Paidéia
2023, Vol. 33, e3312.doi:https://doi.org/10.1590/1982-4327e3312
ISSN 1982-4327 (online version)

Psychology of Health

Children and Adolescents with Depression: Perception of Family Caregivers

Eduarda Ramis Pontes[1]
Mara Regina Santos da Silva[1]
Sandra Dal Pai[1]
Elena Bustos Alfaro[1]
Alessandro Marques dos Santos[1]

Abstract: Depressive disorder affects people of all ages, including children and adolescents, compromising the family's quality of life. This study aimed to: (1) analyze the perception of family members about the experience of living with and caring for children and adolescents with depressive disorder; (2) identify the resources mobilized by families to respond to the demands of child and adolescent depression. Data, collected by interviews with 26 family members of children/adolescents linked to two Care Centers, were subjected to thematic analysis. The results showed the perception of family caregivers regarding the depressive disorder, to the child and to family life, and suggest religiosity and the nuclear and extended families as resources they use the most. Therefore, there is a need for professionals to expand assistance to all those who live with children/adolescents with depression, since this disorder impacts family life.

Keywords: depression, children, adolescents, caregivers, resilience (psychology)

Crianças e Adolescentes com Depressão: Percepção de Familiares Cuidadores

Resumo: O transtorno depressivo atinge pessoas de todas as idades, incluindo crianças e adolescentes, comprometendo a qualidade de vida da família. Este estudo teve como objetivo: (1) analisar a percepção de familiares sobre a experiência de conviver e cuidar de crianças e adolescentes com transtorno depressivo; (2) identificar os recursos mobilizados pelas famílias para responder às demandas da depressão infantojuvenil. Os dados, coletados através de entrevistas realizadas com 26 familiares de crianças/adolescentes vinculados a dois Centros de Atenção, foram submetidos à análise temática. Os resultados expressam a percepção dos familiares cuidadores em relação ao transtorno depressivo, à criança e à própria vida familiar, e apontam a religiosidade e as famílias nuclear e extensa como os recursos que mais utilizam. Conclui-se pela necessidade de os profissionais ampliarem a assistência para todos que convivem com a depressão infantojuvenil, uma vez que este transtorno impacta na vida familiar como um todo.

Palavras-chave: depressão, crianças, adolescentes, cuidadores, resiliência (psicologia)

Niños y Adolescentes con Depresión: Percepción de los Familiares Cuidadores

Resumen: El trastorno depresivo afecta a personas de todas las edades, incluidos niños y adolescentes, comprometiendo la calidad de vida familiar. El objetivo de este estudio fue: (1) analizar la percepción de los familiares sobre la experiencia de convivir y cuidar de niños y adolescentes con trastorno depresivo; (2) identificar los recursos movilizados por las familias para responder a las demandas de la depresión infantil y adolescente. Los datos, recolectados de entrevistas realizadas con 26 familiares de niños/adolescentes vinculados a dos Centros de Atención, se sometieron a análisis temático. Los resultados muestran la percepción de los cuidadores con relación al trastorno depresivo; al niño y a la vida familiar; y apuntan a la religiosidad y a las familias nucleares y extensas como los recursos que más utilizan. Se concluye con la necesidad de que los profesionales amplíen la asistencia a todos los que conviven con la depresión infantil, ya que este trastorno impacta la vida familiar como un todo.

Palabras clave: depresión, niños, adolescentes, cuidadores, resiliencia (psicología)

Depressive disorder spreads as a global public health problem with increasing prevalence (World Health Organization [WHO], 2017). Approximately more than 264 million people suffer from symptoms of depression, including children and adolescents, most often females (Chee et al., 2020; Russotti et al., 2020; WHO, 2017).

In Brazil, from 8 to 12% of the children and adolescent have this disorder and about 50% of these young people

---

[1] *Universidade Federal do Rio Grande, Rio Grande, RS, Brazil.*

Article derived from the master's thesis of the first author under the supervision of the second, defended in 2018, at the Graduate Program in Nursing of the Universidade Federal do Rio Grande. Acknowledgments: To the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior – CAPES, for the scholarship Bolsa DS granted to the first author.

Correspondence address: Mara Regina Santos da Silva. Universidade Federal do Rio Grande. Rua General Osório, 1-109, Rio Grande, RS, Brazil. CEP 96.201-900. E-mail: marare2021@gmail.com

remain untreated, which contributes to the worsening of the condition and the increase in mental disorder rates in adult life (Bodner et al., 2018; WHO, 2017). The disease hinders the performance of daily activities, directly impacting the quality of life of a large contingent of children and adolescents and their families (Bodner et al., 2018; Kalin, 2021).

Although the symptoms are not easily identified at this stage of life, the literature highlight some symptoms as the main symptoms. Among these, apathy, lack of interest in the activities of daily living, including social interaction with peers and play, weight change with significant loss or gain without changes in diet, insomnia or hypersomnia, agitation or psychomotor retardation, fatigue, difficulty concentrating, feeling of worthlessness, irritation, instability, propensity to anger crises with highly lethal ideas and suicide attempts (American Psychiatric Association [APA], 2014; Chee et al., 2020; Lippard & Nemeroff, 2020).

In the family context, children and adolescent depression can trigger feelings of powerlessness and insecurity in their kin, since they feel unqualified to take care of the child or adolescent, due to little knowledge about the disease and fear of seeing the young person in this critical situation. These feelings reveal the difficulty of families in coping with the disorder, leading to stress, tensions, conflicts, disharmony, and requiring significant changes in the family's organization (van Harmelen et al., 2016).

In the daily life of the family, the priority often becomes the needs of the child or adolescent that include, among others, coordinating their daily activities, administering medication, accompanying them to health services, managing crisis episodes, and paying expenses (van Harmelen et al., 2016). These changes require readjustment of roles among family members, which demands flexibility, connectivity, and mobilization of social and economic resources to be able to manage the situation they experience.

Notably, each family has its own way of facing challenging situations, such as one of its members with depressive disorder. Some families can mobilize their own resources, unite, reorganize, and even strengthen themselves from the experience, so that family members develop skills to manage the crisis (Walsh, 2016).

Although other families need an external support network and more time to reorganize, they are also able to respond positively to this adverse situation and preserve themselves as a family unit. However, in different families depression can cause such an expressive impact that it leads to chaos and suffering, causing the loss of the family unit. Therefore, the first two situations are aligned with Walsh's (2016) conception of family resilience, which considers it as an active process of resistance, restructuring, and growth in response to the crises and challenges that the family encounters during its life cycle.

To this author, three processes support family resilience. The first involves the ability of its members to extract a meaning of the adversity in which they are immersed, called the belief system. The second refers to the family's ability to maintain clear communication, with open emotional expression, and to commit to the search for collaborative resolution to problems. The third, with the function of mitigating the impact of the situation on the family, comprises flexibility in the family organization, cohesion among its members, and the identification and mobilization of internal and external resources of the family (Walsh, 2016).

The concept of family resilience, used in this study as a theoretical reference, is justified by the fact that it involves two basic conditions. First, family's exposure to an adverse experience, potentially capable of producing a strong negative impact, represented in this study by child and adolescent depression. Second, the manifestation of a positive response, despite the adversity in which the family is immersed, which implies recognizing the existence of certain conditions or processes that help them cope with this situation, represented by Walsh's (2016) "key processes in family resilience".

Based on this theoretical perspective, we developed this study considering the strong impact that depressive disorder causes not only on the life and development of children and adolescents who manifest it, but also on the family and particularly on the caregiver. This study aims to: (1) analyze the perception of family members about the experience of living with and caring for children and adolescents with depressive disorders; (2) identify the resources mobilized by families to meet the demands of child and adolescent depression.

Methods

Participants

This is an exploratory qualitative study conducted according to the recommendations of the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007). The study was developed with 26 family caregivers who live daily with children/adolescents with depressive disorder, who agreed to participate in the study and signed an informed consent form. Caregivers accompanied the children or adolescents in the appointments in two Child Psychosocial Care Centers (CAPS-i) in which they were linked. These CAPS-i are based in the Southern region of Brazil, provide care to children and adolescents up to 18 years old, with mental disorders, residents in their coverage areas, and develop therapeutic activities with family members and guardians on a regular and permanent basis (Ministério da Saúde & Conselho Nacional do Ministério Público, 2014).

These participants were selected by convenience, with the collaboration of the professionals who work in the services, considering as inclusion criteria: being a family caregiver and living daily with the child or adolescent diagnosed with depressive disorder, according to the Diagnostic and Statistical Manual of Mental Disorders-5 (DSM5) (APA, 2014); being at least 18 years old; the child or adolescent being monitored at CAPS-i. The exclusion criteria were being a relative of a child or adolescent with depression, but not having attended the CAPS-i during the data collection period; and being unable to verbally answer the questions in the interview script.

Instrument

Semi-structured interviews, guided by a four-part script, were applied. The first part, focused on the interviewees characterization, included questions about: sex, age, skin-color, degree of kinship with the child or adolescent, marital status, family income, professional activity or occupation, educational level, and religion. The second, focused on the characterization of children and adolescents with depressive disorder, sought information on: sex, age, educational level, and follow-up time at CAPS-i.

The third part was directed to the perception of family members about child and adolescent depression. The fourth addressed the intra- and extra-family resources mobilized by families to respond to the demands of child and adolescent depression.

Procedure

Data collection. Data were collected from December 2017 to March 2018. It began after the participant was informed about the objective, the justification, the risks, and the benefits of the study and signed an informed consent form. The interviews were conducted individually, in rooms made available by the services that hosted the data collection, lasted on average one hour, were recorded with the authorization of the participants, and later transcribed in full. To preserve the privacy of the participants, they were identified by a code, composed of the letter "P" followed by a figure that corresponds to the order in which the interviews were conducted (P_1; P_2; P_3; P_{26}).

Data analysis. The data were subjected to thematic analysis that, according to Minayo (2013), is a procedure that enables identifying the nuclei of meaning in a given empirical material, in this study, the nuclei of meaning converge to answer the proposed objective guided by the conception of family resilience. There are three stages that characterize it: the pre-analysis, the exploration of the material, and the processing of the results.

Initially, a fluctuating and exhaustive reading of all interviews was performed, identifying significant expressions or words, whose presence or frequency contributed to elucidate the study object. The contexts in which these expressions assumed meaning were also demarcated. These elements were organized in charts to help the classification and aggregation of data (Minayo, 2013). Then, the intermediate thematic nuclei were created, which were classified based on the meaning that approximated the corresponding data.

The third stage was dedicated to the creation of three final thematic nuclei (Minayo, 2013), which translate the results: child and adolescent depressive disorder based on the perspective of family caregivers; the child or adolescent with depressive disorder based on the perspective of family caregivers; the family from the perspective of caregivers of children/adolescents with depression. The first nucleus encompasses the aspects related to how the family members perceive the problem, its causes, and the symptoms. In the second nucleus, the personal characteristics of the child or adolescent with depression were included in the view of the caregivers. Furthermore, the third comprised the impact of the depressive disorder on the organization of the family and the necessary and available supports.

Ethical Considerations

The study was approved by the Research Ethics Committee of the Universidade Federal do Rio Grande, CAAE No. 79344117.7.0000.5324, and the determinations of Resolution No. 466/12 of the National Health Council (CNS) were followed. All participants signed an informed consent form. The interviews recordings were used only in the study and after five years will be destroyed.

Results

The study included 26 family members of 24 children and adolescents. From one of the families, two mothers participated (P_{10} and P_{11}), who were in a homosexual union, one being the biological mother and the other, mother by affinity (socio-affective). From another family, both father and mother participated (P_4 and P_5). Among the 26 participants, 23 were female and three were male, with a predominance of White (20), followed by four Mixed-race and two Black people. Age ranged from 31 to 69 years old, with predominance in the age groups 31–39 with 13 participants, followed by 10 aged from 40 to 49 years old. Regarding kinship, 21 were mothers of the children and adolescents, two were grandmothers, two were fathers, and an uncle. One father (P_4) accompanied the adopted child at CAPS-i since the mother was in a high-risk pregnancy (P_5). Another participant (P_{23}) was the uncle of an adolescent who was being monitored at the CAPS. In total, 14 participants were married, four were single, seven were divorced, and one was a widower.

Regarding income, five participants reported that the family lived on less than one minimum wage; 10 with up to one minimum wage; eight with up to two minimum wages, and three with up to three minimum wages. Among the occupational activities, most were called homemakers (7), housekeepers (4), retired (3), secretaries (2), security guards (2). The others were a teacher, a worker in a child protection council, a motorcycle courier, a commercial manager, a manicurist, a production assistant, a sales woman, and one was unemployed. Regarding educational level, one participant had completed higher education, two had incomplete higher education, 13 completed high school, one completed middle school, and nine had incomplete middle school. Participants declared themselves

Catholics (6), Evangelicals (5), *Umbandistas* (5), and 10 did not belong to a specific religion, but stated believing in God.

In total, 17 of the children/adolescents were female and seven were male; eight were aged up to 12 years and 16 were aged from 13 to 18 years; 20 were attending middle school, three high school, and one had completed high school. The follow-up time in CAPS-i ranged from three months to eight years.

The perceptions of family members about the experience of caring for children/adolescents with depressive disorder were grouped into three thematic nuclei. The first brings the perception of 24 participants who considered depression as a disease that needs to be treated: "I always told my husband that there was something wrong, my daughter isn't like that, she's sick" (P_6). Two others considered depression as an inappropriate behavior, resulting from lack of education and the need to draw attention, as in the following statements: "I don't smooth things over, I think a good percentage of her [the adolescent] depression is a no-shame behavior" (P_{20}).

Most participants indicated parental rejection as the triggering cause of child and adolescent depression: "She [the adolescent] was rejected by her father since she was in her mother's womb, she never had any friendly contact, hugs, affection, attention. He always looked upon her as a bother" (P_{12}). Moreover, the loss of significant others due to death or parents divorcing and sexual abuse and issues related to being transgender were mentioned as possible causes: "He [the child] closed himself off from his feelings and began to regress in some areas, after the death of his brother and with the [sexual] abuse it got worse. Another boy abused him, at his fathers' house" (P_{10}):

> The CAPS-i nurse told me: Mother, your [adolescent] daughter identifies as a boy, he assumes the male gender. I almost cried after hearing that, it was like a mourning to me, as if my daughter had died! That's how I feel. I've son now, I'll have to know him. I raised a girl for 13 years, the love is the same, but I need some time (P_9).

Regarding symptoms, most family members reported social isolation: "She [the adolescent] started to isolate herself socially, she was a child who made friends easily, everyone adored her. Suddenly she isolated herself until she had no more friends" (P_{22}). Then they indicated the irritation and the aggressiveness, as evinced in the following statement: "He [the child] has always been very aggressive, he has threatened me with a knife, I took the knife out. I had to take everything that was dangerous away" (P_5). Poor school performance, sadness, crying apparently for no reason, and auditory and visual hallucinations were also mentioned, as well as changes in eating behavior and drastic changes in appearance: "She [the adolescent] sees things and hears voices, she has a habit of thinking that people don't like her" (P_{25}):

> Once she [the adolescent] ate nothing for three days, it was right around the time when we were planning her 15th birthday party. She said she wasn't going to eat, until one day I asked: Do you wanna buy a coffin or do you wanna rent a dress for your 15th birthday? (P_{15}).

In this context, most participants consider depression as a disease that requires treatment and that family organization, rejection of one of the parents, physical and psychological violence, sexual abuse, stigma and prejudice are influencing factors; whether experienced within the family or at school and in the community, where their everyday relationships take place.

The second thematic nucleus deals with the perception of family caregivers about children/adolescents with depressive disorder, 11 had associated comorbidities. Among them, five had seizures: "Other than depression, she [the adolescent] has seizures. They [physicians] say that she was born with this condition, there's no cure" (P_2); two had attention deficits: "He [adolescent] has a lot of troubles learning, this attention deficit almost drives me nuts. We struggle to teach him, sometimes he concentrates, but then he gets distracted, now this medication [risperidone] makes him more focused" (P_{14}); three suffered from panic disorder: "she [the adolescent] had a panic attack. It was in May of last year [2017]. I talked to my boss, she allowed me to take a vacation, I didn't wanna leave her alone, because she couldn't sleep, we stayed with her" (P_{16}); and two had body dysphoric disorder. The adolescent daughter of P_{15} had panic disorder associated with body dysmorphic disorder.

For some family members, the suicide attempt and the seek for treatment was something unexpected, as they had not noticed symptoms or behavior change until then. Another 12 participants revealed that the children had already attempted suicide by hanging: "My son [adolescent] was in a deep depression, he tried to kill himself by hanging at the age of four. Since then, he has tried to kill himself using wires, ropes, scissors, and everything else he sees in front of him" (P_{21}); using cutting material: "He [adolescent] said that he tried to cut his wrists twice, he researched on the internet how to kill himself, looking for the right way to cut his wrists" (P_{14}); with medications: "She [adolescent] was hospitalized, had detoxification and all the procedures, because she took a lot of pills" (P_{20}). Some have attempted suicide several times. The daughters of P_{16} and P_6 attempted by cutting their own bodies and taking medicine; the son of P_8 attempted by hanging and drowning and the son of P_{21} by hanging and cutting. In the parents' perception, this experience generates fear and much anguish:

> To be honest, none of us noticed anything, everything happened very fast, in a week our life turned upside down. He [adolescent] asked to be hospitalized, said he was scared since he had already tried to kill himself. It was the worst thing I have ever heard (P_{14}).

In total, 14 participants reported their children practiced self-harm, mostly by cutting their own body:

> I found out that she [adolescent] cut herself, I hadn't noticed, since she was wearing long sleeves, I didn't see. One day I walked into her room and saw her with her arms cut. She mutilated herself with the sharpener blade, razors, and pencil sharpeners. The fact that she cut herself shocked me! That was the limit, I had to stop her (P_9).

They also performed flogging, slaps, and punches, aiming at self-harm: "Anything makes her angry and she screams, self-harming" (P_2). Three children/adolescents used more than one method of self-harm. The son of P_8 self-harmed with cuts, flogging, slaps, and punches and the daughters of P_6 and P_{15} with cuts, slaps, and punches. Furthermore, 12 children/adolescents presented suicidal ideation: "He said he wanted to die to be with his brother, they even gave me some drawings that he [child] made. They explained that the drawings meant that he wanted to die to be together with his brother, so he was referred to the psychiatrist" (P_{10}). Only one adolescent, the son of P_{14}, was hospitalized for presenting risk to his own life.

The coping with childhood depression by family members has a greater impact when the comorbidities of the disease affect the family structure and base. Based on the family perspective, depression was associated with a series of psychiatric comorbidities, which was defined by family members as the onset of the disease. However, several concomitant factors hindered the family's perception. While children and adolescents were depressed, suicidal ideation and attempt, panic disorder, self-mutilation and self-harm emerged, which led to a distorted and confused perception of depression and its associated factors within the family.

The third thematic nucleus deals with the family from the perspective of caregivers of children/adolescents with depression. When asked about family functioning, P_1, P_9, and P_{15} considered having a united family: "It's a critical moment and it may become even more critical, but it united me and my husband. My husband stood by my side all the time" (P_9). Families struggled to overcome adversity and have a good coexistence with the nuclear and extended family: "The follow-up at CAPS-i helped us a lot, we began to better understand the problems, to accept, and try to solve them. Thus, we always walk together" (P_1).

For P_7, P_{14}, P_{16}, P_{21}, P_{23}, and P_{24}, the relationships between family members were disharmonious, with fragile bonds, poor communication, and difficult relationship with the extended family. Another 15 relatives understood that their families had troubled relationships, with frequent arguments and physical or verbal aggression. The following testimonies exemplify the troubled context:

> The relationship is very difficult, we can't take her out of her comfort zone. She [adolescent] screams, she touches a sore spot, if she says something that hit you, she's happy, she thinks it's great. she bullies her sister until for long periods, she bullies me, bullies her sister, bullies her grandmother. She wanna destroy our moral. Living with her is very difficult (P_{22}).

To preserve children and adolescents, 21 caregivers reported changing their habits to meet the needs of children and adolescents. They reported due to the need to accompany children and adolescents in CAPS-i and to administer the medications, they were deprived of studying, working, or going out for leisure activities: "I deprive myself of many things to take care of him [adolescent]. I had to quit my studies last year, because [he] was hurting himself and drinking vinegar with salt" (P_8). Furthermore, participants pointed out the need to increase the daily time of coexistence to supervise depressive behavior, for fear of self-harm. Consequently, 18 participants said they felt physically and mentally overwhelmed due to the numerous tasks they perform on a daily basis. The following statement exemplifies the context:

> I feel very overwhelmed, I must do everything, because my husband doesn't understand her. He doesn't understand that after all she [adolescent] is young and sick. My son understands the disease, however he is also young, I don't want him to worry, I don't want him to take this responsibility for his sister, but even so, he tries to help me (P_{24}).

In total, eight family members did not feel overwhelmed caring for a child/adolescent with depression: "I did'nt change my behavior with him [child], it did not affect our daily lives" (P_{11}). Another eight did not change their lifestyle habits after the disorder: "For me, my [adolescent] daughter's depression doesn't influence anything. I would take care of everyone the same. For me, taking care of her doesn't take any work" (P_1).

When asked about who or where the family seeks help when they need it, family members referred to religiosity, the nuclear family itself and the extended family, including close people such as bosses. Faith, considered an essential part of religiosity, was mentioned by 16 participants as a force-mobilizing agent, making it easier to develop hope and optimism.

Participants understand that child and adolescent depression represents a learning experience and thus they begin to value common moments, such as simple leisure activities. In these cases, child and adolescent depression is not only harmful to these families, but also has a potential aggregating function capable of strengthening the relationships among family members. For P_7, faith is the support they find in moments of solitude. For other families, faith is what alleviates the burden of depression: "I believe someday everything will get better, one day everything will be fine, I just ask God to give me strength" (P_1). "I talk to God every day, even if I don't follow any religion, He is my counselor, He is my support, my strength comes from this belief" (P_{12}).

> Because I pray and because I know this won't last forever, I can hold tight. I live with this situation wanting to change, I don't accept it [depression], but by faith, I believe that all this has a remedy,

> it is not permanent. Sometimes people have faith, but they don't know that they have this strength to ease the pain (P_7).

In total, 14 participants reported the nuclear family is the most solid resource and makes it easier to face the adversities of child and adolescent depression, since its members get closer, support each other, and participate in taking care, often giving up their personal interests for collective well-being. The support caregivers receive materializes in a rotation to accompany the children/adolescents in the CAPS-i, management of crisis situations and medications, and supervision when the child/adolescent has ideas or suicide risk.

This type of resource reliefs the burden of the main caregiver, precisely since a greater number of family members share the responsibilities for the care not only of the child/adolescent, but also of other family members, including siblings who often receive less attention from their parents: "If I'm missing something, my other daughter helps me. If I need to borrow money, she gives it to me, she also listens to me, and helps me with her sister [adolescent daughter with depression]" (P_1). "My husband supports me, he does everything with my [adolescent] son, something that my son's biological father never did" (P_{21}).

Another type of resource, reported by all family members participating in the study, was financial aid, which was asked to the extended family. The extended family, including the bosses of P_{16}, is mentioned as a source of social, emotional, and financial support: "My boss supports me, I talk to her a lot, a mutual 'let off steam' relationship between us" (P_{16}). "My father helped in the house renovation, since it was recommended to reform the house and give him [son] an exclusive space" (P_{10}).

Notably,13 participants reported having no support in any sense. They did not recognize the family or the CAPS-i as support networks, as exemplified by P_6: "Nobody actually supports me, my husband and mother can't understand the situation. I have no one to talk to, my sister is already dead, in CAPS-i they don't listen to me. So I get everything off my chest alone, I cry alone" (P_6).

Discussion

This study showed that mostly mothers assume the role of main caregivers, which is in line with other studies that present mothers as the main ones involved in the act of caring for family members (Daltro et al., 2018; Matsuda et al., 2021; Nascimento et al., 2020). This fact possibly occurred since some participants experienced divorce during the disease, thus having to assume the responsibilities alone, due to not having any support from the extended family.

We also found that some mothers assumed the role of homemaker since the formation of the family. Other mothers changed their habits due to their child's disease, putting their personal preferences on the back burner and gave up their interests, often to the limit of physical and mental overload. In this way, it is evident the need for professionals who treat children and adolescents with depression to also extend care to other family members, especially caregivers. Thus, health services and professionals can constitute important support resources for caregiver mothers, reducing the impact of the disease on them and, consequently, playing an important role in family resilience.

Furthermore, we highlight the significant number of participants who reported not having a formal work but exercising informal job activity. This can be explained by the fact that informality allows for greater free time to dedicate to the care of children/adolescents with depression (Zhou et al., 2020). On the other hand, it may be related to the low socioeconomic status of the families, living on one and two minimum wages, and some participants lived on less than one minimum wage.

Notably, among relatives who perceived child and adolescent depression as a disease, they often associated it with triggering factors, which have also been highlighted in other studies, such as the rejection of one or both parents (Johnco & Rapee, 2018), the loss of loved ones, either by death or divorce, (WHO, 2017), sexual abuse (Ministério da Mulher, da Família e dos Direitos Humanos, 2021), strong family repression (Gudmundsen et al., 2019; Zhao et al., 2021), childhood maltreatment (Lippard & Nemeroff, 2020); Russotti et al., 2020) and factors related to queers (Lippard & Nemeroff, 2020; Ministério da Saúde & Conselho Nacional do Ministério Público, 2014).

In these situations, we highlight that negative experiences in the family contribute to the child or adolescent becoming more susceptible in other environments, such as school, as well as intensifying the psychological suffering of the child and the caregiver (Souza & Rodrigues, 2020; van Harmelen et al., 2016). In our study, family members associated bullying with the child/adolescent's refusal to attend to school, having poor academic performance, and humiliation by schoolmates, which had repercussions as signs of intense psychological suffering. This perception of family members is in line with the outcomes by Liu et al. (2021), which identified a significant association between the manifestation of depressive symptoms and suicide in adolescents who are bullied in the school environment. In this scenario, it is evident that, as well as health services and professionals, schools and teachers can also develop actions that work as a buffer and reduce the impact of situations that generate suffering on the development and health of children and adolescents (Kieling et al., 2019).

Family faces obstacles understanding the manifestations of the disease, since the perception of caregivers regarding the severity of the depressive disorder, depends on the ability to assess the emotional disturbance and the severity of the disease, especially with interruption of activities, suicide attempts, and disturbances in family and social relationships (Gudmundsen et al., 2019). In cases where suicide ideation and/or attempts occur, caregivers should be instructed to pay attention to the safety of the domestic environment, including protection or removal of firearms, knives, ropes, cables, and belts and monitor the drug intake of children and adolescents (Chee et al., 2020).

We identified family functioning as a factor that impacts the daily life of children and adolescents with depression. When the family is united, it strives to overcome adversity and its members live in harmony, thus it becomes easier to accept and try to solve the problems. According to the authors addressed in this study, positive family relationships support resilience, since members are seen as a foundation and children/adolescents recognize that there is someone to turn to, who reinforces their self-esteem and their sense of competence (Walsh, 2016), improving the prognosis of depressive disease and promoting mental well-being (Chee et al., 2020; Nguyen et al., 2019).

On the other hand, in those families with fragile bonds, quarrelsome relationships, flawed communication, and difficult relationship with the extended family, participants had more difficulties to manage the challenges. Therefore, we found that the family environment influences the emotional health of the child/adolescent with depressive disorder.

We highlight that some family caregivers feel supported by religiosity, the nuclear family, and the extended family. Some participants proved their spirituality expressed by faith as a way to overcome setbacks and accept the disease. This finding is corroborated by Walsh (2016), since the belief system is one of the key processes that helps the family manage the adversities they experience. Thus, the beliefs and practices of faith expressed by family caregivers should be encouraged, to become one of the foundations that help them overcome the challenges of living with child and adolescent depression and reorganize family life.

Some families in this study were able to positively face the demands and the challenges of living with and taking care of a child/adolescent with depressive disorder, since they find support/help in the nuclear and extended family. This result converges with the organizational processes and communication processes of family resilience (Walsh, 2016). Organizational processes include the flexibility of family adaptation in the face of setbacks, as well as connectivity between members strengthened by mutual support, collaboration, and commitment (Walsh, 2016).

Another complementing aspect of family functioning involves social and economic resources (Walsh, 2016), identified in this study by the financial help of the extended family. In our study, communication processes of family resilience are highlighted due to social sharing of emotions among members of the nuclear and extensive family and collaboration in solving the problems (Walsh, 2016) that depressive disorder causes in the family.

Finally, we found that some family members do not identify any supporting factor that help them cope with the adversities that arise due to depression. This finding is an important indicator for the professionals who work with these families, as all children and adolescents were related to this health service, which was created to meet the demands of users and families.

The main limitation of this study lies on the sample being composed only of family caregivers, since it is recommended for studies with families to include all its members. Several family members had no free time due to their job. To remedy this limitation, researchers conducted data collection interviews to record the perception of the participants based on the family perspective.

This study contributes to the field of Health, since it gives visibility to the people who live with and care for children/adolescents with depressive disorder daily, highlighting how they perceive the problem and how the family group acts and reacts to this event. Therefore, the study mentions some main factors to develop actions that can help families face this problem, among them, the processes of organization, communication, and the belief system. Furthermore, health professionals should be trained on this theme, since it goes beyond the clinical care traditionally proposed, also collaborating to improve the health service as an external support network for the family.

References

American Psychiatric Association. (2014). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed.). https://doi.org/10.1176/appi.books.9780890425596

Bodner, N., Kuppens, P., Allen, N. B., Sheeber, L. B., & Ceulemans, E. (2018). Affective family interactions and their associations with adolescent depression: A dynamic network approach. *Development and Psychopathology, 30*(4), 1459-1473. https://doi.org/10.1017/S0954579417001699

Chee, J. N., Wang, K., & Cheung, A. (2020). Depression in children and adolescents. In R. S. McIntyre (Ed.), *Major depressive disorder* (pp. 175-184). Elsevier.

Daltro, M. C. S. L., Moraes, J. C., & Marsiglia, R. G. (2018). Cuidadores de crianças e adolescentes com transtornos mentais: Mudanças na vida social, familiar e sexual [Caregivers of children and adolescents with mental disorders: Social, family, and sexual changes]. *Saúde e Sociedade, 27*(2), 544-555. https://doi.org/10.1590/S0104- 12902018156194

Gudmundsen, G. R., Rhew, I. C., McCauley, E., Kim, J., & Vander Stoep, A. (2019). Emergence of depressive symptoms from kindergarten to sixth grade. *Journal of Clinical Child & Adolescent Psychology, 48*(3), 501-515. https://doi.org/10.1080/15374416.2017.1410823

Johnco, C., & Rapee, R. M. (2018). Depression literacy and stigma influence how parents perceive and respond to adolescent depressive symptoms. *Journal of Affective Disorders, 241*, 599-607. https://doi.org/10.1016/j.jad.2018.08.062

Kalin, N. H. (2021). Anxiety, depression, and suicide in youth. *The American Journal of Psychiatry, 178*(4), 275-279. https://doi.org/10.1176/appi.ajp.2020.21020186

Kieling, C., Adewuya, A., Fisher, H. L., Karmacharya, R., Kohrt, B. A., Swartz, J. R., & Mondelli, V. (2019). Identifying depression early in adolescence. *The Lancet Child & Adolescent Health, 3*(4), 211-213. https://doi.org/10.1016/S2352-4642(19)30059-8

Liu, T. L., Hsiao, R. C., Chou, W. J., & Yen, C. F. (2021). Self-reported depressive symptoms and suicidality in adolescents with attention-deficit/hyperactivity disorder: Roles of bullying involvement, frustration intolerance, and hostility. *International Journal of Environmental Research and Public Health, 18*(15), 7829. https://doi.org/10.3390/ijerph18157829

Lippard, E. T. C., & Nemeroff, C. B. (2020). The devastating clinical consequences of child abuse and neglect: Increased disease vulnerability and poor treatment response in mood disorders. *The American Journal of Psychiatry, 177*(1), 20-36. https://doi.org/10.1176/appi.ajp.2019.19010020

Matsuda, Y., McCabe, B. E., & Behar-Zusman, V. (2021). Mothering in the context of mental disorder: Effect of caregiving load on maternal health in a predominantly hispanic sample. *Journal of the American Psychiatric Nurses Association, 27*(5), 373-382. https://doi.org/10.1177/1078390320907693

Minayo, M. C. Z. (2013). *O desafio do conhecimento: Pesquisa qualitativa em saúde* [The knowledge challenge: Qualitative research in health] (13th ed.). Hucitec.

Ministério da Mulher, da Família e dos Direitos Humanos. Secretaria Nacional dos Direitos da Criança e do Adolescente. (2021). *Abuso sexual contra crianças e adolescentes – abordagem de casos concretos em uma perspectiva multidisciplinar e interinstitucional* [Sexual abuse against children and adolescents – approaching concrete cases in a multidisciplinary and inter-institutional]. https://www.gov.br/mdh/pt-br/assuntos/noticias/2021/maio/CartilhaMaioLaranja2021.pdf

Ministério da Saúde, & Conselho Nacional do Ministério Público. (2014). *Atenção psicossocial a crianças e adolescentes no SUS: Tecendo redes para garantir direitos* [Psychosocial care to children and adolescents in the Brazilian Health System (SUS/Brazil): Weaving networks to ensure rights]. https://bvsms.saude.gov.br/bvs/publicacoes/atencao_psicossocial_criancas_adolescentes_sus.pdf

Nascimento, F. K., Reis, R. A., Saadeh, A., Demétrio, F., Rodrigues, I. L. A., Galera, S. A. F., & Santos, C. B. (2020). Brazilian transgender children and adolescents: Attributes associated with quality of life. *Revista Latino-Americana de Enfermagem, 28*, e3351. http://dx.doi.org/10.1590/1518-8345.3504.3351

Nguyen, H. T. L., Nakamura, K., Seino, K., & Al-Sobaihi, S. (2019). Impact of parent–adolescent bonding on school bullying and mental health in Vietnamese cultural setting: Evidence from the global school-based health survey. *BMC Psychology, 7*(1), 16. https://doi.org/10.1186/s40359-019-0294-z

Russotti, J., Handley, E. D., Rogosch, F. A., Toth, S. L., & Cicchetti, D. (2020). The interactive effects of child maltreatment and adolescent pregnancy on late-adolescent depressive symptoms. *Journal of Abnormal Child Psychology, 48*(9), 1223-1237. https://doi.org/10.1007/s10802-020-00669-w

Souza, S. C., & Rodrigues, T. M. (2020). Depressão infantil: Considerações para professores da educação básica [Child depression: Considerations for basic education teachers]. *Brazilian Journal of Development, 6*(6), 34326-34338. https://doi.org/10.34117/bjdv6n6-106

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19*(6), 349-357. https://doi.org/10.1093/intqhc/mzm042

van Harmelen, A.-L., Gibson, J. L., St Clair, M. C., Owens, M., Brodbeck, J., Dunn, V., Lewis, G., Croudace, T., Jones, P. B., Kievit, R. A., & Goodyer, I. M. (2016). Friendships and family support reduce subsequent depressive symptoms in at-risk adolescents. *PloS One, 11*(5), e0153715. https://doi.org/10.1371/journal.pone.0153715

Walsh, F. (2016). *Strengthening family resilience* (3rd ed.). Guilford.

World Health Organization. (2017). *Depression and other common mental disorders: Global health estimates*. https://apps.who.int/iris/handle/10665/254610

Zhao, J., Xiang, Y., Zhang, W., Dong, X., Zhao, J., & Li, Q. (2021). Childhood maltreatment affects depression and anxiety: The mediating role of emotional intelligence. *International Journal of Mental Health and Addiction, 19*(6), 2021-2030. https://doi.org/10.1007/s11469-020-00297-x

Zhou, Q., Yin, Z., Wu, W., & Li, N. (2020). Childhood familial environment and adulthood depression: Evidence from a Chinese population-based study. *International Health, 12*(4), 299-316. https://doi.org/10.1093/inthealth/ihz084

Eduarda Ramis Pontes is a Ph.D. student at the the Universidade Federal do Rio Grande, Rio Grande, RS, Brazil.

Mara Regina Santos da Silva is a Professor at the Universidade Federal do Rio Grande, Rio Grande, RS, Brazil.

Sandra Dal Pai is a Ph.D. at the Universidade Federal do Rio Grande, Rio Grande, RS, Brazil.

Elena Bustos Alfaro is a Ph.D. at the Universidade Federal do Rio Grande, Rio Grande, RS, Brazil.

Alessandro Marques dos Santos is a Professor at the Universidade Federal do Rio Grande, Rio Grande, RS, Brazil.

Authors' Contribution:
Eduarda Ramis Pontes and Mara Regina Santos da Silva made substantial contributions to the conception and design of this study, to data analysis and interpretation, and to the manuscript revision and approval of the final version. Sandra Dal Pai made substantial contributions to the to data analysis and interpretation, and to the manuscript revision and approval of the final version. Elena Bustos Alfaro and Alessandro Marques dos Santos made substantial contributions to the manuscript revision and approval of the final version. All authors assume public responsibility for content of the manuscript.

Associate editor:
Vanessa Barbosa Romera Leme

Received: Jul. 29, 2022

1st Revision: Dec. 20, 2022

2nd Revision: Feb. 14, 2023

Approved: Mar. 01, 2023

How to cite this article:
Pontes, E. R., Silva, M. R. S., Dal Pai, S. Bustos, E. A., & Santos, A. (2023). Children and adolescents with depression: Perception of family caregivers. *Paidéia (Ribeirão Preto), 33,* e3312. doi: https://doi.org/10.1590/1982-4327e3312