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Occupational performance of users careers at Child and Youth Psychosocial Care Center

Desempenho ocupacional de cuidadores de usuários de um Centro de Atenção Psicossocial Infantojuvenil

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ABSTRACT

Being a caregiver causes changes in various contexts of the subject's life. This study aimed to identify changes in the occupational performance of family members who have become caregivers of children or adolescents undergoing treatment for mental disorders. This is a qualitative study, in which 17 caregivers of children or adolescents who were undergoing treatment in a Child and Youth Psychosocial Care Center participated. Data were collected through the Canadian Occupational Performance Measure and a semi-structured interview and verified through thematic-categorical analysis. Most participants were female, had problems in personal care and in independence away from home; besides, they decreased workload, including tasks, and reduced recreation and socialization. It was concluded that being a caregiver for a child or adolescent with mental illness influences the performance of self-care activity, productivity and leisure.

Keywords: Caregivers. Mental health. Occupational therapy.

RESUMO

Ser cuidador ocasiona mudanças em diversos contextos da vida do sujeito. O objetivo deste estudo foi identificar alterações no desempenho ocupacional de familiares que se tornaram cuidadores primários de crianças ou adolescentes em tratamento de transtornos mentais. Trata-se de uma pesquisa qualitativa da qual participaram 17 cuidadores de crianças ou adolescentes em tratamento em um Centro de Atenção Psicossocial Infantojuvenil. Os dados foram coletados por meio da Medida Canadense de Desempenho Ocupacional e de uma entrevista semiestruturada e averiguados mediante a análise de conteúdo temático-categorial. A maioria dos respondentes eram do gênero feminino, apresentaram problemas nos cuidados pessoais e na independência fora de casa; além disso, diminuíram a carga horária de trabalho, inclusive as tarefas, e reduziram a recreação e a socialização. Concluiu-se que ser cuidador de criança ou adolescente com doença mental influencia o desempenho de atividade de autocuidado, de produtividade e de lazer.

Palavras-chaves: Cuidador. Saúde mental. Terapia ocupacional.

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INTRODUCTION

In Brazil, a family member is usually responsible for taking care of the people who are part of it, especially those requiring more attention. Such action can bring about changes in routine, restrictions in social and professional life, in addition to financial losses due to reduced workload or resigning the job. Therefore, this can have a negative impact on the caregiver's physical, social and emotional health, generating anxiety, stress, personal disorder, decline in quality of life and financial burden[1] - all due to lack of time, unavailability to abdicate the person receiving care, fatigue, performing excessive tasks and continuous supervision. In addition, leisure activities are restricted, leading to social isolation[2].

Thus, in a health care service for children and adolescents, the identified patient should not be the only focus of services and health professionals. This is because the family also suffers the impact of the disease affecting one of its members, which can be reflected in the development of the child or adolescent within the family and, especially, in the caregiver's life [2].

Despite the fact that mental disorders affect a significant portion of Brazilian children and adolescents, the analysis of the scientific literature in the field of mental health for children and adolescents points to a still incipient production on the subject. There are studies that are focused on, in a limited way, stress and quality of life or changes in the occupational performance of caregivers of children or adolescents with serious and chronic diseases[3]. No studies were found on the occupational performance of caregivers of children and adolescents with mental disorders, which justifies the development of this research.

Occupational performance is understood as the ability to perform tasks that allow the execution of occupational and social roles in a satisfactory and appropriate way for the stage of development, culture and environment of the individual[4]. It is also defined by the American Occupational Therapy Association[5] as the ability to fulfill tasks and roles linked to your area of occupation, integrating the individual, activity, context and environment. It is considered satisfactory when it promotes the health and well-being of the individual and is related to several aspects and factors that interfere in the performance of different activities. These factors include areas of human occupation, considered as categories that cover the wide variety of occupations that the individual may have. According to the American Occupational Therapy Association[5], these areas are: activities of daily living; instrumental activities of daily living; rest and sleep; to work; play and leisure; education; and social participation.

Thus, this research aimed to identify changes in the occupational performance of family members who became primary caregivers for children or adolescents who are undergoing treatment for mental disorders.

METHODOLOGY

It is a qualitative, descriptive and exploratory study. Using the qualitative method allows to know facts, processes, structures and people in their entirety and depth, therefore it is appropriate to identify and apprehend relevant phenomena in this field. Realism was used as an etymological and ontological reference that narrates the experiences, meanings and reality of the participants, which recognizes the ways in which individuals create meaning for their experience and, in turn, the ways in which the broader social context is presented in these meanings, keeping the focus on the material and other limits of reality. Thus, realistic research presupposes that the world has a recognizable and real natural truth, discovered through experience and investigation[6].

Therefore, in the light of realism, for the development of research, the following procedures were adopted. The work was carried out in a Child and Adolescent Psychosocial Care Center (CAPSi) in a city in the countryside of Minas Gerais, Brazil, with approximately 330 thousand inhabitants. This was the place where children and adolescents received treatment and where access to participants was possible.

This way, 17 caregivers of children or adolescents who met the inclusion criterion of being the main responsible ones for this task and who followed the treatment of the child or adolescent for at least six months participated in this research. Two caregivers who were not responsible for the monitoring were excluded, actually they were people from institutions for the care of children or adolescents who, on the days of data collection, were present at the consultation. Six were invited three times, in consecutive weeks, but refused, claiming to be in a hurry, being excluded after the third attempt.

The final number of respondents was defined by the criteria of exhaustion for qualitative research. The sample was closed through theoretical saturation, that is, the inclusion of new participants was suspended when the data obtained became a little redundant and it was not considered relevant to persist in collecting them[9]; these were discussed by the researchers for saturation agreement. As for the confidentiality of the interviewees, a code was created in which they were identified by letter "C" for caregiver, followed by the sequential number of their testimony.

Caregivers were invited to participate in the study when they accompanied the child or adolescent, and data collection took place in a private room at CAPSi, with the presence of only one researcher and one participant. The interviews were conducted by one of the researchers trained to carry them out and apply the Canadian Occupational Performance Measure (COPM) and lasted an average of 40 minutes. The other researchers supervised and guided the completion of the work.

To achieve the objectives, the data were collected through COPM and an interview composed of questions about the sociodemographic data and questions about activities that the participant did and stopped doing after he/she started following the treatment of the child or adolescent. In addition, in case there have been changes in this routine, they were asked whether knowing the diagnosis of the child or adolescent influenced this change and if they realized that some strategy could be used to improve the performance of their daily activities.

COPM is an instrument standardized and translated into Portuguese in Brazil, widely used in clinical practice and in research after it has been validated for some populations[7]. It was built aiming to detect changes in the clients' perception of their occupational performance over time. It categorizes occupations into: self-care (personal care, functional mobility and functioning in the community); productivity (paid or unpaid work, housework, school and playing); and leisure (silent recreation, active recreation and socialization). The instrument focuses on the needs and problems of customers individually and is not specific to a certain health condition.

The purpose of the interview was to better understand the changes in occupational performance of caregivers of users (children and adolescents) of a CAPSi after monitoring them in the treatment.

COPM data were recorded on the instrument itself, and those from the interviews, recorded on digital media and later transcribed for analysis. At each interview, a record of impressions about the participants and the context was made in the field notebook, and these data were examined together with those collected among the participants. All information collected was evaluated through thematic-categorical content analysis, with a qualitative approach[8].

First, a complete and exhaustive reading of the selected material was performed, seeking to have a global view, to apprehend the particularities of everything that would be analyzed, to elaborate initial assumptions that would serve as a parameter for the examination and interpretation. From that, the forms of initial classification were chosen and the theoretical concepts that would guide the analysis were determined.

In the second stage, an exploration of the material was carried out, dialoguing with the parts of the analysis text, identifying, by means of inferences, the nuclei of meaning pointed by the textual fragments in each class of the classification scheme, relating the nuclei of meaning with the initial assumptions.

Subsequently, the different cores of meaning present in the different classes of the classification scheme were evaluated; the parts of the text were grouped by the found themes and a writing by theme was elaborated. As a final step, the interpretative synthesis was constructed through an essay that dialogues with the data obtained in the research, the objectives of the study and the theoretical framework found in the literature.

Data collection took place between February and April 2018, only once with each participant. There was no pilot test.

The sample was chosen for convenience. For the selection, all caregivers of children or adolescents attending the service during the period of the research data collection were personally invited; none of the researchers knew them, that is, there was no personal or professional relationship.

All participants became aware of the objectives and phases of the investigation. For this purpose, the Informed Consent Form (ICF) was used, including information about their objectives, method and rights, which was signed before being included in the work. The ethical aspects of this research met the guidelines for good research practices in accordance with resolutions 466/2012 and 510/2016. The study was approved by the Research Ethics Committee of the university to which the authors are linked, according to CAAE 89085318.9.0000.5154 on April 3, 2018.

RESULTS

The results were presented in two sections. First, the sociodemographic and clinical characteristics of the participants (Table 1) and their performance on the COPM instrument were identified, and subsequently, the themes constructed based on the analysis of the two open-ended questions.

Table 1. Characteristics of caregivers

Caregiver	Gender	Age	Degree of kinship	Does therapy	Use of psychiatric medication
C1	Female	39	Mother	Yes	Yes
C2	Female	47	Mother	No	No
C3	Male	51	Father	No	No
C4	Male	50	Father	No	No
C5	Female	44	Mother	Yes	Yes
C6	Female	35	Mother	Not informed	Not informed
C7	Female	39	Mother	No	No
C8	Female	29	Mother	Yes	Yes
C9	Female	40	Mother	No	No
C10	Female	29	Mother	No	No
C11	Female	25	Mother	No	No
C12	Female	36	Mother	No	No
C13	Female	30	Mother	No	No
C14	Female	43	Mother	No	Yes
C15	Female	69	Grandmother	No	No
C16	Female	36	Mother	No	No
C17	Female	40	Mother	Yes	No

Source: Research data.

Concerning the children or adolescents that the caregivers monitored (Table 2), ten underwent treatment at CAPSi for over a year - a prolonged period of time, evidencing the impact of this task on the caregivers. Although two participants reported having recently started this follow-up at CAPSi (one a month ago, the other, four months), the children under their supervision were seen at other mental health care services, and they lived and realized the consequences of care; for this reason, they were included in the research.

Through the Canadian Occupational Performance Measure (COPM), it was found that four caregivers did not identify problems regarding occupational performance. Concerning the "self-care" category, with regard to personal care, ten pointed out problems due to the lack of time to take care of themselves and the limitation in the performance of activities, always prioritizing the attention to the other. One of them referred to the difficulty of functional mobility, and six, of independence outside the home, with stories about restriction and sacrifice in carrying out activities that require the child or adolescent to accompany them, due to the inappropriate behaviors they present.

Table 2. Characteristics of children and adolescents that the caregiver accompanies

Caregiver	Assistance at CAPSi	Diagnosis
C1	5 years	Hyperactivity and depression
C2	Almost 1 year	Suicidal behavior
C3	5 years	Schizophrenia
C4	2 years	Not informed
C5	7 years	Schizophrenia
C6	1 month	Not informed
C7	2 years	Attention deficit hyperactivity disorder
C8	5 years	Attention deficit hyperactivity disorder
C9	7 months	Hyperactivity and aggressiveness
C10	1 year	Unconcluded diagnosis
C11	4 months	Attention deficit hyperactivity disorder and oppositional defiant disorder
C12	More than 1 year	Hyperactivity
C13	2 years	Autism and mental retardation
C14	8 months	Unconcluded diagnosis
C15	2 years	Depression and agitation
C16	6 years	Schizophrenia
C17	More than a year	Unconcluded diagnosis

Source: Research data.

In the case of the "productivity" category, nine caregivers identified problems with work - the loss of a job (paid work) was considered as a result of taking care of the other, which increases pressure, responsibility and demand for time. Two responded that household chores become limited, overburdened and left for later, as there are other concerns.

As for the "leisure" category, four signaled difficulties with silent recreation, and seven, with active recreation, as they stopped performing leisure activities, since caring for the child or adolescent or, even, the behavior they present outside the home don't allow that to happen. Six identified problems in socialization: the participants informed that they isolate themselves or are isolated as a result of the behavior of the child or adolescent, in addition to perceiving the stigma and judgment on the part of the other.

From the set of the participants' testimonies, obtained through the interview, it was possible to construct three thematic categories: job loss; restriction of social participation and socialization; and overload and feeling guilty for exercising the role of caregiver.

JOB LOSS

The loss of work, in the opinion of caregivers, seems to be related to the fact of taking the child/adolescent for treatment:

> *Because of the schedule, I was not able to leave to bring him to CAPSi and then go back to work, I was taking him on a motorcycle, that is, I passed my responsibility to someone else to be able to work, so, no, to me it was not advancing. (C9)*

Moreover, when quitting paid work, there is a loss of financial independence and resources to take care of the family: "I worked, I would like to work, because I always had my independence, now it is complicated to depend on others" (C1). Even autonomous activity, such as providing cleaning services, is not possible, as it is necessary to accompany the child or adolescent more, in various situations: "My housekeeping work has decreased, I would like to work, because I depend on work to take care of them. I have four children" (C6). Still, being out of the job market leads to loss of personal space and socialization: "I worked outside the home, had my salary, also interacted with other friends, had greater freedom, more space for me, today I don't have it anymore"(C17).

Unlike the female caregivers, among the two male participants, only one reported that he worries more during work, however this did not lead him to reduce or leave his job, nor even change his actions in the work environment: "I feel worried with him during work, but all I gave up was soccer. I already thought about going to the gym, but you always have to be with him, together with him"(C4).

RESTRICTION OF SOCIAL PARTICIPATION AND SOCIALIZATION

The socialization of the participants seems to be affected in different aspects by the mental disorder of the child/adolescent of which the adult is the main caregiver. They start to have behaviors different from those of other children, which is observed by society with misunderstanding and, often, judgment. They need to take medication at specific times, causing a social commitment to leave due to the drowsiness that some drugs cause. Thus, caregivers feel stigmatized in the eyes of society:

> *This interferes, because [he] has to take medicine and, sometimes, you are in a place and need to leave because of him, because he wants to sleep, so lots of things change. It is not possible to stay in every situation, sometimes, the type of behavior [that he presents], you are in a place where he has a type of behavior, not everyone understands that it is a [health] problem. (C5).*

Such a situation ends up restricting social life "I used to go out more often, I didn't go out so much, you know, I also traveled, I used to go to Maranhão, you know? I traveled sometimes, now I'm not going anymore, I'm going less (C12)". In addition, it limits coexistence and activities within the home itself: "I used to socialize more with people, but now I stay more with them myself, I stay more at home, I hardly go out, I hardly see my relatives" (C16).

In contrast to the female caregivers, the male caregiver points out that the only changes in leisure are to quit physical activity and stop going to bars with friends. In the first case, it influences physical well-being, causing pain in the legs; in the second, there is a report that it is not needed, and the new posture provides more time with the child: "I stopped going to the bar and playing football. But not going to the bar is good, and I managed to get close to my son, I can take more care of him"(C4).

Although the study had the participation of only two male caregivers, there are differences in changes regarding occupational performance when gender is taken into account. Women suffered a greater impact of care, which may be due to the incorporation of the role of primary caregiver, in addition to the other roles and tasks previously assumed.

OVERLOAD AND FEELING GUILTY FOR EXERCISING THE ROLE OF CAREGIVER

Caregivers also comment on the burden and the feeling of guilt for the role they play: [Did your child's diagnosis influence any of your activities?] "A lot, he's not different, but he is a child who needs care that demand a lot from me, sometimes I'm overwhelmed and he wants more from me"(C10).

Many participants were touched during the testimony, reporting the difficulty they go through: "I sometimes think about giving up everything, everything blames me, you know? But, there are times when I think: my children need me, I have to be strong, I have to take care of them, because it is very difficult"(C12).

Most participants initially stated that there was no change in the performance of their activities after accompanying the child or adolescent at CAPSi. However, during the interviews, they reported changes in their routine: "Before I went for a walk, I went to the mall, I went to my relatives' or friends' homes, today I don't do that; I used to take them for a walk in the square, take a walk in the street, I used to go to the supermarket, today I don't do that"(C1).

DISCUSSION

Data were collected using two instruments: COPM and an interview about the sociodemographic characterization and occupations of participants after becoming caregivers for a child or adolescent undergoing treatment at the mental health service. The analysis showed that the responses reflected the same meanings between one instrument and another, validating not only the information, but also representing the impact of care on occupational performance in these people's lives.

From the very beginning, in most cultures, women have taken on the responsibility of looking after the home and providing the extension of the family. Such scenario is reflected today in gender inequality and the burden on one of the caregivers who adds several functions, such as taking care of the other, home and professional career[10].

This can also be seen in the findings of this study, according to which only two of the 17 participants were men - therefore, the majority were female. Research on gender relations among family members, caregivers of children and adolescents showed that the main responsible for all care for children, including health care, are women and that the presence of the mother in the life of the child or adolescent is predominant . What is more, she is given the role of primary caregiver, that is, the female presence appears prominently in the caregiver function[11].

It is important to highlight that, in a study about the care of children and adolescents with mental disorders[12], the authors describe the prevalence of females in this task. Although it was not the focus of the present study, in another study on family skills related to the prevention and treatment of diseases in children up to six years of age[13], the participation of mothers as caregivers is evident, both for the results presented, in which the tables do not even mention the fathers, due to the research context. In this research[13], it is possible that such participation by mothers occurred due to the fact that data collection was carried out at home, during business hours. This is another data that corroborates the findings of this study, because, even if the child does not have a health problem, it is the woman who abdicates work outside the home to take care of her children.

The population assisted at CAPSi is being treated for some chronic mental health disorder. Chronic conditions are those of a more or less long or permanent course that require continuous and integrated responses and actions from the health care system, from professionals and people who use it, for its effective and efficient control, and with quality. Such conditions can be accompanied by symptoms or be asymptomatic, consequently causing changes in the life of subjects and people around them, directly and indirectly, having a greater impact among those with greater involvement in care. It is observed that the different diagnoses affect the lives of individuals in a different way, also influencing their prognosis[14].

The care provided influences the caregiver's life in different ways - within the scope of the professional career, in sexual activity, in emotional, physical and social life, in addition to the change in routine -, characterized by being an exhausting and stressful process[15]. In this study, it was noticed that the participants demonstrated changes in their daily lives, focusing on self-care, productivity and leisure activities that result from the process of providing care, which demands corresponding actions and services. When taking the responsibility for taking care of the person with a mental disorder, overload occurs due to the accumulation of tasks; caregivers have problems in their daily lives, involving self-care, which is done in a precarious or undeveloped manner[16]. Still, in a research on self-care and aging experiences of family caregivers for the elderly, the authors[17] characterize that care without relay with another person results in the lack of time to perform self-care.

It is also noticed that self-care, which involves attention to hygiene, dressing, food and bathing, in addition to independence outside the home (means of transport, shopping and home finances), was repeatedly identified by the participants as something that has been carried out in an unsatisfactory way, or even abandoned by them; the role of caregiver influences this change in performance. Due to the lack of time to take care of themselves and the limitation they encounter on a daily basis by the demands of the person being cared for, they place the care of the other always first. In addition, they find restriction and difficulty in carrying out activities that require leaving the house in the company of the child or adolescent, due to the inappropriate behaviors that they often present.

With regard to paid work, respondents reported that the reason for quitting is related to the care demanded by children/adolescents, confirming changes in this context. In a survey conducted in the municipality of Patos (PB) in 2018[18] with caregivers of children and adolescents being monitored at CAPSi, it was found that a great one gave up their jobs to dedicate to the task. Such characteristics may be due to the demands of the care action, causing changes in the routine that make it impossible to maintain what was previously done.

It is possible to observe that there were also changes in the context of leisure, especially giving up activities carried out before the illness of the child and/or adolescent, or the reduction of them, according to the care needs. In the same study conducted in Patos (PB)[18], the authors found changes in leisure activities that were carried out with greater constancy before the illness of the one being cared for and with a decline in the current incorporation of the caregiver role. Another study, carried out among caregivers of cancer patients with reduced functional capacity[19], also corroborates these data: during the care period, most did not have moments of leisure, as they needed to respond to the demands of the sick person.

Another change presented refers to the restriction of social participation and socialization. The role of caregiver generates an impact that influences life and interpersonal relationships and can cause social isolation, which can subsequently cause some problem in mental and emotional health[20]. The findings show that several caregivers stopped being in contact with other people, even with family members, due to the excess of activities they have to perform and the needs and behavior of children and adolescents.

It is yet observed that there is also an overload in the caregivers' routine, which concerns what is excessive and added to the normal load. The caregivers in this study reported such situation, as well as the feeling of guilt for exercising the role of caregiver for the child and/or adolescent, describing difficulties they face, abdicating their own lives to fulfill the tasks. This finding is in line with what Reis and collaborators[22] concluded, describing the different roles and functions that the primary caregiver has to assume, in addition to caring for the child and/or adolescent with a chronic condition, which causes them to abandon their routine.

Another research[16] covers the subject, addressing the types of burden (objective and subjective) that result from the lack of help from other relatives and the accumulation of tasks, predisposing caregivers to exhaustion. And yet, a study[20] with caregivers of children with cerebral palsy points out the lack of time and the overload of tasks, compromising personal life and, subsequently, the caregiver's daily life.

The fact that it was performed in only one service is recognized as a limitation of this study, which can be reflected in the results only for the population being assisted there. Furthermore, it is emphasized that the research city has characteristics of places in the countryside, where people live with an extensive support network. This is different from the reality of others, larger ones, in which perceptions about changes in social and leisure activities could be perceived differently.

CONCLUSION

It is concluded that being a caregiver of a child or adolescent with a mental disorder has a negative impact on the occupational performance of the adult responsible for this task, causing lack of self-care, loss or reduction of the workload, deficits in leisure and social participation, influencing the physical, social and emotional life. Thus, the objective of the study was reached, namely, to identify changes in the occupational performance of family members who became primary caregivers of children or adolescents in the treatment of mental disorders.

The need for attention and care for these people is recognized, as well as that the health of the child and adolescent depends on the health of their caregiver. Thus, it is necessary to turn the attention of health professionals to this population, with a view to promoting more humanized and specialized care, as well as making society aware of the issue, in order to reduce the stigma and prejudice suffered.

Occupational therapy has an important role in working with this population, guiding and promoting reflection on this topic, in addition to reframing and resuming activities that were previously done. Abandoning or modifying occupational performance for the sake of caring is not healthy and can negatively compromise the subject's health.

REFERENCES

1. Peres PAT, Buchalla CM, Silva SM. Aspectos da sobrecarga e qualidade de vida de cuidadores de pacientes hospitalizados: uma análise baseada na Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF). Rev Bras Saúde Ocup. [Internet]. 2018 [citado em 2020 jan. 14]; 43:e12. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0303-76572018000100207&lng=en. doi: http://dx.doi.org/10.1590/2317-6369000013617.

2. Estanieski I, Guarany N. Qualidade de vida, estresse e desempenho ocupacional de mães cuidadoras de crianças e adolescentes autistas. Rev Ter Ocup Univ. São Paulo (Online) [Internet]. 2015 [citado em 2020 jan. 14];26(2):194-200. Disponível em: http://www.revistas.usp.br/rto/article/view/84621

3. Salvador MS, Gomes GC, Oliveira PK, Gomes VLO, Busanello J, Xavier DM. Estratégias de famílias no cuidado a crianças portadoras de doenças crônicas. Texto Contexto Enferm. 2015; 24(3): 662-9.

4. Caldas A, Facundes VL, Silva H. O uso da Medida Canadense de Desempenho Ocupacional em estudos brasileiros: uma revisão sistemática. Rev Ter Ocup Univ. São Paulo (Online) [Internet]. 2011 [citado em 2020 jan. 14];22(3):238-44. Disponível em: http://www.revistas.usp.br/rto/article/view/46397

5. American Occupational Therapy Association. A Estrutura da prática da Terapia Ocupacional: domínio & processo - 3ª ed. traduzida. Rev Ter Ocup Univ. São Paulo (Online) [Internet]. 2015 [citado em 2020 jan. 14];26(esp):1-9. Disponível em: http://www.revistas.usp.br/rto/article/view/97496

6. Braun V, Clarke V, organizadoras. Successful qualitative research: A practical guide for beginners. London: Sage; 2013.

7. Chaves GFS. Estudo de confiabilidade e validade da Medida Canadense de Desempenho Ocupacional (COPM) em idosos com comprometimento Cognitivo Leve (CCL) [dissertação]. São Paulo: Faculdade de Medicina da Universidade de São Paulo; 2012. 76p.

8. Bardin L. Análise de conteúdo. 3ª reimp. Lisboa, Portugal: Edições 70; 2016.

9. Fontanella BJB, Luchesi BM, Saidel MGB, Ricas J, Turato ER, Melo DG. Amostragem em pesquisas qualitativas: proposta de procedimentos para constatar saturação teórica. Cad. Saúde Pública. 2011; 27(2):389-94.

10. Sousa LP, Guedes DR. A desigual divisão sexual do trabalho: um olhar sobre a última década. Estud Av. 2016; 30(87):123-39. doi: https://dx.doi.org/10.1590/S0103-40142016.30870008

11. Muylaert CJ, Delfini PSS, Reis AOA. Relações de gênero entre familiares cuidadores de crianças e adolescentes de serviços de saúde mental. Physis [Internet]. 2015 [citado em 2020 jan. 14]; 25(1):41-58. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-73312015000100041&lng=en.

12. Buriola AA, Vicente JB, Zurita RCM, Marcon SS. Overload of caregivers of children or adolescents suffering from mental disorder in the city of Maringá, Paraná. Esc Anna Nery [Internet]. 2016 [cited in 2020 Jan. 14]; 20(2):344-51. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1414-81452016000200344&lng=en. doi: http://dx.doi.org/10.5935/1414-8145.20160047.

13. Oliveira FA, Ximenes FJM, Monteiro ACS, Farias OO, Mendes IC, Silva e Moura DJM. Competências familiares relacionadas à prevenção e tratamento das doenças nas crianças de até seis anos. Saúde e Pesquisa, Maringá (PR) [Internet]. 2018 [citado em 2020 jan. 14]; 11(2):257-65. Disponível em: http://docs.bvsalud.org/biblioref/2018/09/912403/6201-30298-1-pb.pdf

14. Mendes EV. Entrevista: A abordagem das condições crônicas pelo Sistema Único de Saúde. Ciência & Saúde Coletiva [Internet]. 2018 [citado em 2020 jan. 14]; 23(2):431-5. Disponível em: https://www.scielosp.org/pdf/csc/2018.v23n2/431-436/pt

15. Mota AS, Silva ALA, Souza AC. Educação permanente: Práticas e processos da enfermagem em saúde mental. Rev Port Enf de Saúde Mental [Internet]. 2016 [citado 2020 jan. 14]; (spe4):9-16. Disponível em: http://www.scielo.mec.pt/scielo.php?script=sci_arttext&pid=S1647-21602016000400002&lng=pt. http://dx.doi.org/10.19131/rpesm.0135.

16. Gomes MLP, Silva JCB, Batista EC. Escutando quem cuida: quando o cuidado afeta a saúde do cuidador em saúde mental. Rev Psicol Saúde [Internet]. 2018 [citado em 2020 jan. 14]; 10(1):3-7. Disponível em: http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S2177-093X2018000100001&lng=pt. http://dx.doi.org/10.20435/pssa.v10i1.530.

17. Nicolato FV, Santos CM, Castro EAB. Autocuidado e vivências do envelhecer de cuidadores familiares de idosos: contribuições para enfermagem gerontológica. Tempus, actas de saúde colet. 2017; 11(1):169-86. doi: http://dx.doi.org/10.18569/tempus.v11i1.2050

18. 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 [citado em 2020 jan. 14]; 27(2):544-55. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-12902018000200544&lng=en. http://dx.doi.org/10.1590/s0104-12902018156194.

19. Moreira NS, Sousa CS, Poveda VB, Turrini RNT. Self-esteem of cancer patients' caregivers with reduced functional capacity. Esc Anna Nery [Internet]. 2015 [cited in 2020 Jan. 14]; 19(2):316-22. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1414-81452015000200316&lng=en. doi: http://dx.doi.org/10.5935/1414-8145.20150043.

20. Pereira ARPF, Matsue RY, Vieira LJES, Pereira RVS. Análise do cuidado a partir das experiências das mães de crianças com paralisia cerebral. Saúde Soc. [Internet]. 2014 [citado em 2020 jan. 09]; 23(2):616-25. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-12902014000200616&lng=en.

21. Reis KMN, Vilaça AG, Araújo BT, Oliveira LG, Pinto BP. A vivência da família no cuidado domiciliar à criança com necessidades especiais de saúde. Cienc enferm [Internet]. 2017 [citado em 2020 jan. 14]; 23(1):45-55. Disponível em: https://scielo.conicyt.cl/scielo.php?script=sci_arttext&pid=S0717-95532017000100045&lng=es. doi: http://dx.doi.org/10.4067/S0717-95532017000100045.