) and bipolarity (40.6%). This finding seems to be corroborated by the relationship of the outcome with the degree of dependence measured through the Activities of Daily Living scale, which indicated a higher prevalence of work disruptions to the extent that degree of dependence of the user was higher.

In addition to disruptions to work activities, as previously pointed out in studies in the field,¹⁰ although without further close examination in terms of the magnitude of occurrence, this study brings to light a perspective little explored in research conducted with caregivers of people with mental disorders: study-related disruptions. It is noteworthy that 9.9% (n=53) of the surveyed family caregivers had to stop studying after the user's illness.

Although this is a low prevalence when compared to the other studied outcomes, this is a perspective that deserves to be highlighted, given the low level of education of family caregivers of people with mental disorders observed in a recurrent way in the studies of the area.^{4-5,8-9}

Regarding leisure activities, the prevalence of disruptions observed was 38.7% (n=208) among the studied family caregivers. In this way, among the studied disruptions, this was the most prevalent. This aspect corroborates that pointed out by another study,¹⁹ which indicated that restrictions on leisure and social activities constitute the main permanent change in the lives of mental health family caregivers. It is noteworthy that the perspective that leisure possibilities among this population are reduced is also pointed out by other studies, which also indicate the absence of this type of activity as an associated factor of burden.²⁰⁻²²

Among the characteristics related to the history of these disruptions were female gender, a lower level of education and income, not sharing care, assisting users diagnosed with schizophrenia, bipolarity, and anxiety as well as caring

for individuals with a higher degree of dependence.

It is noteworthy that there were significant differences in the prevalence of disruptions to leisure activities between men and women who composed the sample, with a higher occurrence of these among women. This is an aspect that contributes to the discussion regarding gender asymmetries observed in the field of informal mental health care, as punctuated by other authors,²³⁻²⁵ who found a higher occurrence of negative repercussions from care in the lives of female caregivers.

The higher occurrence of leisure disruptions among family caregivers who had a lower income is in line with the results of another study,²⁶ which, when investigating, among other issues, leisure among family caregivers of children and adolescents with mental health disorders, found that many leisure-related deprivations, besides being related to the fear of harming the physical and psychological integrity of the assisted individual, were due to a lack of income.

It is noteworthy that different from that observed in relation to work disruptions, in addition to the relationship with the degree of dependence and with diagnoses traditionally associated with a greater degree of dependence (such as mental retardation, schizophrenia and bipolarity),²⁷ a high prevalence of leisure disruptions was found among family caregivers of users diagnosed with anxiety. This is an aspect that may be related to social phobia, often arising in cases of anxiety, thus causing the user and, consequently, his or her family

caregiver to refrain from social activities.²⁸

The prevalence of disruptions related to visiting the home of friends or family, like work and leisure disruptions, featured significant prevalence among the family caregivers studied (34.3% n=184). This finding corroborates that pointed out by another study¹⁰ when indicating that it is common among family caregivers of people with mental disorders to lose social support and experience a breakdown in interpersonal relationships due to the user's illness.

This is a worrying perspective since that social support has been considered essential for the maintenance of mental health and for coping with stressful situations caused by care. In previous studies, for example, satisfaction with family relationships was an important predictor for maintaining the caregiver's quality of life.²⁹

In addition to this perspective, it is noteworthy that the non-division of care was also related to the disruption in the visiting of the home of friends or family, corroborating the teachings of another study¹⁰, that the family is not always organized for care, delegating this task to only one of its members. This situation points to the need for facilities to encourage the caregiver to seek assistance from people in the family as well as to resort to other community resources in the search for a stronger support network and the construction of coping strategies.³⁰

Finally, we highlight the prevalence of disruptions related to romantic relationships, which, as well as disruptions to studies, are still little

explored by studies conducted with caregivers of people with mental disorders. In this study, this type of disruption was present among 9.9% (n=53) of the family caregivers surveyed, thus highlighting the need to deepen investigations about the repercussion of care on the lives of these people, since, in addition to already well-documented dimensions, such as objective overload,¹⁸ a series of other factors can shed light on the best approaches and actions to be taken with this population.

Some limitations presented by this study must be considered. It is a cross-sectional study, which is, therefore, unable to predict causality. It is also noteworthy that the analyzed outcomes were evaluated only for their occurrence, with no additional details on specific aspects of each event. In this regard, future studies could further investigation on the subject.

CONCLUSION

It was observed that disruptions to work, leisure and the visiting of the home of friends and family were recurrent, thus pointing to the perspective that the mental illness of a family member who begins to require care involves a considerable social impact, in addition to the individual and collective impact among the family members. This aspect is also corroborated by the presence of a considerable portion of family caregivers who had to stop studying after the user's illness.

In the personal sphere, a significant prevalence of family members who experienced disruption in a romantic relationship due to demand for care can also be observed. Thus, in addition to the

perspectives reported recurrently in the literature, other complex personal factors may be related to the repercussions that have been documented among this population.

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