

Experiences of families that have children with mental disorders

Vivência de familiares de crianças com transtornos mentais

Vivencia de familiares de niños con trastornos mentales

Eliane Rosso^I, Miriam Aparecida Nimtz^{II}, Marcio Roberto Paes^{III}, Mônica Macedo^{IV}, Mariluci Alves Maftum^V, Camila Bonfim de Alcantara^{VI}

Abstract: Objective: to describe the experiences of members of families that have children with mental disorders.

Method: qualitative research, with the hybrid oral thematic history method carried out with eight family members in a Specialized Educational Service Center. Data were collected from March to May 2017, via semi-structured interviews. **Results:** two categories emerged: Emotions, feelings and difficulties experienced by family members of children with mental disorders; and, Support for family, social and health support for children with mental disorders. The family reported tiredness, exhaustion, guilt and insecurity, revealing important changes in the family dynamics following the diagnosis of mental disorder. **Final considerations:** family members lack information about mental disorders; need to adapt the family routine to attend to the child; and require support from family, friends, teachers and other professionals so that they can take care of their child.

Descriptors: Mental health; Family; Mental disorders; Child; Nursing

Resumo: Objetivo: descrever a vivência de familiares de crianças com transtornos mentais. **Método:** pesquisa qualitativa, com o método história oral temática híbrida realizada com oito familiares em um Centro de Atendimento Educacional Especializado. Os dados foram coletados de março a maio de 2017, mediante entrevista semiestruturada. **Resultados:** emergiram duas categorias: Emoções, sentimentos e dificuldades vivenciadas por familiares de crianças com transtornos mentais; e, Suporte de apoio familiar, social e de saúde à criança com transtornos mentais. Os familiares referiram cansaço, desgaste, culpa e insegurança, evidenciando mudanças importantes na dinâmica familiar após o diagnóstico de transtorno mental. **Considerações finais:** os familiares carecem de informações sobre o

^I Nurse, Master in Nursing, Collaborating Professor at the Universidade Estadual do Centro Oeste. Guarapuava, Paraná, Brazil. E-mail: eliane_ros@yahoo.com.br . Orcid: <https://orcid.org/0000-0002-1794-2606>

^{II} Nurse, PhD in Nursing, Adjunct professor in the nursing department and collaborating professor in the post-graduate nursing program, Universidade Federal do Paraná (UFPR). Curitiba, Paraná, Brazil. E-mail: miriamnmtz@uol.com.br . Orcid: <https://orcid.org/0000-0001-7491-5789>

^{III} Nurse, PhD in Nursing, Adjunct Professor in the Nursing Department, UFPR. Curitiba, Paraná, Brazil. E-mail: marropa@ufpr.br. Orcid: <http://orcid.org/0000-0003-0305-1500>

^{IV} Occupational therapist, PhD in Psychology, Adjunct professor in the occupational therapy department, UFPR. Curitiba, Paraná, Brazil. E-mail: terapeutamonica@hotmail.com. Orcid: <https://orcid.org/0000-0002-6831-4490>

^V Nurse, PhD in nursing, Permanent professor of the post-graduate nursing program, UFPR. Curitiba, Paraná, Brazil. E-mail: Maftum@ufpr.br. Orcid: <https://orcid.org/0000-0001-8706-7299>

^{VI} Nursing student, Scientific initiation scholarship holder from CNPq, UFPR, Curitiba, Paraná, Brazil. E-mail: cbalcantara47@gmail.com. Orcid: <https://orcid.org/0000-0001-8175-9569>



transtorno mental, apresentam necessidade de adaptar a rotina familiar para atender à criança, e apoio de familiares, amigos, professores e outros profissionais para que consigam cuidar de seu ente.

Descritores: Saúde mental; Família; Transtornos mentais; Criança; Enfermagem

Resumen: **Objetivo:** describir la vivencia de familiares de niños con trastornos mentales. **Método:** pesquisa qualitativa, con el método historia oral temática híbrida realizada con ocho familiares en un Centro de Atención Educativa Especializado. Los datos han sido recogidos de marzo a mayo de 2017, a través de entrevista semi-estructurada. **Resultados:** han surgido dos categorías: Emociones, sentimientos y dificultades vividas por familiares de niños con trastornos mentales; y, Soporte de apoyo familiar, social y de salud a los niños con trastornos mentales. Miembros de la familia han informado cansancio, desgaste, culpa e inseguridad, evidenciando cambios importantes en la dinámica familiar después del diagnóstico de trastorno mental. **Consideraciones finales:** los familiares carecen de informaciones sobre el trastorno mental, necesitan adaptarse a la rutina familiar para atender las necesidades de los niños, y apoyo de familiares, amigos, profesores y otros profesionales para que logren cuidar de su ser querido.

Descriptor: Salud mental; Familia; Trastornos mentales; Niños; Enfermería

Introduction

The mental health of Brazilian children has only recently been considered a public health problem, since the theme “children” was attributed to the educational sectors. However, with the Psychiatric Reform Movement that has been taking place since 1978, health services have become responsible for child mental health care, now being one of the promoters to overcome the exclusionary character of care for this specific population.¹

The family's involvement in caring for children's mental health is also recent, and here the family is understood as the maximum expression of private life, considered as a place of intimacy, in which meanings and expressions of feelings are constructed as well as the psychological suffering that imposes itself on the lives of human beings. It is also perceived as a space for affection and relationships that are essential for the socialization of individuals, who develop a feeling of belonging to relationships that include them in life within society.²⁻⁴

The family structure can be significantly affected by the occurrence of mental disorders in children, mainly affecting the parents' self-esteem, because it can represent a failure in the child raising process. The scant knowledge regarding mental disorders together with the social stigma attributed to its occurrence in childhood, accentuates the difficulties experienced by family members and results in suffering among the entire family.²⁻⁵

Family problems are also related to the social role attributed to the child, because having a close relationship of dependence with the parents, their illness can lead to unity or parental disruption.⁵⁻⁶ It is estimated that 10 to 20% of children suffer from mental disorders and of these, 3 to 4% require intensive treatment. In this population, autism, childhood psychosis and anxiety disorders are seen most.⁴⁻⁷

In Brazil, there are few specific data on the main causes of emergency mental health care. On the other hand, with regard to childhood, behavioral changes without an established diagnosis, report of suicidal behavior, diagnosis of depression and aggression, situations of drug abuse and situations of violence are more frequent.⁷⁻⁹

It is also important to consider the change in perception regarding the social status of children and adolescents throughout history, as there is an understanding that these are individuals who are in the development phase and who are citizens with rights since birth. The landmark of this change is the enactment of Law No. 8,069, of July 13, 1990, which governs the Statute of Children and Adolescents (ECA).¹⁰⁻¹¹

In an attempt to ensure these rights, several actions were instituted, among them initiatives in the area of education, social assistance, and in the legal and health environments. The latter sought to meet the needs of children and their families by implementing Child Health Programs in primary care and specialized care, offering care in mental health outpatient clinics and establishing Child Psychosocial Care Centers (CAPSi), in cities with capacity for such service according to the specifics of the current legislation.¹⁰

When the mental disorder occurs in a child, it is necessary to make more family time available to perform the care and this leads to changes in the family dynamics. There are changes in the way of organizing life, in the relationship of individuals with work, in the relationship between parents and children, as well as in the marital relationship, also needing, in some situations, financial control in order to provide better treatment for the child.

Consequently, family members can experience physical and emotional exhaustion, with a more significant impact on the person who is responsible for the child's care.^{1,12}

Considering the impact of mental disorders on the family nucleus, it is important that health services and professionals in the area understand the entire family unit as the object of care, that is, all family members and the family relationship itself must be considered in care planning, since only then will it be possible to offer comprehensive care, which must be provided through multidisciplinary care performed by a multidisciplinary team. Strategies should also be considered to assist in promoting family ties.^{6,13}

The nurse, as an integral part of the health team, plays a fundamental role in assisting the child and their families, because a close relationship with them and the establishment of a therapeutic bond, enables the expression of thoughts, feelings and questions about the disorders and psychosocial treatment.^{1,6} In addition, strategies such as listening and therapeutic conversation help nurses to identify the most immediate needs of children and their families, as well as their needs in the medium and long term. Such strategies are fundamental because they ensure individualized care planning, considering both the demands of family members and the child.^{6,14}

Nursing assistance in mental health, guidance actions and health education as a whole are necessary with the aim of helping family members to understand the pathophysiology of mental disorders and the various therapeutic approaches proposed. In doing so, they instruct family members to provide child care in order to encourage and promote their personal development with autonomy and independence. These activities also help family members and the child to find strategies for handling the signs and symptoms of disorders, including actions to be taken in crisis situations, as manifested by the worsening of symptoms.^{1,6,15}

Recognizing the importance of this theme, it is considered that studies with a focus on family members who experience daily life with children presenting mental disorders, are

relevant in the sense of contributing scientific evidence to support nursing practice. Thus, in this research, we sought to answer the research question “What are the experiences of family members of children with mental disorders?” The answer to this question meets the objective of this study, which is to describe the experiences of members of families that have children with mental disorders.

Method

This is a qualitative research centered on the hybrid thematic oral history method, carried out in a Specialized Educational Service Center, located in the city of Guarapuava in Paraná state, Brazil.

This service integrates the Psychosocial Care Network (PSCN) in the municipality and is intended to offer health care and educational support to children with mental comorbidities, through specialized medical care in psychiatry and neurology, as well as multiprofessional assistance, via a team of psychologists, speech therapists, psychopedagogues and educational advisor. The team can also include an occupational therapist and social worker.¹⁶

This methodological approach makes it possible to investigate the experiences, perceptions and life of individuals or collective groups regarding a reality, events and or phenomena, considering the subjective aspects that, although rich in significance and meaning cannot be measured quantitatively. Through the collection of narrative material it is possible to capture and record the meaning of experiences for individuals who participate in a social process.¹⁷

The oral history method has three distinct approaches, namely oral life history, thematic and oral tradition. For this research, the thematic approach was chosen, which is further subdivided into hybrid and pure. Considering that the first values the construction of the narrative path and the second focuses on specific issues, the hybrid approach was considered to

be appropriate. Thus, the method of this study, the hybrid oral thematic history, has a central focus that justifies that in the act of the interview a cut is made and conduction of the project with more objectivity. For this a questionnaire is used, allowing the establishment of criteria for covering the themes, cooperating for the progress of the research and reaching the answer to the proposed objective.¹⁷

This research counted on the participation of family members who live with children presenting mental disorders and undergoing treatment. They were contacted and invited to participate in the study from March to May 2017. All family members who were registered with the service were invited. The invitation took place on Wednesdays, between 8 am and 10 am, a period in which consultations with a psychiatrist took place, thus with the presence of a higher number of family members of children with mental disorders.

The inclusion criteria were: to be a family member of the child who has a diagnosis of mental disorder and is attending the Specialized Educational Service Center (the person who is dedicated to the care of the child, whether a father, mother, grandparent or another member of the family, with or without consanguineous ties) and as an exclusion criterion, be a family member under the age of 18 years. The study received 13 refusals, so that the final sample consisted of eight family members, two of whom were fathers and six mothers, aged between 25 and 48 years.

The data were collected through individual interviews with the support of a semi-structured instrument, prepared by the authors, composed of open questions that covered their experiences with the child with mental disorders. The narratives were recorded with the aid of the digital recorder of a mobile device, in a reserved place within the service itself, at a time the participants were available.

Three phases were followed for data analysis, the first denominated absolute transcription, in which the spoken words in raw state are maintained, likewise, the question and

answer structure, as well as the repetitions, errors and words without semantic weight are also maintained. The second phase is textualization, in which questions are eliminated, grammatical errors are excluded and words without semantic weight are corrected. Sounds and noise are eliminated in favor of clearer and smoother text. At this moment, a guide phrase called “vital tone” is chosen, since it contains the essence of the discourse’s meaning.¹⁷

The third phase, called transcription, consists of presenting the text in its final version, which must be read and authorized by the author of the speech, after which it comprises the series of interviews for the project. In this phase, there is an approximation between the sense and the original intention of what is said by the interviewees. It is underscored that the interviews, if analyzed in isolation, are not considered as oral history, thus, the analysis process implies crossing the various internal logics of each discourse, such that the proposal indicated in the project is resolved, or that is, the analysis does not imply a rational division of the interviews, but rather, starting from the whole to define the relevant themes.¹⁷

In accordance with the recommendations of Resolution no. 466 of December 12, 2012, the confidentiality and anonymity of the identity of those involved, free access to the information collected and access to the final product, as well as the right to withdraw, at any time, from the research were guaranteed; if they manifested this desire.¹⁸ Furthermore, after providing clarifications regarding the research and participation, they were asked to sign the Free and Informed Consent Form, and the Letter of Rights Assignment. This study was approved by means of a resolution issued by the Research Ethics Committee, COMEP-UNICENTRO, under number 1,814,756, on November 8, 2016.

Results

From the analysis, themes emerged that favored the description of the experiences of family members of children with mental disorders.

Emotions, feelings and difficulties experienced by family members of children with mental disorders

Parents sometimes expressed tiredness and exhaustion when saying that they did not know what else to do, how to deal with the situation of having a child with mental disorders, making it evident that their children's behavior makes them feel embarrassed and ashamed. Guilt often appeared in the reports, as well as fear and shame:

I felt guilty, as if I had done something wrong, I had not paid enough attention, because the psychologist told me that I had to stay close, present, pay attention. But it is not always easy, I need to work and there are times when I get work in another city and I have to travel, I try not to stay too long and come back every weekend. (F1 Father)

I felt disoriented, ashamed, lost, guilty, afraid, and if she tries this madness again, what am I going to do? And this thing that she hears? My God! I don't know what to say when she says she heard or dreamed about that damn black guy with no face. I went to school to talk to the principal to tell what was going on. That was not easy. How was I going to get there and say my daughter was crazy? We don't know what to do. I feel ashamed. (F2 Mother)

I feel ashamed when I go to a family or friend's party, because he doesn't leave the table. You can't take your eyes off him otherwise he puts food in his pockets. (F5 Mother)

The relatives' discourses show that after the diagnosis, there was a change in their attitudes and feelings towards the child's behavior, either by increasing the sense of responsibility for these parents, or through a new perception of reality. Some family members highlighted the importance of receiving professional support to assist them during this process

of accepting the diagnosis and understanding the disorder as a pathology that requires treatment. Furthermore, they point out that after this process there was an improvement in the relationship with the child. They also reported difficulty in reconciling the care of other children and maintaining the marital relationship, referring to experiencing physical and emotional exhaustion, as shown below:

He has frequent consultations, he goes to therapy every week and plays chess, he is very good at chess. But to get to the point we are considering today, for this acceptance, I had to seek help, I had to go to therapy to be able to accept my son's illness, because I did not want to believe that a child brought up with so much love, affection and so much expectation could be harmed. (F3 Mother)

As B. grew up, the whole family was adapting to the needs she has. There are nights when I sit in bed and feel the weight of the day, because they drain me. I don't think I can put the other two aside, because the youngest needs me more. This happens, sometimes, and I blame myself for not being able to serve everyone to the same degree. There's my husband, too. It is rare for us to go out just the two of us. (F8 Mother)

We used to fight, but it's not as much as it was before, because I have more patience with her than I did before. The doctor said it is a disease and that we have to be patient. We do some things together. (F2 Mother)

Family, social and health support for children with mental disorders

Through the discourses, it is possible to observe that some people are often asked to support the family during the care of children with mental disorders. Among the possibilities are grandparents, aunts, uncles, trusted people hired to assist in child care, teachers, educators, and others. Such people are asked and called upon to contribute to the family's adaptation to the new reality imposed after the diagnosis. The importance of this support for the organization of

the family routine is emphasized; thus people who are close relatives are mentioned in most interviews as providing care support:

I have a lot of help from my sisters and Granny [grandmother]. When I'm not working early, I make coffee for us to watch TV together. My sisters are going to clean the house. The aunts care a lot about her, play a lot, give clothes, toys. They try to make her laugh, even teaching her to paint, embroider and fold clothes. These things they are teaching. (F1 Father)

On Monday there is class and there is swimming, on Tuesday there is class and there is chess class, and when he wants, on Tuesday, in the afternoon he goes to his grandmother's house, but it is not always that he wants to go, and we have an agreement at home to respect his wishes in this regard. (F3 Mother)

Grandma also wants to be with them, sometimes my mom too, because his mom doesn't live here, but she always calls to see how they are doing. Some Saturdays they stay with their grandmother and I take the opportunity to wash the car, and their mother to do things for her college. (F4 Father)

Teachers, the educational system and professionals who provide care at the Educational Service Center are also seen by family members as a source of support. Family members perceive the school as a reference to help with child management, and have expectations related to this help in caring for children at the time they are attending the school. It is evident in the discourse of family members that the Specialized Educational Assistance Center and its professionals were important in the process of accepting the diagnosis of the disorder and in directing treatment, representing a support space for the anxieties that arise in daily life:

The teacher was very good, concerned about her. All the school teachers seem to want to take care of her, too. (F1 Father)

The teachers are really good, because they manage to resolve the most difficult situations and are always in contact with us and write in his notebook if something different happens in the day-to-day of the school. I know that he is well cared for there, I think that the greatest fear of a mother of a child who needs special care is having someone who takes care with affection and who does not mistreat, because I know how much patience is needed. (F3 Mother)

[...] They sent me to the Center (for special educational assistance) and started the treatment, they made the diagnosis that he eats compulsively and also has anxiety, then he started going to the psychologist, sent to the nutritionist and the “head doctor” [psychiatrist] gave the medications. (F5 Mother)

Discussion

The impact of the diagnosis of a mental disorder imposes on family members the need to adapt to the new situation, in addition this discovery is often permeated by stigma and prejudice.⁵ The problems experienced and reported have many features in common, however each of them has their individualities and peculiarities in the way of feeling, reacting and expressing their experiences in various situations.^{14,19-20}

The way the diagnosis is communicated is important in the process of acceptance and understanding of the child's behavior, an aspect that also contributes for the family members to obtain a new perception of reality, adapting expectations regarding the growth and development of their child. In addition, knowing the pathophysiology of mental disorders and the need for various therapeutic approaches is essential so that they are also responsible for promoting and recovering the child's health.²¹

For this reason, nurses and other health professionals who work in the PSCN need to be able to listen and determine the needs of each family member in a unique way. They should also be able to guide them, clarifying doubts about disorders, thus contributing to better coexistence

and acceptance. Adequately oriented family members can be the basis of support for care, as they begin to identify the need to seek new ways of relating to the child and the importance of finding strategies for the management of attitudes and behaviors related to disorders, in order to promote their personal and social development with autonomy and independence.^{14,19-20}

However, this process is complex and can be associated with prejudice related to the type of disorder, such that the child can become stigmatized both within the family and in the social environment in which he or she lives. Especially with regard to the family environment, the perception of this new reality may be accompanied by feelings of disruption, exhaustion and physical and emotional overload, especially affecting the person who is directly responsible for the care of this child.⁵

The information that a child needs mental health care for an indefinite period is a major challenge for the family, the social environment and the public health service that attends them. So that professionals working at the PSCN must be prepared to facilitate interaction within the child - family - society triad, while always respecting the sociocultural subjectivity and peculiarity of each reality, contributing to coping with mental disorders and collaborating to reduce family overburden.²⁰⁻²²

No matter how much care is exercised before diagnosis, after family members receive the information that their child has a mental disorder, this care intensifies and becomes a daily and uninterrupted need.^{5,22} The impact of mental disorder on daily life affects various aspects of family life, which can be considered an overburden factor, since it requires family members to put their needs and desires in the background, interrupt their routine and consequently change their life.⁵

The families refer to experiencing emotions and feelings ranging from shame and embarrassment related to the child's behavior in public, to the perception of guilt associated with the onset of the disorder and fear in the absence of control in different situations of daily

life.^{5,21 -22} Guilt associated with the diagnosis of the disorder is one of the feelings most frequently expressed by family members, this recurring thought generates constant discomfort in an attempt to understand the disorder.^{19,21}

On taking care of a child with mental disorders, there is sometimes a change in the family structure and from this restructuring new roles can emerge; rules come into existence and common everyday situations can be perceived as generating suffering. In addition to internal changes in the family environment, external relations are also affected, because in view of the limitations imposed by the new condition, the family redefines its commitments, plans, social relationships and even its way of interacting with the social and work environment. This whole process is exhausting, but necessary, so that the family, the child and the society in which they are inserted can live with mental disorders in the best possible way.²¹

Based on the above, it can be said that family members and the child require social support through an extensive support network composed of various family members, by the health, education and social assistance sectors, as well as other social groups and institutions that assist in coping with the adversities that occur in daily life arising from mental disorders. Being able to count on a support network, enables care to be expanded as the family can use other strategies to attend the child's needs.^{6,23-24}

The education sector is an important component of the social support network, as education professionals often identify early changes in the child's behavior and guide family members to seek health assessment and follow-up by a trained professional. This important relationship with the education system was demonstrated by a study in which this sector was responsible for a significant number of referrals to mental health services, most frequently due to learning difficulties and less frequently suicidal behavior. The other reasons for requesting an evaluation by a specialized mental health service were complaints related to anxiety and aggressiveness.²⁵

Another important strategy found by family members who experience the care process of these children is social articulation through interpersonal relationships, which allows seeking support from people outside the family, such as non-governmental organizations and help groups that offer the assistance necessary to overcome those barriers that the mental disorder imposes.⁶ Thus, the support network, besides helping to solve the daily problems and difficulties, consists of a means of relief for everyday tensions by providing a means to share experiences and express feelings.^{6,23-24}

Final considerations

Living with children with mental disorders is often permeated by emotions and feelings of fear, guilt, shame and exhaustion. There is a need to adapt the family routine to better attend the child and, in the face of difficulties, family relationships can be weakened, because when prioritizing the care of those with the disorder, other children can be neglected and the marital relationship can be compromised.

The investigation of the experiences of these family members also showed that the feeling of helplessness is frequent, as expressed through the verbalization of not knowing how to act in the face of the child's behavior. This shows the importance of a complex support network formed by educational and health services that are able to guide, instruct and assist them in child care. Furthermore, the importance of encouraging the participation of other family members in treatment and care is emphasized, with the aim of promoting a feeling of family unity and avoiding the physical, emotional and financial burden for a single member.

The hybrid oral history method enabled the investigation of such experiences with deepening of feelings and understanding of meanings. By giving family members the opportunity to express their emotions, feelings, thoughts and attitudes, they were also encouraged to reflect and re-signify their perception of the reality imposed on them.

Similarly, the establishment of a therapeutic bond between health professionals and patients / family members provides the expression of feelings, thoughts and doubts. The nurse, as an integral part of the health team, must valorize and encourage the expression of both the child and their family members. This strategy helps to identify weaknesses and potentialities, individual and collective demands as well as expectations regarding treatment. Such information offers tools for nurses in the planning of comprehensive and individual care.

The importance of conducting research that addresses the experiences of family members of children with mental disorders in various stages of treatment and that consider the different stages of child development is highlighted. Such findings would make it possible to identify the demands of family members and children at different moments. It is also relevant to describe the experiences of family members according to the type of disorder that the child has, since there is greater social stigma in relation to severe disorders and greater difficulty in the management of symptoms.

It is hoped that the present study will stimulate new reflections on the theme and encourage further research in the area. It is also hoped that these results will strengthen the practice of nursing and the multidisciplinary team in working with family members of children with disorders, as they show that the provision of social and health support to this population contributes to their personal, educational and social development.

References

1. Buriola AA, Vicente JB, Zurita RCM, Marcon SS. Sobrecarga dos cuidadores de crianças ou adolescentes que sofrem transtorno mental no município de Maringá - Paraná. Esc. Anna Nery Rev. Enferm [Internet]. 2016 [acesso em 2018 Fev 07];20(2):344-351. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1414-81452016000200344&lng=en&nrm=iso&tlng=pt. doi: <http://dx.doi.org/10.5935/1414-8145.20160047>.
2. Estevão AR, Teodoro FC, Pinto MNR, Freire MHS, Mazza VA. A família no cuidado de enfermagem à criança: revisão integrativa. Cogitare enferm [Internet]. 2016 [acesso em: 2019 Mar 28];21(4):01-09.

Disponível em: <https://revistas.ufpr.br/cogitare/article/view/46551/pdf>.
Doi:<http://dx.doi.org/10.5380/ce.v21i4.46551>.

3. Moreno V, Barbora GC. Familiares de pessoas portadoras de transtorno mental: conhecimento dos direitos à saúde. *Rev. gaúcha enferm* [Internet]. 2015 [acesso em: 2019 Mar 28];36(1):43-8. Disponível em: <https://repositorio.unesp.br/bitstream/handle/11449/140690/S1983-14472015000100043-pt.pdf?sequence=2&isAllowed=y>. Doi:<http://dx.doi.org/10.1590/1983-1447.2015.01.47915>.

4. Daltro MCSL, Moraes JC, Marsiglia RG. Cuidadores de crianças e adolescentes com transtornos mentais: mudanças na vida social, familiar e sexual. *Saúde Soc* [Internet]. 2018 [acesso em 2019 Mar 28];27(2):544-555. Disponível em: <https://www.scielo.org/article/sausoc/2018.v27n2/544-555/>. Doi:<http://doi.org/10.1590/S0104-12902018156194>.

5. Jackson L, Keville S, Ludlow A. Mothers' experiences of accessing mental health care for their child with an autism spectrum disorder. *J Child Fam Stud* [Internet]. 2020 [acesso em 2020 Fev 18];29:534-545. Disponível em: <https://link.springer.com/article/10.1007/s10826-019-01662-8?shared-article-renderer#citeas>. Doi: <https://doi.org/10.1007/s10826-019-01662-8>.

6. Brusamarello T, Maftum MA, Alcântara CB, Capistrano FC, Pagliace AGS. Famílias no cuidado à saúde de pessoas com transtorno mental: reflexos do modelo de assistência. *Saúde e pesqui* [Internet]. 2017 [acesso em 2019 Mar 28];10(3):441-449. Disponível em: <http://periodicos.unicesumar.edu.br/index.php/saudpesq/article/view/5993/3127>. Doi:<http://dx.doi.org/10.177651/1983-1870.2017v10n3p441-449>.

7. Ministério da Saúde (BR). Atenção psicossocial a crianças e adolescentes no SUS: tecendo redes para garantir direitos. Brasília (DF): Ministério da Saúde; 2014.

8. Rossi LM, Marcolino TQ, Speranza M, Cid MFB. Crise e saúde mental na adolescência: a história sob a ótica de quem vive. *Cad. Saúde pública* [Internet]. 2019 [acesso em 2019 Mar 28];35(3):e00125018. Disponível em: <https://www.scielo.org/pdf/csp/2019.v35n3/e00125018/pt>. Doi: 10.1590/0102-311X00125018.

9. Martins MMM, Souza J, Silva AA. Crianças e adolescentes usuários de substâncias no serviço de emergência psiquiátrica. *Acta paul. enferm* [Internet]. 2015 [acesso em 2019 Mar 28];28(1):13-8. Disponível em: http://www.scielo.br/scielo.php?pid=S0103-21002015000100013&script=sci_arttext&lng=pt. Doi:<http://dx.doi.org/10.1590/1982-0194201500004>.

10. Gomes FMA, Cintra AMO, Ricas J, Vecchia MD. Saúde mental infantil na atenção primária à saúde: discursos de profissionais médicos. *Saúde Soc* [Internet]. 2015 [acesso em 2018 Fev 07];24(1):244-258. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-12902015000100244&lng=en&nrm=iso&lng=pt. doi: <http://dx.doi.org/10.1590/S0104-12902015000100019>.

11. Brasil. Lei n.8.069 de 13 de julho de 1990 (BR). Dispõe sobre o estatuto da criança e do adolescente e dá outras providências. Diário Oficial da União, Brasília (DF) [Internet] 1990 [acesso em 2018 Fev 07]. Disponível em: http://www.planalto.gov.br/Ccivil_03/leis/L8069.htm
12. Campelo LLCR, Costa SME, Colvero LA. Dificuldades das famílias no cuidado à criança e ao adolescente com transtorno mental: uma revisão integrativa. Rev. Esc. Enferm. USP [Internet]. 2014 [acesso em 2018 Fev 07];48(spe):192-198. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0080-62342014000700192&lng=en&nrm=iso&tlng=pt. doi: <http://dx.doi.org/10.1590/S0080-62342014000600027>.
13. Vicente JB, Higarashi IH, Furtado MCC. Transtorno mental na infância: configurações familiares e suas relações sociais. Esc. Anna Nery Rev. Enferm [Internet]. 2015 [acesso em 2018 Fev 07];19(1):107-114. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1414-81452015000100107&lng=en&nrm=iso&tlng=pt. doi: <http://dx.doi.org/10.5935/1414-8145.20150015>.
- 14.-Vicente JB, Marcon SS, Higarashi IH. Convivendo com o transtorno mental na infância: sentimentos e reações da família. Texto & contexto enferm [Internet]. 2016 [acesso em 2018 Fev 07];25(1):e0370014. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-07072016000100314&lng=pt&nrm=iso&tlng=pt. Doi: <http://dx.doi.org/10.1590/0104-0707201600370014>.
15. Siqueira DF, Botega MSX, Serbim AK, Terra MG. Redes sociais de apoio no cuidado à pessoa com transtorno mental: reflexões. Rev. enferm. UFSM [Internet]. 2018 [acesso em 2019 Mar 28];8(4):859-869. Disponível em: <https://periodicos.ufsm.br/reufsm/article/view/26118>. Doi:10.5902/2179769226118.
16. Guarapuava. Decreto n. 005 de 24 de janeiro de 2000. Aprova o regimento interno do Centro Municipal de Atendimento ao Portador de necessidades educacionais especiais. Guarapuava, Paraná, Brasil, 2000 [Internet]. [acesso em 2017 mar 12]. Disponível em: <http://leismunicipa.is/qhnai>
17. Meihy JCSB, Holanda F. História oral: como fazer, como pensar. 2ª ed. 3 reimpressão. São Paulo: Contexto; 2014.
18. Brasil. Ministério da Saúde. Conselho Nacional de Saúde. Resolução n. 466, de 12 de dezembro de 2012 [Internet]. 2012 [acesso em 2018 Fev 07]. Disponível em: <http://conselho.saude.gov.br/resolucoes/2012/Reso466.pdf>.
19. Brusamarello T, Maftum MA, Mantovani MF, Alcantara CB. Educação em saúde e pesquisa-ação: instrumentos de cuidado de enfermagem na saúde mental. Saúde (Santa Maria) [Internet]. 2018 [acesso em 2019 Mar 28];44(2):1-11. Disponível em: <https://periodicos.ufsm.br/revistasauade/article/view/27664>. Doi:<http://dx.doi.org/10.5902/2236583427664>.
20. Noronha AA, Folle D, Guimarães NA, Brum MLB, Schneider JF, Motta MGC. Percepções de familiares de adolescentes sobre oficinas terapêuticas em um centro de atenção psicossocial infantil. Rev. gaúcha enferm [Internet]. 2016 [acesso em 2019 Mar 28];37(4):e56061. Disponível em:

<https://www.lume.ufrgs.br/bitstream/handle/10183/150385/001008937.pdf?sequence=1&isAllowed=y>.
Doi:<http://dx.doi.org/10.1590/1983-1447.2016.04.56061>.

21. Dovgan KN, Mazurek MO. Differential effects of child difficulties on family burdens across diagnostic groups. *J Child Fam Stud* [Internet]. 2018 [acesso em 2020 Fev 18];27:872-884. Disponível em: <https://link.springer.com/article/10.1007/s10826-017-0944-9>. Doi: <https://doi.org/10.1007/s10826-017-0944-9>.

22. Souza ALR, Guimarães RA, Vilela DA, Assis RM, Oliveira LMAC, Souza MR et al. Factors associated with the burden of Family caregiver of patients with mental disorders: a cross-sectional study. *BMC psychiatry* [Internet]. 2017 [acesso em 2020 Fev 18];17:353. Disponível em: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5655908/>. Doi: <https://doi.org/10.1186/s12888-017-1501-1>.

23. Cattani NA, Ronsani APV, Welter LS, Mello AL, Siqueira DF, Terra MG. Família que convive com pessoa com transtorno mental: genograma e ecomapa. *Rev. Enferm. UFSM* [Internet]. 2020 [acesso em: 2020 Fev 12];10(e:1-19). Disponível em: <https://periodicos.ufsm.br/reufsm/article/view/36517/pdf>. Doi <https://doi.org/10.5902/2179769236517>.

24. Horta ALM, Daspett C, Egito JHT, Macedo RMS. Vivência e estratégias de enfrentamento de familiares de dependentes. *Rev. bras. enferm* [Internet]. 2016 [acesso em: 2019 Mar 28];69(6):1024-30. Disponível em: http://www.scielo.br/scielo.php?script=sci_abstract&pid=S0034-71672016000601024&lng=en&nrm=iso&tlng=pt. Doi:<http://dx.doi.org/10.1590/0034-7167-2015-0044>.

25. Cunha MP, Borges LM, Bezerra CB. Infância e saúde mental: perfil das crianças usuárias de um centro de atenção psicossocial infantil. *Mudanças, Psicologia da Saúde* [Internet]. 2017 [acesso em 2018 Fev 07];25(1):27-35. Disponível em: <https://www.metodista.br/revistas/revistas-ims/index.php/MUD/article/view/7289/5719>. doi: <http://dx.doi.org/10.15603/2176-1019/mud.v25n1p27-35>.

Corresponding author

Eliane Rosso

E-mail: eliane_ros@yahoo.com.br

Address: Rua Jaraguá, n. 190, Bairro Morro Alto, Guarapuava, Paraná, Brazil.

CEP: 85065-630

Contributions of Authors

1 – Eliane Rosso

Conception and planning of the research project; data collection and analysis; redaction of the manuscript and discussion of the data.

2 – Miriam Aparecida Nimtzt

Conception and planning of the research project; Guidance and supervision during data collection; Critical review of the redaction, results and discussion of the data

3 – Marcio Roberto Paes

Critical review of the redaction, results and discussion of the data.

4 – Mônica Macedo

Critical review of the redaction, results and discussion of the data.

5 – Mariluci Alves Maftum

Critical review of the redaction, results and discussion of the data.

6 – Camila Bonfim de Alcantara

Redaction of the manuscript and discussion of the data.

How to cite this article

Rosso E, Nimtz MA, Paes MR, Ignácio MMM, Maftum MA, Alcantara CB. Vivência de familiares de crianças com transtornos mentais. Rev. Enferm. UFSM. 2020 [Acesso em: Anos Mês Dia]; vol.10 e36: 1-19. DOI:<https://doi.org/10.5902/2179769237292>