Esc Anna Nery 2016;20(2):344-351

RESEARCH | PESQUISA

EEAN.edu.br

Overload of caregivers of children or adolescents suffering from mental disorder in the city of Maringá, Paraná*

Sobrecarga dos cuidadores de crianças ou adolescentes que sofrem transtorno mental no município de Maringá - Paraná

Sobrecarga del cuidador de niño o adolescente con trastorno mental en la ciudad de Maringá - Paraná

Aline Aparecida Buriola[1]
Jéssica Batistela Vicente[2]
Robsmeire Calvo Melo Zurita[2]
Sonia Silva Marcon[2]

1. Universidade do Oeste Paulista.
Presidente Prudente - SP, Brazil.
2. Universidade Estadual de Maringá.
Maringá-PR. Brazil.

Abstract

Objective: To identify the burden of caregivers of children and adolescents suffering from mental disorder. **Methods:** This is a cross-sectional, descriptive, exploratory, and quantitative study, conducted with 82 caregivers/family members of children and adolescents treated at the Children Psychosocial Care Center in the city of Maringa, Parana, Brazil. Data collection was conducted from December 2012 to July 2013, and used the Overload Scale for Family Members of Psychiatric Patients, as well as a socio-demographic questionnaire were used. **Results:** A high objective overload related to assistance in daily activities such as supervision over the administration of drugs, and high subjective overload resulting from contact with problematic behaviors. **Conclusion:** In this context it is essential to link the family in care actions provided in health services, requiring that professionals act aiming to enhance the strengths of the family that lives with these children and adolescents, solving doubts and being supportive to the family in terms of the difficulties that arise in the interaction.

Keywords: Mental Health; Caregivers; Family; Community Health Services.

Resumo

Objetivo: Identificar a sobrecarga do cuidador de criança ou adolescente com transtorno mental. **Métodos:** Estudo transversal, descritivo, exploratório, quantitativo, realizado com 82 cuidadores/familiares de crianças e adolescentes atendidos no Centro de Atenção Psicossocial infantil do município de Maringá, Paraná, Brasil. A coleta foi de dezembro de 2012 a julho de 2013, utilizando-se a Escala de Sobrecarga dos Familiares de Pacientes Psiquiátricos e um questionário sócio-demográfico. **Resultados:** Identificou-se sobrecarga objetiva elevada quanto à assistência em atividades da vida cotidiana, como supervisão na tomada de medicamentos, e sobrecarga subjetiva alta decorrente do convívio com comportamentos problemáticos. **Conclusão:** Nesse contexto é imprescindível vincular a família nas ações de cuidado prestadas nos serviços de saúde, sendo necessário que os profissionais atuem potencializando pontos positivos da convivência da família com essas crianças e adolescentes, sanando dúvidas e sendo o suporte da família para as dificuldades que surgem no convívio.

Palavras-chave: Saúde Mental; Cuidadores; Família; Serviços de Saúde Comunitária.

Resumen

Objetivo: Identificar la sobrecarga del cuidador de niños o adolescentes con trastorno mental. **Métodos:** Estudio transversal, descriptivo, exploratorio, cuantitativo, realizado con 82 cuidadores/familiares de niños y adolescentes atendidos en el Centro de Atención Psicosocial infantil del municipio de Maringá, Paraná, Brasil. La recolección de datos fue hecha de diciembre de 2012 a julio de 2013, utilizándose la Escala de Sobrecarga de los Familiares de Pacientes Psiquiátricos y un cuestionario sociodemográfico. **Resultados:** Se identificó sobrecarga objetiva elevada en cuanto a la asistencia en actividades de la vida cotidiana, como supervisión en la toma de medicamentos; y sobrecarga subjetiva alta debido a la convivencia con comportamientos problemáticos. **Conclusión:** En este contexto es imprescindible vincular a la familia en las acciones de cuidado prestadas en los servicios de salud, siendo necesario que los profesionales actúen potencializando puntos positivos de la convivencia de la familia con estos niños y adolescentes.

Palabras clave: Salud Mental; Cuidadores; Familia; Servicios de Salud Comunitaria.

Correspondent author:
Aline Aparecida Buriola.
E-mail: aliburiola@bol.com.br

Submitted on 05/28/2015.
Accepted on 02/28/2016.

DOI: 10.5935/1414-8145.20160047

INTRODUCTION

Currently, in Brazil, the mental health of children and adolescents is a public health issue, as historically this issue has been delegated to other sectors, such as education. However, with the Psychiatric Reform, which began in Brazil in the 1970s, the peculiarities of its care began to be considered, based on the overcoming of the exclusive nature of mental health care through a model of community-based care and family[1].

According to the Ministry of Health, 3% of the general population suffers from serious or severe mental disorder, and more than 12% needs some mental health care, whether continuous or occasional. Children and adolescents are included in these percentages[2].

However, a study conducted in Italy shows a lack of research on the mental health services directed to children and adolescents in Europe, and this is a limitation for researchers and professionals in the field as many mental disorders begin in childhood and adolescence. An effective intervention, especially in the vulnerable stages of development, could prevent chronicity[3].

It is noteworthy that, with the fall in infant mortality, children who were previously exposed to the biological risk of dying currently experience stress concerning the conditions offered by increased urbanization, violence and changes in family structure, which makes them vulnerable to the appearance of early mental disorders[1]. This aspect could lead to the overload of family members who act as preferred caregivers of these children/teenagers.

Thus, the permanence of this young individual suffering from mental illness in the family causes changes in routine, habits and family habits. The discovery of the diagnosis and the impact of the family lead to a need to adapt to the new situation, which can be permeated by stigma and prejudice related to the disease. The imposed changes can produce situations of wear and physical and emotional burden on family members - specially for the preferred caregiver[1,4,5], that is, the person, from the family or not, who provides most or all the child care[6].

A study conducted in the United States with caregivers of children with mental disorders shows the physical and psychological exhaustion of those identified as preferred, as they state that the care directed at children and adolescents with mental disorders demand 24 hours attention during the seven days of the week[7].

Two features characterize the family burden resulting from the action in health care. The first is the objective aspect, which makes reference to the concrete and observable negative consequences resulting from the caregiver role, such as financial losses, disruption in the routine of family life, the excessive number of tasks that the family member is supposed to perform in the daily care of the individual and supervisions to problematic behaviors[8,9].

The second is the subjective aspect, which scores the perception or personal assessment of the family in terms of the situation involving their emotional reaction and the feeling of being suffering an overload attributed by them to the caregiver role. It refers to the degree to which family members perceive behaviors or dependency of patients as a source of concern or psychological stress[8,9].

In Brazil, studies that seek to identify the burden of families living with children or adolescents with mental disorders are scarce. It is believed that, by detecting the overload of caregivers and identifying areas with higher wear, it is possible to think of interventions to improve family coping in relation to mental disorder at home and the quality of life of children, adolescents and their families. This study aimed to identify the overload of the caregivers of children and adolescents suffering from mental disorders.

METHODS

This is a cross-sectional, descriptive, exploratory study, using a quantitative approach that was held in Maringa/PR, municipality in which, since 2011, the care of children and adolescents with mental disorders occurs at the Children Psychosocial Care Center (CAPSi).

The sample size was estimated from the monthly average of visits in the service, which was 140, according to the Outpatient Actions Registry of Health (RAAS), available on the website of the Department of the Unified Health System (DATASUS). The sample included 82 caregivers/family members considering a 95% confidence interval, estimated error of 5% and prevalence of mental disorders in children and adolescents of 15% (average of what is reported by some studies, ranging between 9% and 20%)[10].

The study population consisted of caregivers/family members of children or adolescents treated at the CAPSi. The criteria for inclusion in the study were: being 18 years or older, accompanying the child or adolescent during the service, and being the preferred caregiver of the child or adolescent.

Data were collected in the period from January to July 2013 in alternate days, periods and schedules, by means of a structured interview. The request for participating in the study was done in person, at which were explained the objectives and the type of desired participation. Interviews were conducted in a private room at the service site, while waiting for the care or shortly after it, and took an average of 40 minutes.

During the interview an instrument consisting of two parts was used: one that aimed to collect data regarding the sociodemographic characteristics of the participants and the other consisting of the Overloading Scale of Psychiatric Patient Family (FBIS-BR), initially developed at the University of Massachusetts[11] and adapted and validated for use in Brazil[12].

This scale consists of 52 items that assess care overload objectively and subjectively in five dimensions: a) assistance in everyday life; b) monitoring the problematic behaviors of the patient; c) expenses related to the patient; d) impact on the daily routine of the family; e) concern for the patient.

The objective burden is assessed in the Likert scales of five points (1 = no time to 5 = every day), indicating the frequency with which the family members performed patient care tasks, dealt with problematic behaviors, and underwent changes in social and professional life.

The subjective overload, in turn, is evaluated in the Likert scale of four points (1 = no time to 4 = a lot) to the level of discomfort by providing daily care and changes in life, and in scales of five points (1 = no time to 5 = always or almost always) for the frequency of concerns and expenditure weight with patients.

The FBIS-BR also evaluates the type and amount of expenses with patients, their contribution to cover such expenses and permanent changes in the life of the caregiver. The FBIS-BR questions refer to the 30 days preceding the interview, with the exception of one item, which evaluates the overload during the last year. This scale has no cutting score established; therefore, the high overload identification is based on the percentage of answers - always and almost always - of each subscale and their issues.

The data were compiled, organized and stored in Microsoft Excel spreadsheets 07 and the average of scores was calculated for each question. Soon after, they were analyzed using descriptive statistics.

In preparing the study, all ethical principles were taken into consideration and the project was approved by the Permanent Committee on Ethics in Research Involving Human Beings of the State University of Maringá (Opinion Nº 169,526/2012). All participants signed an informed consent in two ways.

RESULTS

The sample studied consisted of 82 caregivers/family members of children and adolescents with mental disorders, of which 73 were women and nine were men. The majority (56) were mothers, 14 grandmothers, six fathers, two grandfathers, a stepmother, a social mother, a brother and a sister. Their ages ranged between 18 and 75 years. With regard to their profession, 24 performed activities exclusively at home, 44 had regular jobs, 8 were retired, 2 were students and 4 were unemployed. Children and adolescents in the study were aged between 7 and 16 years, and the majority (72%) was boys. Other data were not investigated because the study was not aimed at correlating overload level with the type of mental disorder or any other characteristic.

It was observed that the average score in the objective and subjective dimension was 2.63 and 2.18 respectively. The standard deviation was homogeneous, with 0.03 in the objective part and 0.06 in the subjective part.

The data presented in Table 1 show that more than half of children and adolescents with mental disorders need help for the development of most daily activities - from three to six times a week and/or every day, showing high burden on who is responsible for them.

Also in the subscale A (Table 1), the most frequently cited daily care activity was taking care of household chores and preparing food, which is understandable since these are caregivers of children and adolescents, which naturally require more routine care.

Regarding subscale B (Table 1), excessive attention necessity appears as the most prominent item, since 32 (39%) interviewees referred deal with problematic behaviors on a daily basis.

In the subscale D (Table 2), which refers to the impact on the daily routine of the caregiver, it is observed that the interference that the care provided to children or adolescents brings to family relationships showed higher prominence as it hampers or prevents the realization of social and leisure activities for their continued dedication to care, triggering stress and overload.

In Table 3, regarding the subscale A, it is identified that when most caregivers/family members provided cared in everyday life, they had high subjective overload in all aspects evaluated, especially in relation to problematic behaviors.

Regarding the subscale B (Table 3) low overload related to the supervision of problematic behaviors, characterized by aggression, smoking, alcohol and drug use was observed. This is because they were infrequent and even absent in children and adolescents in the study.

In evaluating the financial expenditure (Table 4) due to the mental disorder, it was found that 19 (23.3%) caregivers/family members were very overwhelmed and more than half (57.3%) did not report increased expenses due to illness. This may be related to the fact that the psychotropic medication used by children and adolescents is provided free of charge by UHS.

During the interview it was identified that caregivers had many doubts in terms of the prescribed drug treatment for children/adolescents, which is an anxiety generating factor, since not always they understood the real importance of a controlled therapeutic regimen. They also reported difficulties in making children/teenagers naturally accept the continued use of a certain drug, giving rise to interpersonal conflicts in the everyday family life at the time of administration of these compounds.

Table 1. Distribution of the answers of family members to the questions aimed at evaluating the objective burden regarding the assistance in daily life and behavior problems. Maringá, 2015

Subscales	Items	Not once	Less than 1 time/ week	1 or 2 times/ week	3 to 6 times/ week	Every day
		N (%)	N (%)	N (%)	N (%)	N (%)
A: Assistance in everyday life	Hygiene	23 (28)	4 (4.9)	4 (4.9)	4 (4.9)	47 (57.3)
	Medication	23 (28)	1 (1.2)	7 (8.5)	2 (2.4)	49 (59.9)
	Household chores	12 (14.6)	3 (3.7)	2 (2.4)	7 (8.5)	58 (70.8)
	Shopping	32 (39)	1 (1.2)	9 (11)	2 (2.4)	38 (46.3)
	Alimentation	9 (11)	-	4 (4.9)	5 (6.1)	64 (78)
	Transport	7 (8.5)	7 (8.5)	23 (28.0)	8 (9.8)	37 (45.2)
	Money	54 (65.9)	2 (2.4)	4 (4.9)	1 (1.2)	21 (25.6)
	Time occupation	17 (20.7)	4 (4.9)	7 (8.5)	14 (17.1)	40 (48.8)
	Medical consultations	29 (35.3)	6 (7.4)	18 (22)	12 (14.6)	17 (20.7)
B: Supervision of problematic behaviors	Problematic behaviors	20 (24.4)	10 (12.2)	18 (22)	10 (12.2)	24 (29.2)
	Request excessive attention	18 (22)	9 (11)	12 (14.6)	11(13.4)	32 (39)
	Bothering overnight	43 (52.4)	-	11 (13.4)	8 (9.8)	20 (24.4)
	Insulting someone	21 (25.7)	17 (20.7)	20 (24.4)	7 (8.5)	17 (20.7)
	Talking to dying or committing suicide	48 (58.5)	14 (17.1)	5 (6.1)	7 (8.5)	8 (9.8)
	Drinking alcohol	78 (95.2)	2 (2.4)	2 (2.4)	-	-
	Drinking or Eating excessively	47 (57.3)	7 (8.5)	5 (6.1)	5 (6.1)	18 (22)
	Illegal drug use	74 (90.3)	2 (2.4)	-	-	6 (7.3)

Table 2. Distribution of the answers of family members to the questions that evaluate the objective burden, related to the impact on the daily routine of the caregiver, Maringá, 2015

Subscale	Items	Not once	Less than 1 time/ week	1 or 2 times/ week	3 to 6 times/ week	Every day
		N (%)	N (%)	N (%)	N (%)	N (%)
D: Impact on the daily routine of the caregiver	Delays and absences to appointments	29 (35.4)	12 (14.6)	19 (32.2)	10 (12.2)	12 (14.6)
	Change in terms of caregiver leisure	44 (53.6)	6 (7.3)	13 (15.9)	5 (6.1)	14 (17.1)
	Changes in the service/home routine	43 (52.5)	6 (7.3)	15 (18.2)	5 (6.1)	13 (15.9)
	Decreased attention to other family members	47 (57.2)	8 (9.8)	8 (9.8)	8 (9.8)	11 (13.4)

DISCUSSION

The presence of a normal child in the family means intense care needs in daily life, since they require support with daily tasks such as eating, getting dressed, among others. This, however, is aggravated in the presence of a mental disorder, as this leads to behavioral changes that require more attention from the family for a longer period of time in the supervision of daily activities performed by the child[7].

The daily life in an environment that requires intensive care can lead to interruptions in the functioning of the system response to stress, both from caregivers as to those who are cared for, causing adversities in human development, characterized by changes in the autonomic nervous system and the hypothalamic-hypophysis-adrenal axis[13]. Thus, it is believed that the decrease in the functioning of the stress response system can influence the burden on caregivers/family members of children and adolescents with mental disorders and compromise the quality of care offered.

Families living with individuals who suffer from mental disorder also show concern, helplessness and fear against the disease, which contributes to the increased demand for care

Table 3. Distribution of answers of the to family members questions concerning the subjective overload in relation to assistance in daily life and behavior problems, Maringá - PR, 2015

Subscale	Items	Not once	Less than 1 time/week	1 or 2 times/week	3 to 6 times/week
		N (%)	N (%)	N (%)	N (%)
A: Assistance in everyday life	Hygiene	19 (23.2)	4 (4.9)	18 (22)	18 (22)
	Medication	41 (50.0)	2 (2.4)	7 (8.5)	9 (11)
	Household chores	25 (30.5)	4 (4.9)	15 (18.3)	26 (31.7)
	Shopping	29 (35.4)	1 (1.2)	9 (11)	11 (13.4)
	Alimentation	61 (74.4)	2 (2.4)	3 (3.7)	7 (8.5)
	Transport	51 (62.2)	2 (2.4)	13 (15.9)	9 (11)
	Money	19 (23.2)	1 (1.2)	1 (1.2)	7 (8.5)
	Time occupation	21 (25.6)	3 (3.7)	25 (30.5)	16 (19.5)
	Medical consultations	32 (39.0)	5 (6.1)	7 (8.5)	9 (11)
B: Supervision to problematic behaviors	Problematic behaviors	5 (6.1)	4 (4.9)	18 (22)	35(42.7)
	Excessive attention request	19 (23.2)	6 (7.3)	24 (29.3)	15(18.3)
	Bothering overnight	7 (8.5)	6 (7.3)	7 (8.5)	19 (23.2)
	Insulting someone	13 (15.9)	7 (8.5)	13 (15.9)	28 (34.1)
	Talking to dying or committing suicide	3 (3.7)	1 (1.2)	5 (6.1)	25 (30.5)
	Excessive alcohol consumption	-	1 (1.2)	1 (1.2)	2 (2.4)
	Eating or drinking what you should not	12 (14.6)	-	11 (13.4)	12 (14.6)
	Illegal drug use	-	-	-	8 (9.8)

Table 4. Distribution of the answers of family members to questions related to subjective overload, regarding expenses and concerns for patients. Maringá - PR, 2015

Subscale	Items	Not once	Less than 1 time/ week	1 or 2 times/ week	3 to 6 times/ week	Every day
		N (%)	N (%)	N (%)	N (%)	N (%)
C: Expenses	Weight in terms of expenses with patient	35 (42.7)	12 (14.6)	16 (19.5)	5 (6.1)	14 (17.1)
E: Concern for patients	Physical security	3 (3.7)	4 (4.9)	3 (3.7)	8 (9.8)	64 (78)
	Treatment quality	40 (48.8)	50 (6.1)	12 (14.6)	5 (6.1)	20 (24.4)
	Social life	12 (14.6)	5 (6.1)	11 (13.4)	14 (17.1)	40 (48.8)
	Health	5 (6.1)	4 (4.9)	8 (9.8)	12 (14.6)	53 (64.6)
	Housing	47 (57.3)	2 (2.4)	4 (4.9)	10 (12.2)	19 (23.2)
	Finances	24 (29.3)	2 (2.4)	7 (8.5)	5 (6.1)	44 (53.7)
	Future	1 (1.2)	1 (1.2)	4 (4.9)	7 (8.5)	69 (84.1)

related to daily activities in order to protect their family members[14]. Consequently, it also increases overload, especially in cases of children and adolescents, which can lead to physical and emotional stress.

Another important issue is related to the challenges experienced by the family members of these children/adolescents when they seek help in health services. Many parents face barriers in terms of communication between professionals and the family, difficulties in accessing specialized services in child health, and have doubts related to the knowledge related to the disease. These aspects favor the emergence of overload in carers/family members[15].

In this sense, the family involvement in treatment groups related to confront the difficulties experienced as a caregiver is essential. In these groups the complex factors related to this situation are discussed and are beneficial in order to show them that they are not alone in the task of caring for, and that the difficulties encountered are also relevant to other families experiencing the presence of mental disorder in the life of their loved one[14].

The inclusion of content related to the daily care in personal development programs for parents of children/adolescents who have mental impairment can reduce the negative influences that such stressful situations cause to these families. Such projects should focus on the experiences related to the care that is directed to children with psychosocial needs.

Another challenge for the care provided to these families is the development of tools to assess the changes in the daily lives of these families. In addition, there is also the objective of implementing proposals for family adjustment according to every particularity, and to minimize daily care overload, improving communication skills and interpersonal relationships among family members[16].

The need to supervise the administration of medicines in children appears as a greater overload generator aspect for the caregiver. This occurs due to the risk of errors in the implementation of the treatment regimen such as overdose, for example; it thus forces this activity to be exercised exclusively by another family member.

A possibility to minimize the burden of the family derived from the necessary control over the use of drugs is the support offered by the professionals involved in the various health services. In this context, conducting home visits focusing on drug counseling and answering questions can be a valuable measure for greater adherence of children and adolescents to drug treatment, as well as a way to reduce the overload of caregivers/family members since these individuals can be encouraged to try to share this activity with other family members[17].

The pathological aggressiveness or behavioral problems of children and adolescents is also a complicating factor for the care process related to mental illness, thus bringing greater overload on family caregivers. This type of maladaptive behavior clearly clashes with the cultural patterns of the social group in which the child or adolescent is inserted, causing in this social circle discomfort in terms of the lack of understanding on the most appropriate attitude towards behavioral crises. In this sense, the final result of a deficient interaction causes children and adolescents to move away from family life and leads them to isolation[18].

Faced with such a situation it is important that families receive guidance on how to live with a child or adolescent with mental disorders and how to address problematic behaviors. For this they need to rely on a network of social support organized and prepared to meet their emotional and physical demands as well, and to offer support so that they can articulate the internal resources needed to cope with situations related to inappropriate behavior exhibited by their family members[14].

A study describing the attitude of the family in seeking treatment for children and adolescents in psychological distress also showed that family members realize that their behavior has changed, and has become abnormal and strange. Thus, this illness is not very clear to the community; it scares the family and, when it is related to madness, which is so stigmatized, it causes ill individuals and their families, especially those closest, to be segregated, first from their family environment and then excluded by society[4].

Another issue that involves caregivers/family members is the idea that children or adolescents pose a danger to the people around, which is a cause of difficulty and burden on these families that are normally not used to dealing with changed and strange behavior. Thus, the disease becomes a heavy burden to everyone around the patient, especially caregivers/family members who are not even minimally prepared to deal with such responsibility and conflicting situations[4].

The subjective burden is assessed according to the degree of disturbance when performing activities related to patient care, supervision to problematic behaviors, the frequency of their concerns with patients, and the perception of caregivers/family members in relation to permanent changes in their lives.

The results in table 3 are consistent with those found in a study involving ten relatives of people suffering from schizophrenia in Rio de Janeiro, in which the sub-scale A showed that most of them feel extremely uncomfortable to provide assistance in the daily lives of patients, as this resulted in a high subjective burden characterized by a serious effect on their mental health[19].

Thus, it was possible to conclude that the age of the person with mental illness is a determining factor in terms of subjective overload. Families of sick children, for example, feel more intensely the impact of having to meet the intensive care needs related to mental disorder, as in general they have to abdicate their own lives and their desire to meet the attention demand due to the need to manage the behavior and the lives of sick people.

An international study points to the exhaustion of preferred caregivers of children with mental disorders, as they reported the need to constantly monitor their children in their daily activities in order to prevent harmful behavior by children for themselves and others[7].

A study conducted with caregivers of children with mental disorders found that the mothers of these children have moments of frustration regarding the care they provide to them, since they blame themselves for not having generated a child according to normal standards[4]. Given this context, it is possible to infer that the simple fact that these are mothers of a children with mental disorder may generate a great emotional burden on them, which may compromise daily care in case health professionals do not realize that these mothers also require attention and care.

The data found in Table 4 were not evidenced in another study of caregivers of adults with mental illness. These studies indicate the inability of individuals suffering from mental disorder to contribute financially to the family, straining the finances of caregivers, because in addition to performing caring activities, which usually takes a lot of their time, they also have to ensure the survival of their being[20].

Regarding this aspect, the data from this study allow us to infer that the need for more frequent monitoring of children's and adolescents' behavior, greatly interferes with the professional activity of caregivers/family members, and therefore in the financial condition of the family, as they often need to abandon their remunerated activities to devote themselves exclusively to the care of the child or adolescent with mental disorders.

In this sense, a study conducted with schizophrenic patients assisted in four Reference Centres for Mental Health in the public network of Belo Horizonte, it was observed that, while 52% of them possess their own income, the family still needed to pay for expenses, which affected approximately 13% of the family budget[21].

The data related to the subscale E show that the biggest and most frequent concerns of caregivers/family members were related to the future, physical safety and health of the children/adolescents. The fear for the physical safety associated with intense concern for the health and the future of the children and adolescents treated at CAPSi increases the emotional burden of these families. These results corroborate the study that examined the overload of relatives of people with schizophrenia treated at a public mental health service[19].

Given this reality of emotional overload related to behavioral changes in children and adolescents with mental disorders, the nurses, members of the multidisciplinary team in CAPSi, can contribute to the care by performing suitable hosting and attentive listening in individual consultations, group activities or home visits[22]. These professionals can advise and assist families by addressing their experiences, feelings and apprehensions as a whole, trying to alleviate the suffering and the burden of care[23-25]. Thus, they may be present indirectly in the everyday life of these families, offering for example, situational support in times of distress.

The changes in the care model in terms of mental health, arising from the Brazilian Psychiatric Reform, imposed families the effective participation in the rehabilitation process of their mentally ill family members[26]. This may bring many difficulties to the members of the family, in case they do not receive adequate and consistent guidelines from healthcare services, since caring means monitoring the difficulties or disabilities of a family member to perform every day and regulatory functions, which can represent an overload for the family members who need to take on the additional role of caregivers, besides the role they already have the familiar scenario[24].

Despite the innovative actions in mental health imposed by the Psychiatric Reform and the breakthrough occurred in such a short period of time characterized by the provision of specialized services, the construction of a public mental health policy focused on children and adolescents continues to be one of the biggest challenges in the sector, since it still does not cover the family as a pillar of care to be exercised in this context[1].

Thus, it is necessary to involve several services and professionals in favor of effective guidance and care along with the family members living with mental illness in their homes. This should be the object of a humanized and qualified health practice in the struggle to demystify mental illness and its social implications. It should also be instrumented with knowledge in order to maximize and enhance care along with the children and adolescents with this disease[1].

FINAL CONSIDERATIONS

The presence of mental disorder in childhood and adolescence is a cause of great physical and emotional stress for those in charge of the daily care. The results showed that the objective burden for those who take care of children or adolescents with mental disorders every day is high, especially with regard to assistance in daily life related to medication use and supervision of problematic behaviors.

It was also shown that the subjective burden, when referring to the inconvenience in the support of daily activities is not high; however, caregivers/family members have high overload when dealing with problematic behaviors, as 42.7% reported feeling very uncomfortable in dealing with confusing behavior, and this can lead to anxiety, fear, and prejudice, both by the family and the community.

The impact of mental illness in everyday life reaches various aspects of family life and can be regarded as an overload factor, since it requires that caregivers/family members put their needs and desires in the background; demands them to interrupt their routines and, consequently, change their lives. This is why the family needs support and care from the health team.

Given this scenario, this study has the potential to bring forth discussions involving the family, and especially the caregivers/family members in the care actions performed in health services, especially those directed to mental health care. Professionals need to dare and break through the prejudices related to the disease, seeking to establish health actions that aim to strengthen families by encouraging their good points, and seeking to ease the overload arising from the experience with mental illness, and finally seeking to increase the level of interaction and empathy in the family. In this context, nurses, as members of the multidisciplinary team, are enabled to help the families of children and adolescents with mental disorders to cope with this condition in the best possible way.

A limitation of this study is the fact that the data reflect the information obtained at a given time and in a specific location and are subject to temporal and socio-cultural influences. Thus, the search process adopted in this study does not intend to generalize beyond the limits of the study site and is not intended to exhaust the subject.

REFERENCES

1. Brasil. Secretaria da Saúde de São Paulo. Políticas de saúde mental: baseado no curso Políticas públicas de saúde mental, do CAPS Luiz R. Cerqueira. São Paulo (SP): Instituto de Saúde; 2013. 400p. Disponível em: http://www.saude.sp.gov.br/resources/instituto-de-saude/homepage/outras-publicacoes/politicas_de_saude_mental_capa_e_miolo_site.pdf
2. Brasil. Ministério da Saúde. Secretaria de Atenção à Saúde. Departamento de Ações Programáticas e Estratégicas. Coordenação Geral de Saúde Mental. Saúde Mental em Dados. Ano II, n. 4, agosto de 2007.
3. Pedrini L, Colasurdo G, Costa S, Fabiani M, Ferraresi L, Franzoni E et al. The characteristics and activities of child and adolescent mental health services in Italy: a regional survey. BMC Psychiatry. 2012 Set; 12(7):2-11.
4. Monteiro ARM, Teixeira LA, Silva RSM, Rabelo KPS, Tavares SFV, Távora RCO. Sofrimento psíquico em crianças e adolescentes - a busca pelo tratamento. Esc. Anna Nery. Rev. Enferm. 2012 jul/set;16(3):523-529.
5. Dutra VFD. O cuidado oferecido a pessoas que vivenciaram a experiência da desinstitucionalização. Cienc. cuid. saude. 2011 abr/jul; 10(2):218-225.
6. Lima M F, Arruda G AO, Vicente JB, Marcon S S, Higarash IH. Crianças dependentes de tecnologia: desvelando a realidade do cuidador familiar. Rev. RENE. 2013; 14(4): 665-673.
7. Oruche MU, Gerkensmeyer J, Stephan L, Wheeler CA, Hanna KM. The Described Experience of Primary Caregivers of Children With Mental Health Needs. Arch. psychiatr. nurs. 2012 Oct; 26(5): 382-391
8. Maurin JT, Boyd CB. Burden of mental illness on the family: a critical review. Arch. psychiatr. nurs. 1990 Apr; 4(2): 99-107.
9. St. Onge M, Lavoie F. The experience of caregiving among mothers of adults suffering from psychotic disorders: factor associated to their psychological distress. Am. J. Community Psychol. 1997 Feb; 25(1):73-94.
10. Tanaka OU, Lauridsen-Ribeiro E. Desafio para a atenção básica: incorporação da assistência em saúde mental. Cad. Saúde Pública. 2006 set; 22(9): 1845-1853.
11. Tessler RC, Gamache GM. The Family Burden Interview Schedule - short Form (FBIS/SD). Department of Sociology social and Demographic Research Institute, Machmen Hall- University of Massachusetts. Amherst. MA, 1994
12. Bandeira M, Calzavara MGP, Castro I. Estudo de validade da escala de sobrecarga de familiares cuidadores de pacientes psiquiátricos. J. bras. psiquiatr. 2008 abr/jun; 57(2):98-104.
13. McLaughlin KA, Sheridan MA, Tibu F, Fox NA, Zeanah CH, Nelson CA. Causal effects of the early caregiving environment on development of stress response systems in children. Proc. Natl. Acad. Sci U S A. 2015 May; 112(18): 5637-42.
14. Tabeleão VP, Tomasi E, Quevedo LA. Sobrecarga de familiares de pessoas com transtorno psíquico: níveis e fatores associados. Rev. psiquiatr. Clín. 2014 mai/jun; 41(3):63-6
15. Lemacks J, Fowles K, Mateus A, Thomas K. Insights from parentes about caring for a child with Bird defects. Int j. environ. Res. public health. 2013 Aug; 10(8): 3465-82.
16. Peña M, Máiquez ML, Rodrigo MJ. Efectos de la inclusión de contenidos de desarrollo personal en un programa de educación parental para familias en riesgo psicosocial. Anál. psicol. 2014 jan/mar; 30(1): 201-210.
17. Palmarola-Ginesta J, Chirveches-Pérez E, Puigoriol-Juvanteny E, Bleda-García F, Vila-Ribas E, Arrufat-Nebot FX. Adherencia al tratamento y utilización de servicios de salud. Pacientes con psicoses. Rev enferm. 2014 Abr; 37(4): 282-89
18. Teixeira EH, Jacintho A, Celeri HV, Dalgalarrondo P. Atypical antipsychotics in the treatment of pathological aggression in children and adolescents: literature review and clinical recommendations. Trends psychiatry psychother. 2013 jun/set; 35(3):151-159.
19. Gomes MS, Mello R. Sobrecarga gerada pelo convívio com o portador de esquizofrenia: enfermagem construindo o cuidado à família. SMAD, Rev. eletrônica saúde mental álcool. drog. [Internet]. 2012 [citado 2014 fev. 20];8(1): [about 5 pp]. Disponível em: http://pepsic.bvsalud.org/pdf/smad/v8n1/02.pdf
20. Schein S, Boeckel MG. Análise da sobrecarga familiar no cuidado de um membro com transtorno mental. Saúde. & transf. soc. 2012 abr/jun; 3(2): 32-42
21. Barroso SM, Bandeira M, Nascimento E. Fatores preditores da sobrecarga subjetiva de familiares de pacientes psiquiátricos atendidos na rede pública de Belo Horizonte, Minas Gerais, Brasil. Cad. Saúde Pública 2009 set; 25(9):1957-1968
22. Dias CB, Aranha e Silva AL. O perfil e a ação profissional da(o) enfermeira(o) no Centro de Atenção Psicossocial. Rev. Esc. Enferm. USP. 2010 mar/abr; 44(2):469-475.
23. Drombi-Barbosa C, Neto MMB, Fonseca FL, Tavares CM, Reis AOA. Condutas terapêuticas de atenção às famílias da população infanto-juvenil atendida nos Centros de Atenção Psicossocial Infanto-juvenis (CAPSi) do estado de São Paulo. J. Hum. Growth Dev. 2009 ago; 19(2): 262-268
24. Cavalheri SC. Transformações do modelo assistencial em saúde mental e seu impacto na família. Rev. Bras. Enferm. 2010 jan/fev; 63(1): 51-7.
25. Sousa Luz VLES, Barjud ACP, Moura AS, Sales JCS, Coêlho DMM, Duarte MR. Ações realizadas pelo enfermeiro em Centros de Atenção Psicossocial. Rev Interdisciplinar. 2014 out/dez; 7(4):1-12.
26. Colleti M, Martins CB, Tanios BS, Rocha THR. A Reforma Psiquiátrica e o papel da família no restabelecimento de um sujeito psicótico. Rev. SPAGESP. 2014 jan/jun; 15(1): 123-135.

---

* Research developed as a final requirement of the lecture evaluation: Health care at different cicle of life", postgraduation course - nursing doctorate, State University of Maringá, 2014.