Parents and children suffering from mental distress: coping mechanisms, understanding and fear of the future

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Abstract *The aim of the study was to learn about the parents' coping experiences regarding the mental suffering of their children. This is an ethnographic study. Data was analyzed through content analysis. Three categories have been identified: 1. Coping with everyday situations 2. Understanding of mental suffering as a life situation; 3. Fear of the future, feeling of social and governmental helplessness. Mental suffering imposes situations that need to be quickly resolved on families and arrangements in an attempt to balance the family system; family members coexist with mental suffering in the perspective of a chronic illness, and seek coping mechanisms for day-to-day situations; lastly they fear the future of their sick relatives and feel helpless due to public policies. Research is needed in the area to assess the impact of this issue on the lives of families, institutions and public policies.*
Key words *Mental illness, Family, Coping*

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Introduction

Mental suffering can be understood from different perspectives, from a divine punishment to a life situation with which to learn something. Explanatory models for mental illness are constructed according to culture, the advancement of science, and the understanding of people who coexist with the person with mental distress[1].

It is understood, in this study, that although it is a situation of suffering, where situations of exclusion and abandonment are present, there are cases in which mental disorders, even considering the limitations of different orders imposed on patients, can be seen as a circumstance of life that does not necessarily translate into continuous and uninterrupted suffering in the perception of their relatives.

It is assumed that some relatives of people with mental disorders, among them collaborators of this study, can give meaning to this experience of illness, have an efficient support network and exercise their rights as a citizen through the empowerment of their actions and rights to society and to the public and private services that are offered in assisting that portion of the population.

The most recent census in the United States pointed out that nearly 58 million adults were diagnosed with mental disorders. As in Brazil in that country before deinstitutionalization and advances in the development of psychotropic drugs, people with severe mental disorders lived in institutions, and were mostly removed from their families[2].

Today, these individuals live in their communities. Although some independently, many still reside with family members, who care for and help them manage their lives. Even if they do not reside in the same house, family members are usually involved in the care of these people. Family members of mentally ill people can withstand considerable stress and physical, social and financial burdens, but this situation can jeopardize their own health, quality of life and impair the functioning of the family[2].

However, if family members can withstand the stress of mental illness of one of their members, they can preserve their own health and the health of their family by taking coping measures for the overload situations of care that arise in the day to day[2].

In Switzerland, families realize that children with mental health problems compared to physical problems have a greater severity and impact on family life, in addition to that the use of health services is greater in the first case. The research was conducted from the National Survey of Children with Special Health Care Needs in Switzerland. For those interviewed, mental health problems, despite having a greater impact on the family (such as financial impact), can be minimized when government services offer support[3].

Regarding the experiences of parents of mentally ill children and adolescents with health services, a study indicates that access to services is challenging, there is little availability of specialized services and lack of information for parents[4].

Caregiver parents expressed the need for information, involvement in decision-making during treatment, access to flexible activity schedules offered by services, need for school support, and parental support groups. The nature and quality of the relationship with the team was fundamental for the positive experience with the service; but frequent changes of the doctor and team members were considered complicators in the relationship[4].

The mechanisms of coping with mental suffering are diverse and involve actions by parents that are not always understandable, given that it is their daily experience with their children and everything that involves their lives.

From the understanding of the complexity that exists in elaborating coping mechanisms for the daily situations of these families, the objective of this study was to learn about the experiences of coping with caregiving parents in relation to the mental suffering of their children.

Methods

This is an ethnographic study. Ethnography is a qualitative research strategy that aims to understand human behavior within its cultural context. Ethnography is a descriptive work of a group's culture, including how people solve their problems, communicate, interact. It also includes understanding ones actions and feelings in the face of adversity. All groups have a constant and complex way of behaving in the face of events around them[5,6].

The informants of the ethnographic study should be selected according to the degree of involvement with the phenomenon of interest of the researcher. The key informant is the one who, besides holding the knowledge about the phenomenon, also knows the people involved in the development of the phenomenon and its unfolding. Information collection was carried out at the

research collaborators' home or at predefined sites between researcher and collaborator[6]. The data collection instrument was a script of interviews where the collaborators talked about the subject in a free way for a time between 60 and 120 minutes. The field diary to record the researcher's impressions was also used.

The interviews were recorded and later transcribed. The definition of the collaborators at first was through the snowball technique, where one indicated the other and thus the study sample was composed. The sample consisted of 21 people (mothers and fathers) who lived directly with mentally ill children who had been using public mental health services and who had been in treatment for more than five years. Only nine co-workers in the study were in constant contact with the mental health services where their children were treated, the others did not seek the services unless they were in demand.

The sample of ethnographic studies is formed by a clipping of reality, where events can be observed, activities, information, documents at different times, so the data collection was performed in more than one moment and in some cases in different scenarios (home, public space, mental health service). All the interviewees signed the Informed Consent Term and the research was approved by the Research Ethics Committee of the home institution of the main investigator.

The data was evaluated by means of content analysis, comprising 1. Pre-analysis; 2. The exploitation of the material; and, finally, 3. Treatment of the results[7]. The data was tabulated using the software of analysis of texts, videos, audios and Web images Qualitative Data Analysis (WebQDA). The system is organized in three areas: 1. Sources - where the system is fed with the research data, organized according to the researcher's need; 2. Creation of codification or categories - interpretative or descriptive and 3. Questioning - the researcher creates the dimensions, indicators or categories, whether interpretative or descriptive, that will be analyzed from agreements with models of analysis previously elaborated for each of them[8]. The analysis categories identified were: 1. Coping with everyday situations 2. Understanding of mental suffering as a life situation; 3. Fear of the future, feeling of social and governmental helplessness.

Results

Coping with daily situations

With regard to coping with the situation of a child suffering from mental illness, 16 of the 21 interviewees consider that the best way is to seek help from their own family.

The support of family members was considered fundamental to face the difficulties of the day to day, they can help in direct and indirect care (taking care while the parent, directly responsible for the care, works, or while leaving for some activity where they can not take the child (with help in the purchase of medicines, treatment, alternative therapies among others) and support in the moments of decision making of what is best for the person in mental suffering and for the family in situations considered of daily stress, especially attacks of aggression and escape from the home (families are mobilized in the search for the patient and help to contain them in moments of aggression).

Another form of effective confrontation was the search for help and support in the social support network, especially religious agencies, which help and support in different ways (helping families financially, dividing care, integrating their children into the community without stigma or prejudice, supporting their decisions regarding the patient and in the day to day, especially in the moment of tiredness of the caregiver through the listening of their complaints and words of encouragement). For parents in religious agencies their children are treated as equals, with attention and respect.

It is important to mention that during the interviews and observations of the researcher at no time were the children denominated by the parents as: patients, mental health users, mentally ill, crazy, nerve-sick or some other nomenclature that approaches the usual way to define these people and their health condition. Parents / caregivers referred to their children by their names. What was evaluate as an even if not an explicit mechanism of coping with prejudice and stigma related to the condition of life and health of the person with mental suffering.

Non-governmental organizations were cited, in third place, as places where children can de-

velop skills in protected environments and under supervision. These sites were also cited when parents need information about social rights and doubts about the benefits their children may have, especially with the country's social security and other government services.

The health services and governmental social or legal assistance were cited as places that do little to cope with situations that present themselves in relation to life with a child with mental suffering.

The situations of daily life that are considered as promoters of greater stress and that demand immediate and creative coping, were: crisis, especially when there are episodes of hetero aggression or self-directed suicide attempts, use of drugs concomitant with mental disorder, to manage the administration of medication for daily use, social difficulties (such as exits to public places). At such times parents feel that their children are discriminated against and that people in general observe them with curiosity and looks of sorrow, sometimes in a disrespectful way.

The educational issue was cited by six parents as something that worries them. For them government is not interested in the issue, they are clear that their children have difficulties in learning, but stress that this does not happen all the time and that they need to study in inclusive schools, that are ready to deal with their limitations and needs. Another point cited was the evaluation and perception that children, young people and adults in mental suffering, studying in places destined to people with neurological disorders does not seem to be a good educational strategy for their children.

Faced with this fact, these parents have sought inclusive schools or nongovernmental organizations that undertake this educational task, in some cases (3) they carry out activities with their children at home, but believe that these arrangements are not the most appropriate.

Another issue cited by 15 parents was health care outside the psychosocial care network services, such as dental care, gynecological care, and other specialties. Parents say that services in general do not want to serve their children, some said that in the private network, service is easier than in public services.

In general, they try to hide their children's illness when they seek care so that it is not denied, stating that the child has "a disease of the nerves or of the head" in the sense of a neurological and non-psychiatric pathology. Service in public health services is assessed as inadequate.

"Even a criminal is better treated at the health center than my son"; "My son needed to go through six doctors to have someone medicate him when he had conjunctivitis," "to get to the gynecologist I have to go ready to fight because no one wants to take care of it." "He broke his leg playing ball and had to go to three services to be attended, only knew to refer to the psychiatric hospital and I explained a thousand times that the problem was broken leg."

They are everyday situations of parents and children who, when they present themselves, consume a good part of their time, something relatively simple as a dental treatment becomes an inconvenience for all involved and physically and psychologically wears out the caregiver.

Understanding of mental suffering as a life situation

For some parents (5) life with their children is a learning, for others it is suffering. Those who evaluate it as learning, state that in general any effort to see their children happy should be realized. Some affirm that care is adapted according to the clinical picture of the child "... there are days that are better, there are days that are not, he is usually quiet, he does not give me work, I can do my things and hestays around , I take him to the consultation and he frequents a place nearby to get distracted a bit, but there are days when he is in crisis that the father has to help, because he beats and breaks everything he sees ahead, he is small but has a lot of strength and bites us. " "My son is not crazy all the time, they are days that he is in a good mood, quiet, we talk and do things together, he is very intelligent, he does poetry, music, he is a good son, he does not use drugs, he goes to church with me , does not steal, helps at home with small things, and if not in crisis is always smiling and loves to dance. He has this disease but that's all ".

Those who evaluate their relationship with the sick child as suffering in general have quoted the word "tolerate" several times and in different situations, "is something to be tolerated," "we have to tolerate," "it is not easy to tolerate." Another constant is the reports of impatience with the behavior of the child and the fact that they have the perception that sometimes the children lie, pretend and are only taking advantage of the situation to gain something. "... I think he lies all the time," "he takes advantage of the disease to get into trouble," "... sometimes I think he's pretending".

Parents evaluate that after the illness has settled, there is nothing to do to change, they usually refer to the cause of the child's illness as "problems" at childbirth (12), family cases (6), and God's will (3).

The situation of children's lives is seen as something that in the first moment generates revolt, incomprehension and difficulty to understand, but over time is something to be accepted or tolerated: "... we have to conform, there is nothing we can do, I've tried everything, I even took him to do spiritual treatment and nothing, so now it's care, there's nothing more to do ".

In other cases the parents feel revolt at the situation: "... I take care but I do not accept it, I think this is not right, a girl so beautiful in this way, does not give a damn about anything, does not say anything with anything, I have to watch her all the time, because she's beautiful and there are people who want to take advantage of her, I'm tired, but there's no way, now it's to conform and wait ... I do not even know what for ".

It is observed that younger parents have greater difficulty in caring for their sick children. Some parents have stated that they do not care and only come to the service when called, which rarely occurs. It is up to the government to take care of their children, in the form of permanent hospitalization. These parents mostly delegated the care of their children to their maternal grandparents.

One of them pays a person near their house to "look after their child" during the day and the night takes him to sleep in the grandparents' house. "I do not have the structure to take care of him, he's an adult and he behaves like a child, I do not have the time and the patience for that, if I had a place to leave him, I would."

Parents, in accepting their children's life situation, make family arrangements to try to control the situation of life in which they find themselves. In general, these arrangements involve the whole family and social network, and it takes time and affective investment for life to be given in a minimally quiet course. "... at first it was very difficult, he fell ill, he was only 18 years old and now he is 38, the time passed quickly, we are older and tired, but at first it was worse, he also had more energy to give us trouble, now it's easier, he's quieter and we have more patience. "

Older parents with adult children evaluate that over time, they and the family become "accustomed" to the family member in mental distress, this situation becomes something of the daily life of the family and all its members, directly or indirectly help with the care.

Fear of the future

The parents interviewed are unanimous in saying that day to day with their children is not easy, due to several factors, but the uncertainty of the future of their children makes them fearful. Fear of the future is a constant.

They are unanimous in reporting that they understand their relatives' refusal to take care because they consider that the lack of support from government health and social services and the day-to-day difficulties make this difficult.

Among the day-to-day related difficulties that make it difficult for other family members to take care were: the unpredictability of behavior (now well, sometimes aggressive, otherwise suspicious, or smiling and happy); the financial question (it is someone who does not produce, some have retirement, but this amount does not cover financial expenses when all expenses are assessed; it is a constant care that wears over time and may be too heavy for someone who is not a father or mother).

In relation to government support, when mentioned, one observes the perception that: the services do not take care of the families; in some moments do not value the information of the relatives in relation to the patients; there is no policy of support for families; everyone is treated the same regardless of whether or not they want to take care of their children. Health and social services are precarious, there is a feeling that patients are only being medicated, but that there is no real concern with improving the overall picture.

Fear of the future is present in the speeches of those interviewed, even those who believe they could take better care of their children, but are too tired to do so. A mother reports that she was more careful at the beginning: "... I always kept an eye on her, worried about bathing, brushing my teeth, taking her to school, being more dedicated, but then life changed, my husband died, I I had to work, my other children grew up, they took care of their lives and it was the two of us. She does not help at home, barely goes to the consultations, spends the day sleeping and I'm always tired of work. I know I do not take good care of her, but I'm too tired to do everything myself. I wonder what it's going to be like when I die ... what's going to happen to her, will someone care, ... that worries me "

Among the parents interviewed, 12 cited that their children receive a government financial benefit, but they estimate that the value is

not enough to live alone and that in general they do not know how to handle the money received. A father requires the child to pay some bills at home, according to him it is a way of teaching to deal with the money and to understand that one day he will have to assume the expenses of the house and his care alone. He reports that he is afraid that relatives will drive him out of the house in the event of his parents' death and take his benefit, so he has been looking for ways to protect his child should this happen in the future.

Discussion

The situations cited by the subjects that collaborate with the research and who demand coping, are part of the daily life of the families of the users of the mental health services and are frequently reported in the health services. Caregiver parents report needing help and feeling helpless.

Family-oriented educational actions, especially the parents of mentally ill people, have presented satisfactory results both in strengthening coping and handling of daily family matters and in strengthening families as a system that can withstand crisis situations[9].

Psychoeducation programs, including providing emotional support, educational measures, providing resources and care in times of crisis, and developing skills to solve problems for the family is necessary and obtaining good results in improving the quality of family life and in coping with mental distress, however, investment in this area has been limited associated with lack of understanding of its importance by family members, physicians, and managers of mental health services[9].

The situations of risk as self and straight aggression are the main points listed by the research collaborators as moments that require immediate responses and clear and precise coping measures.

There is scientific evidence that parents and children with mental disorders are at risk. From this understanding interventions should be undertaken to help parents fulfill their role as caregivers. A study with parents after one year of the diagnosis of their children showed that the most frequently performed interventions were home visiting programs, community programs, home care, and on-line interventions. Using different forms of interventions was a strategy identified in the study with the goal of developing parental skills and understanding the impact of mental ill-

ness on parents in order to help them cope with the problem[10].

In the United Kingdom, from the psychiatric reform of that country, where care has been transferred to community-based services, it is understood that responsibility for psychosocial care has been shared and transferred to family caregivers, especially parents[11].

A systematic review of the literature on the role of family caregivers aimed to investigate: what caregiver parents expect of themselves in relation to the care offered to the sick child. The natural instinct to care for the family, especially of the children, regardless of their health situation, were identified as recurrent themes; the desire to care effectively; the barriers that exist when they realize that children are not able to show care and affection towards the family, and how to overcome the barriers created in the relationship between parents and children[11].

Living in the home was also cited as something that needs to be managed primarily with the other family members, especially the siblings and the household.

A qualitative exploratory study investigated the experiences and needs of family caregivers of mentally ill people in Ireland. Most caregivers state that they had difficulties coping with the situation of living with the sick relative, but when the relative lived with the family, the use of proactive coping strategies was observed, such as occupying the patient with a work activity that would not generate overhead for him, but would make him more independent. When the sick relative lived independently, these strategies were less utilized and the minor conflicts within the home, although the isolation of the patient was evidenced. The conclusions of this study highlight the importance of a contextual approach to the study of coping modes[12].

Most caregiver parents over time try to understand the sick children and the life situation they face, but realize and evaluate that life changes drastically when one lives this situation, including in relation to their choices and way of living[13].

Few studies are conducted to evaluate the quality of life among caregivers of people suffering from mental illness. A survey conducted in Taiwan evaluated stigma, social support, quality of life and health, and socio-demographic data of caregivers. The results highlight that among women caregivers, health and quality of life were strongly associated. It is pointed out the marked presence of stigma in relation to the caregivers

by the family and the community in general. Women caregivers had a higher level of quality of life compared to men. The study suggests that attempts to improve caregivers' lifelong health should include ways to deal with the stigma associated with their caregiver position of a person in mental distress[14].

For caregiver parents, health workers do little to help. The perception of some is that their interventions, at times, hinder the relationship between the child and the family. They feel alone in the act of caring and the health service is seen as a place for the child to pass the time.

One study evaluated and compared the care provided by a family in relation to the care provided by a professional. The authors point out that the role of caregiver can be stressful associated with the fact that this activity creates physical and psychological tension for long periods of time, is unpredictable and uncontrollable at times, has the capacity to create stress and tensions in various domains of life , such as work and family relationships, and often requires a high level of vigilance and attention. Hence the perception that they are involved and burdened with care[14].

The care of the health professionals was evaluated as punctual and segmented, besides not being articulated to the family arrangements to organize the care at home. For the authors, the family caregiver lives constantly under tension, and due to this situation their health is critical and fragile, which is not considered by the health professional during the treatment of the sick child[14].

Fear of the future was pointed out as a recurring theme among caregiver parents, there is concern about what will happen to the child if they become ill or when they die. In general, families encourage their children to cope with the day-to-day management of the money they receive, encourage them to seek work, but when their coping strategies fail they seek alternatives to delegate child care to other family members who can potentially take charge and care in the future. The issue of employment and professional qualification was not a theme present in this study, only two caregivers reported initiatives for professional qualification and insertion in the labor market[15].

One study compared the professional training and the insertion of the person in mental suffering in assisted jobs. It was observed that people with previous professional training and treatment in the community network were more active at the time of entering the job market and were able to maintain employment longer. People in mental suffering in assisted employment have gained and worked more than people with professional training and without mental disorders. For the authors, this shows that the previous professional training facilitates the insertion in the market of assisted work and allows the person in mental suffering to be more competitive[16].

The parents also point out difficulties in the search for health care of their children when it comes to diseases other than mental disorder, they are afraid that in their absence the children will get sick and not receive adequate care.

Research points out that there is an abyss between parent caregivers and mental health services when it comes to the care of their sick children. This abyss takes place by the following barriers: the politics and management of the services; lack of interinstitutional collaboration; the attitude of the worker, skill and knowledge; issues related to the direct caregiver; the family, including the patient. To minimize this chasm pointed out by the authors, it is necessary to carry out organizational audits to identify the most urgent barriers that prevent the actors involved in the care process from communicating effectively[17].

People with severe mental illness have higher morbidity and mortality rates from chronic diseases than the general population, some reasons for these health disparities are listed, such as health service limitations to address such clientele, health behaviors and the effects adverse effects of psychotropic medication[18,19].

Conclusions

The research data corroborates the scientific production in the area, although it presents the limits of the cultural context in which it was developed and the limitation of the little production on the subject. The discourses of the research collaborators are intertwined at different moments, sometimes approaching a consensus on the subject, sometimes distancing, divergent, but complementary. This indicates the need to deepen research on the imbricate relationship between parents and children in mental suffering and coping with everyday situations.

The results point out advances in the perception and understanding of the subject of mental suffering, approach and treatment by the actors involved in the study, perhaps as a reflection of the country's mental health policy. Some ad-

vances and setbacks can be identified, such as acceptance of community treatment and the defense of some parents for the hospitalization and guardianship of the sick child by the state. The need for research with groups in extended contexts is pointed out.

It is necessary to discuss how and what to do to sensitize parents, family and health professionals about the difficulties of everyday life and the possible forms of coping for each case. The need to think about how to deal with the tensions between the actors involved was also pointed out when there is a divergence between the understanding of the mental disorder. The study, despite its limitations, advances and innovates when it gives voice to the caregiver parents, and suggests a new perspective for the researches in the area.

Collaborations

AMS Reinaldo participated in the design, design, analysis and interpretation of the data; writing and review; final approval of the version to be published. MO Pereira participated in the design, analysis and interpretation of the data; writing and review; final approval of the version to be published. MLO Tavares and BD Henriques participated in the analysis and interpretation of the data; writing and review; final approval of the version to be published.

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