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OVERLOAD OF CAREGIVERS OF CHILDREN WITH MENTAL DISORDERS DURING THE COVID-19 PANDEMIC

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Abstract: The coronavirus pandemic brought significant changes in people's lives and, for caregivers of those with mental disorders, there was an increase in the burden. **Goal:** To analyze burden on caregivers of children with mental disorders. **Method:** a cross-sectional, descriptive study with caregivers of children aged four to 12 years in psychiatric outpatient follow-up, who answered questions and the Zarit Burden Interview. **Results:** Fifty caregivers participated, all women, 94% (n=47) mothers; 70% had their children's care suspended during the pandemic; for 46% the children's classes became online and 66% of the patients showed worsening of symptoms. The majority (90%) needed to intensify their activities as caregivers, showed irritability in the presence of the child (86%), perceived damage to their own health as a result of caring (76%), felt uncertainty about how to help the child (96%), believed they needed to "do more" for their child (84%) and felt increased overload during the pandemic (90%). **Conclusions**: the pandemic has increased the difficulties of caregivers of children with mental disorders and health services must also offer care to caregivers.
Keywords: Mental Health, Children, Mental Disorders, Covid-19, Caregivers, Overload.

INTRODUCTION

The pandemic caused by the coronavirus has brought significant changes to the lives of people around the world. Although it had a global impact, more vulnerable parts of the population were especially affected. Children, for example, need a minimum state of order and linearity to organize and develop (FIOCRUZ, 2020). Sanitary measures, social distancing and suspension of classes affected the children's routine and interpersonal relationships. The limitation of circulation resulted in the restriction of services, including health care, which had their capacity affected and limited, harming those people who needed continuous care (Moretti, 2020).

The economic crisis installed during the pandemic, associated with unemployment and reduced income, illness and death of close people, had an important impact on mental health. These changes had implications for children's sense of security and, consequently, for their mental health (Dong, 2020).

Mental, neurological and substance use disorders account for 10% of the global burden and 30% of the non-fatal disease burden. Approximately one in five children and adolescents in the world has a mental disorder. In addition, it is estimated that about half of mental disorders begin before age 14 (PAHO, 2020).

Variables that determine mental health and mental disorders go beyond individual characteristics and biological predisposition and include, for example, competence for social interactions and emotional self-regulation (Haydon & Salvatore, 2022; Romppanen et al., 2021). Social, economic, political and environmental factors, such as national public policies, social protection, living and working conditions, as well as social support from the community, also have an important impact on mental health, an inseparable part of the idea of health. Mental health, like other aspects

of health, is multi-determined by a number of factors, including socioeconomic factors (World Health Organization, 2020).

Although a significant portion of people affected by emergencies experience changes such as distress, insomnia, anxiety, sadness, hopelessness, anger or irritability, pain and fatigue, these tend to improve over time. The prevalence of common mental disorders such as depression and anxiety, however, is expected to more than double in a humanitarian crisis (World Health Organization, 2020). It is possible to infer, therefore, that the health emergency today foreshadows the need for a contingency plan for mental health in the near future (Hallal et al., 2020).

Children with mental disorders have multidisciplinary demands. Considering the significant social vulnerability that most of them present and the context of social distancing, which restricts the necessary global care, it is possible to infer a worsening in the conditions and greater demand for caregivers (Esposito & Savoia, 2006). Caring for a child with a mental disorder entails important changes in the caregiver's life (Daltro, Moraes, & Marsiglia, 2018; Maridal et al, 2021).

This study aims to investigate the burden on caregivers of children with mental disorders during the pandemic.

METHOD

Cross-sectional and descriptive study, with a convenience sample.

PARTICIPANTS

A non-probabilistic sample of caregivers of children aged between four and 12 years, who perform multidisciplinary follow-up at the child psychiatry outpatient clinic of a high complexity hospital, were invited to participate. The study was carried out between November 2020 and May 2021.

Inclusion criteria were being an informal caregiver of the child and agreeing to participate in the study; exclusion criteria were being a caregiver of a child in the first consultation at the clinic and having limitations that prevented their participation (eg, cognitive impairment).

MATERIAL

- ***Quizz:*** age, sex/gender, residence, degree of kinship and caregiver's education; history of illness and mental disorders in the family; family income; diagnosis of the child and treatment performed; recent changes in areas such as education, access to health services, changes in children's symptoms and behavior; financial difficulties.

- ***Shortened version of the Zarit Burden Interview:*** Brazilian version of the Burden Interview Scale, reduced version (Gratão et al., 2019), which assesses health, social and personal life, financial and emotional situation, well-being and interpersonal relationships.

PROCEDURE

Initially, the daily schedule of the child psychiatry team was consulted to identify patients and caregivers present. Then, caregivers were approached and invited to participate if they met the inclusion criteria. Those who agreed to participate received detailed information about the research and signed an informed consent form. Then, they responded individually to the instruments in one of the outpatient rooms.

DATA ANALYSIS

Descriptive statistical analysis was performed.

ETHICAL ASPECTS

Study approved by the Research Ethics Committee of the Faculty of Medicine of São José do Rio Preto (CAAE: 38250920.4.0000.5415), Opinion Number:

4,300,354, of September 25, 2020.

RESULTS

A total of 120 caregivers were approached. Of these, 50 were excluded according to the exclusion criteria used and 20 refused to participate. Therefore, 50 caregivers were included in the study.

The characteristics of the children seen at the clinic and under the responsibility of caregivers are shown in Table 1.

Most children were between 8 and 12 years old, were male and all were on medication. The most frequent diagnosis was hyperactivity (hyperkinetic disorder), followed by mild mental retardation, depression, and oppositional and defiant disorder.

Each caregiver interviewed was accompanying a single patient and their characteristics are shown in Table 2.

All caregivers were women, especially mothers (94%), who reported taking care of their children full-time. More than half had completed high school, followed by complete elementary school.

Most caregivers (72%) do not have a diagnosis of mental disorder, but the others (28%) are undergoing drug treatment for some disorder, mainly depression and anxiety.

Changes in family, academic and occupational life, resulting from the pandemic, are presented in Table 3.

For most children (70%) there was an interruption of multidisciplinary care during the pandemic. For more than half (52%) the schools provided material to be used at home with the help of the caregiver and for 46% the classes were kept online.

Most children showed worsening of symptoms (66%) and 20% started to show new symptoms during the pandemic. For 44% of families, relationships worsened during the period and 36% had losses in family income.

For 66% of the participants, some family member or friend had COVID, 14% needed hospitalization and 4% reported that there was death from the disease.

Data about the burden of caregivers are presented in the table 4.

Only 10% of caregivers reported not having needed to dedicate more time to the child during the pandemic, which resulted in less time for themselves. More than half of the caregivers (62%) reported irritability and tension in the presence of the child and only 24% did not identify any damage to their own health during the period.

Approximately half of the caregivers reported uncertainty about what to do to help the child (64%) and believed they must be "doing more" (42%). Caring for the child during the pandemic was perceived as an overload by almost all the participants (90%).

DISCUSSION

The data from this study indicated that the caregivers were all women, mainly mothers of the children seen at the child psychiatry outpatient clinic. Data from around the world indicate that it is predominantly women who assume the role of informal caregiver in families, possibly due to expectations regarding gender roles (Sharma, Chakrabarti, & Grover, 2016; White Swan Foundation, 2018).

When the burden associated with the role of caregiver is compared between men and women, data indicate that the former use more adequate coping strategies (eg, problem-focused, distancing) to deal with stress than women (eg, denial, avoidance).) (Sharma et al., 2016). Thus, the predominance of female caregivers, the less effective coping strategies usually used by them, as well as the negative impact of caring on quality of life (Daltro et al., 2016), emphasize the need to integrate the caregiver into the therapeutic plan. of the patient (eg support groups).

Variables	Participants	%
Age		
5 to 7 years	7	14
8 to 12 years	43	86
Gender		
Male	40	80
Female	10	20
Mental disorder (CID 10)		
F 90 - Hyperkinetic disorders	15	18,75
F 70 - Mild Mental Retardation.	11	13,75
F 32 - depressive episodes	9	11,25
F 91.3 - Defiant and oppositional disorder	9	11,25
F 41 - Other anxiety disorders	5	6,25
F 84 - Pervasive developmental disorders	5	6,25
G 40 - Epilepsy.	5	6,25
F 39 - Unspecified mood (affective) disorder	4	5
F 71 - Moderate Mental Retardation	4	5
F 06.9 - Unspecified mental disorder due to brain damage and dysfunction and physical illness	4	5
F 91 - Conduct disorders	3	3,75
F 20 - Schizophrenia	2	2,5
F 98 - Other behavioral and emotional disorders with onset usually during childhood or adolescence	2	2,5
F 31 - bipolar affective disorder	1	1,25
F 81 – Specific disorders of the development of school skills	1	1,25

TABLE 1 - Sociodemographic and clinical characterization of children under the responsibility of caregivers (N=50)

Variables	N	%
Degree of kinship with the child		
Mother	47	94
Maternal grandmother	2	4
Maternal aunt	1	2
Education		
Complete elementary school	10	20
Incomplete elementary school	7	14
Complete High school level	26	52
Incomplete High school level	5	10
Complete University level	1	2
Incomplete University level	1	2
The person has a diagnosis of mental disorder		
No	36	72
Yes	14	28
Caregiver mental disorder (CID-10)		
F 32 - Depressive episodes	7	41,18
F 41 - Other anxiety disorders	6	35,30
F 41.0 – Panic disorder	2	11,76
F 20 - Schizophrenia	1	5,88
F 19 – Mental and behavioral disorders due to multiple drug use and the use of other psychoactive substances and related illnesses.	1	5,88

TABLE 2 - Characterization of caregivers (N=50)

Variables	N	%
Was there an interruption of any multiprofessional assistance service?		
The person was not followed up with a multidisciplinary team	8	16
Yes, calls have been suspended	35	70
There was no interruption, followed in person	3	6
There was no interruption, however, the follow-up continued through information and communication technologies	4	8
With the closing of schools, how was school learning?		
Schools provided materials to be applied at home by the primary caregiver	26	52
Classes were held by an online platform	23	46
There was total interruption of teaching by schools	1	2

Has the person noticed a worsening in the child's symptoms?		
There was no worsening	6	12
The person has had a worsening of the symptoms they had	33	66
The person has new symptoms	10	20
The person got worse and had new symptoms	1	2
With more staying at home and closeness between family members, what has changed in the way they relate?		
There was no change in the relationships	23	46
Relationships got worse (e.g., intensified fights)	22	44
Relationships have improved (eg, less fighting, more activities together)	5	10
Has there been a change in family income?		
No	32	64
Yes, due to dismissal or suspension of the employment contract	11	22
Yes, due to the impossibility of keeping the work establishment open	1	2
Yes, due to the decrease in consumption of the population in the sector that works	6	12
Has any family member or close friend had COVID?		
No	8	16
Yes, the person had mild symptoms	24	48
Yes, the person had moderate symptoms and was hospitalized	7	14
Yes, the person had severe symptoms and died	2	4

TABLE 3 - Impact of the Covid-19 pandemic on family life

Variables	**0**	**1**	**2**	**3**	**4**
More time devoted to the child and less time devoted to self	10%	2%	**54%**	10%	24%
Irritability in the child's presence	14%	4%	**62%**	14%	6%
Health damage due to the child	24%	10%	**50%**	8%	8%
Uncertainty in how to help the child	4%	6%	**64%**	16%	10%
Feeling of having to do something more for the child	16%	14%	**42%**	16%	12%
Child care burden during the pandemic of Covid-19	10%	2%	18%	30%	**40%**

0 = Never; 1 = rarely; 2 = sometimes; 3 = often; 4 = always

TABLE 4 - Caregiver burden (N=50)

The process of deinstitutionalization of patients with mental disorders and their treatment in services offered in the community itself means that the family must receive support to assist in the care provided within the family context. However, the complexity of caring for a patient with a mental disorder, associated with the difficulties of existing services to meet all the demand, puts even more burden on the caregiver. It has been pointed out in the literature that families, who constitute the fundamental support of these patients, are poorly prepared to play this role (Daltro et al., 2018). In addition, the pandemic had a negative impact on the mental health of the population and on the care offered to patients with mental disorders.

According to the World Health Organization (World Health Organization, 2021), one in seven young people (10 to 19 years old) has a mental disorder, the most prevalent disorders being depression, anxiety and conduct disorder. In Brazil, mental disorders in childhood and adolescence are highly prevalent and are estimated to affect one in 10 children (Anselmi et al., 2010; Fleitlich & Goodman, 2002).

An investigation carried out at the child psychiatry outpatient clinic of the institution where this study was carried out indicated a predominance of males among the patients and, as the most prevalent, attention deficit/ hyperactivity disorder, mental retardation and conduct disorder (Machado et al., 2014).).

Externalizing (eg, attention deficit/ hyperactivity disorder, conduct) and internalizing (eg, depression, anxiety) disorders are highly related to depression and maternal burden. The burden tends to be even higher in minorities and in low-income populations (Wagner & Valdez, 2020), such as that seen at the institution where the study was carried out.

The Covid-19 pandemic has brought new challenges for families and caregivers of children and adolescents with mental disorders. In addition to the interruption of care (including caregivers who also had mental disorders), there was also interruption of school activities or online classes, social isolation and financial and personal losses. All these factors may have contributed to the worsening presented by an important part of the children and to the burden of caregivers, who needed to intensify care.

The data from this study indicate that it is necessary to pay attention to the difficulties of caregivers and promote care strategies focused on their needs.

CONCLUSIONS

The children showed worsening of pre-existing symptoms during the pandemic period, contributing to an increase in caregiver burden. Without the necessary preparation to meet the needs of children, high rates of overload can be observed. Thus, it is necessary to expand access to multidisciplinary care in order to minimize the damage caused by the pandemic to the mental health of children and caregivers.

Although the data found are compatible with the literature, the convenience sample used does not allow generalizations.

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