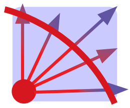
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Original Article

Experiences of family members of people with mental disorders

Experiências dos familiares de pessoas com transtorno mental

Experiencias de familiares de personas con trastorno mental

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The study aims at knowing the experiences of family members of people with mental disorders in small-sized counties in the countryside of the state of Paraíba, Brazil. This is an exploratory research with qualitative approach made with 14 family members of people with mental disorders. The data collection took place in February and March 2013 through the technique of oral history of life guided by a semi-structured interview. For data analysis, we used the thematic content analysis. The results showed a significant suffering and difficulties of family members in the care of people with mental disorders, once they feel alone, most often without a family, political or professional support. The overload of these family members was evidenced by the occurrence of chronic diseases, the use of medications, and marital separation. The improvement of the existing health services and the formulation of county policies can promote a better quality of life to these subjects.
Descriptors: Mental Health; Primary Health Attention; Family Health.

Objetivou-se conhecer experiências de familiares de pessoas com transtorno mental em municípios de pequeno porte, no Alto Sertão Paraibano, Brasil. Pesquisa exploratória com abordagem qualitativa, realizada com 14 familiares. A coleta de dados foi realizada nos meses de fevereiro e março de 2013, por meio da técnica história oral de vida guiada por roteiro semiestruturado de perguntas. Para análise dos dados, utilizou-se a análise de conteúdo temática. Os resultados evidenciaram um expressivo sofrimento e dificuldades dos familiares no cuidar do sujeito com transtorno mental, já que se sentem sozinhos, na maioria das vezes sem apoio familiar, político e profissional. A sobrecarga desses familiares foi evidenciada pelo surgimento de doenças crônicas, uso de medicações e separação conjugal. A melhoria dos serviços de saúde existentes e a formulação de políticas municipais poderão promover uma melhor qualidade de vida a esses sujeitos.
Descritores: Saúde Mental; Atenção Primária a Saúde; Saúde da Família.

El objetivo fue conocer experiencias de familias de personas con trastorno mental en municipios de pequeño porte, en el Alto Sertão Paraibano, Brasil. Investigación exploratoria, cualitativa, llevada a cabo con 14 parientes. La recolección de datos se llevó a cabo en febrero y marzo de 2013, utilizando la técnica de historia oral de vida, basada en guión semiestructurado de preguntas. Para interpretación de los datos, se utilizó el análisis de contenido temático. Los resultados señalaron expresivo sufrimiento y dificultades de la familia en la atención a la persona con trastorno mental, ya que se sentían solos, a menudo sin apoyo familiar, político y profesional. La sobrecarga de estas familias fue destacada por enfermedades crónicas, uso de medicamentos y separación matrimonial. La mejora de los servicios de salud existentes y la formulación de políticas municipales podrán promover mejor calidad de vida a estas personas.
Descriptores: Salud Mental; Atención Primaria a la Salud; Salud de la Familia.

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Introduction

Along the centuries, madness was subordinated to institutionalization. Soon the function of care to people with mental disorders was attributed to the mental institutions. Considering the family as guilty regarding the mental disorders, the psychiatric management put the patient away from the familiar nucleus, thus strengthening the psychiatric institutions and the culture of social isolation of the mentally ill[1].

In the mental institutions, the patients going through mental suffering were victims of violence and exclusion, so, in the XX century, several questionings to the mental institutions model emerged, whose summit involved movements in favor of the reformulation of the psychiatric assistance. In the decade of 1970 the movement for Psychiatric Reform began in order to promote the humanization in the psychiatric assistance and the active rehabilitation of the patient going through mental suffering[1-2].

The movement of the Psychiatric Reform made the creation of the Law project No. 3.657/89 of Paulo Delgado feasible, which proposed the progression extinction of mental institutions, the elaboration of substitute services, besides the regulation of the compulsory psychiatric hospitalization, which was consolidated with the approval of Law No. 10.216, of April 06, 2001[2].

So, the Psychiatric Reform proposed the implantation of a new model of assistance, this time focused on the community and on the surroundings creating a net of attention in mental health, basic attention, among others. These services aim at considering the family, the social relations and the link of the patient who is experiencing a situation of suffering and assist him within the surroundings where he lives, that is, the community, with actions of promotion, prevention, treatment and rehabilitation[3-4].

The strategy used by the Health Department was the redirecting of the assistance with the implantation of communitarian mental health services following a model of articulated net. The Psychosocial Centers of Attention (PSCA) are the strategic services in the organization of the entrance door and regulation of this net of attention.

The Health Department regulates, by law that the psychosocial attention must be offered in counties that have at least a population of 20 thousand inhabitants. The small counties don't have financing for the implantation of these services, so, it is up to them to structure actions of mental health with the basic net of health in teams of the Family Health Strategy (FHS)[5].

In Brazil, there are 1,650 counties with more than 20 thousand inhabitants, but most of them are small-sized counties, representing 73% of the country[6]. Paraíba has 64 PSCAs and has a rate of 1.23 PSCA for 100,000 inhabitants, considered as a very good assistential net[7]. In short, in the state of Paraíba there are 23 counties with PSCA and 200 small-sized counties which structure the attention in mental health through the Basic Health Units (BHU)[8].

So, the attention in mental health and small and average-sized counties is attributed to the teams of the BHU. However, such factor does not mean that the counties have control of a project of mental health based on the principles and guidelines of the Psychiatric Reform. Many of those counties comply with this responsibility through psychiatric hospitalization and prescription of medicine[9].

Besides that, the attention in mental health in the Family Health Strategies is fragile, above all, by the lack of training of the health professionals in dealing with the patient in mental suffering, prescriptions of the medicine concerning symptoms and difficulty to establish reference and counter-reference, constituting a challenge for its effectiveness and whole assistance to the different patients/families[10].

Facing this reality, many times the family members are segregated from their daily reality in the care of the patient going through mental suffering. The new way to take care of mental health, made possible

the living experience with the patient going through mental suffering, imposing an overload to the family when taking care of the family member with acute and chronic manifestation of the mental disorder. They force the caregiver to stop living his own life, causing the loss of the social links, the decrease of moments of leisure and leading them to the absorption of suffering and therefore they go into a social process of weariness(11).

This work is justified due to the assistential transformations which came with the Psychiatric Reform and they required attention turned to the surrounding and to the context where the patient going through mental suffering. However, there is frailty is Basic Attention, concerning the actions of mental health in small-sized counties, consequently these patients need actions in mental health aimed at providing assistance to a person with mental disorder and his family member.

That is why the study is relevant due to a great number of counties that experience the inexistence of a specialized net in mental health. And still, through the experiences of the family members, it is possible to collaborate for the directing of actions in organization of services. That is, through the evaluation of the satisfaction of the user, it is possible to adopt strategies or improve the existing ones to quality the results of care, contributing for the implementation of actions which are aimed at improvements in the assistance of mental health in the scope of Basic Attention.

So, the study is aimed at knowing the experiences of the family member of people with member disorders in small-sized counties in the countryside of Paraíba, having the objective to investigate the assistance offered by the net of health in the county in the scope of mental health and still analyze the perspective of family members with people with mental disorders regarding the experiences in a county that does not have a net of mental health.

Method

This is an exploratory research with qualitative approach, developed in February and March, 2013 in Jericó and Mato Grosso, small-sized counties, located in the countryside of Paraíba, Brazil. Both of them do not have specialized services in mental health structured in the system of local health. The first one has an estimated population of 7,538 inhabitants, being 2,134 families, having a population of 175 subjects with mental suffering. The county of Mato Grosso, in turn, is constituted by a population of 2,072 inhabitants, being 776 families, with 101 bearers of mental disorders distributed in the rural and urban area(12).

To establish the participation in the study, the following items were used as criteria of inclusion: a) render care to the family member going trough mental suffering, b) be 18 years old or older, c) live in the urban area. Among the criteria of exclusion are: a) do not understand the proposal of the study, b) incapacity of verbalization, c) live in the rural area, d) do not accept the visit of a Health Communitarian Agent (HCA).

14 family members of people with mental disorder participated in the study, being eight subjects from the county of Jericó and six from de county of Mato Grosso. These were chosen among the visits made by the HCA to the counties, summing up 15 HCA, who knew the number of families that have a member suffering with mental disorders, as well as their address and the facilities and difficulties of access to the family members by the HCA.

The technique used in the research was the oral history of life, which aims at the data collection on the person life of the interview. This method aims at listing the narratives and reports, a phenomenon or an experienced fact, within a period of time(13). The data analysis procedure through the technique

of analysis of content, in its thematic form, which works with text extracts in units of registers and make the classification, association of the information and elaboration of thematic categories possible[14].

For the data collection, the semi-structured interview was used as instrument, making the statements of the subjects on their experiences as family members of people with mental health disorder in small-sized counties possible. Thus, the subject was approached in the opportune possible way through the following questioning: Tell me about your life as a caregiver of a person with mental disorder. There was the minimum interference possible, only if there were the need to redirect their speeches or clarify some details.

With the collected information, the procedure of collection obeyed the following stages: 1) initial contact with the interviewees in order to establish a relation of trust researcher/informant; 2) Clarification on the investigation; 3) having the agreement of the interviewee the data collection started, and the information was registered in a recorder or scheduled for another date, according to the availability of the object involved.

When reaching saturation point, that is, when the statements become repetitive and do not add new information to the previous statements, the collection was finished, so, the recorded information was transcript in a precise manner and analyzed according to the technique of analysis of content in its thematic. Later on, there were stages of pre-analysis, exploration of the material with the elaboration of two thematic categories and the last stage used was for the treatment of the results and interpretation.

From the thematic within the statements of the interviewees, two categories were organized: a) the family and the assistance in mental health, which portrays the feelings of family and interaction with the services of health; b) Difficulties and challenges of care, which exposes the confrontations of the family member in the care of mental health in small-sized counties.

The study was submitted to the Committee of Ethics in Research of the University Hospital Alcides Carneiro of Campina Grande Federal University, with the favorable legal opinion of the process CAAE N° 13731313.7.0000.5182. The subjects of the study were categorized in their statements trough the codifications (S1 a S14) to preserve their anonymity. There was the application of the Informed Consent Form signed by the family members, containing information on the research among them, the justification, the objectives and the procedure used.

Results

Characterization of the subjects of the research

14 family members were interviewed: thirteen women and one man. According to their kinship, seven were mothers, three wives, one sister, um father, one daughter and one grandmother. The age range of the caregiver was concentrated between adults and elderly, ranging from 30 to74 years of age.

Concerning marital status, seven subjects were married, three divorced, two widows and two single. There is a significant predominance of those who had high school, only two did not have any schooling, two had an incomplete university degree and one with a complete university degree. Four of the interviewees had a job, with function of HCA, auxiliary function, commercial management and teacher. Four were retired, four are housewives, one is a farmer and one is unemployed. They present an income higher or equals to two minimum wages, only two presented income lower or equals to one minimum wage.

The family and the assistance in mental health

During the research, when stimulate to talk about their lives as a caregiver of a person with mental disorder, most of them reported to have a life permeated by suffering and difficulties, once leading with a person with mental disorder represents effort, dedication and commitment for them. Still, it

is mentioned as an apprehensive and tense life, once the disorder impregnates itself in the life of these people, who expect the strange behavior and crisis at any time. The worrying and the sensation of anguish are also observed by the family members facing the impossibilities and limitations, that is, dealing with a problem that they say they don't know how to solve, as it is clear in the following statements: *I felt worried, sometimes we have that anguish to have a problem we cannot solve, we suffer without solving it, we want to, but we can't* S3 (Jericó*). It is painful, because you know, a person taking care of two people, is rather painful (S6 Mato Grosso). To live with a person with this disorder is very complicated, first because you automatically get shaken....so life is very apprehensive, you live afraid of everything, afraid she will have a crisis* (S14 Jericó).

Sometimes, the statements of the subjects highly expressed the overload of the experience of the sick family members. With of the detailing of this experience, it is perceived the occurrence of chronicle diseases, the use of medications such as sleeping pills, the separation of the spouse, the physical lesions and depressions. As we can notice in the statements as follows. *Because so, generally they don't talk things that please you, he talks a lot of repetitive stuff, which generally makes your mind tired. So, when you are living with that person, the day is tiring, at night when you go to sleep, you dream about the thing you live in the day the whole night. You live practically as if you walked beside that problem, and somehow that problem reaches you* (S14 Jericó). *Because it is due to this problem that I noticed that my blood pressure became too high....I don't know if my separation has to do with C., it can be, but sometimes I think I work too much with this problem and his father didn't worry as much as I did, he didn't have the work I have* (S12 Mato Grosso).

The overload on these people, facing the experience with a family member with mental suffering, causes several implications in their lives, being common the separation of the couple, once the women is busier with the care, excessively dedicating herself to it. It ends up with an overload of work. The use of tranquilizers and medications, for making the patterns of sleeping and food stable, and still the physical and psychological aggressions, once the closer victims are the family members. For such, due to the excessive dedication rendered in the adequate care to the relative, the family member is deprived of her own life and consequently the physical and psychic overload emerges.

In order to investigate the health assistance which came to these families in the mentioned counties, the services the town had for the assistance in mental health were questioned. With significant predominance, nine interviewees, answered they didn't know or had not ever even been informed about the existence of a health service which renders assistance in mental health, two other answered they had never looked for it, a subject of the county of Jericó reported that currently there is a link of the county with the CAPS of Souza, however, during the first time he needed the services, there was no such link, and two, in the county of Mato Grosso answered that there was this service rendered in the Center of Health in the House of the Family, and, whenever the needed, he looked for these services, according to these statements: *no, they never came here, never, old Jericó is closed (isolated)* (S1 Jericó). *It is in this area of health over there, in the center of health, in the house of the family, we needed to go there* (S12 Mato Grosso).

Facing the above statements, it is possible to notice the frailty found in both counties for the development of actions of mental health in basic attention. The teams of health of the family, even though they know the reality of the families within their area of covering, many times going through psychic suffering, do not render the due care to this population, and they end up reproducing the hegemonic psychiatry model. Therefore, the family members feel alone in the care and look for services of hospitalization and medication of the relative, as can be seen in the following statements: *I looked everywhere, I am not lying. I went to João Pessoa, everywhere, I just didn't go to São Paulo. People said that such doctor is good, such doctor is good, we rented the car, it was just to take medicine, than she got worse. She was hospitalized in João Pessoa and spent a month in hospital* (S1 Jericó). *His doctor is from Caicó, Doctor S, but the takes this medicine,*

but he never gets betters, he just relaxes a little (S7 Mato Grosso).

Still on this matter, the interviewees were asked is they had already needed some health professional help and which professional they had looked for. They answered they had already needed and they always needed, facing the situations they experience.

In most of the times, they appointed the doctor as the most wanted professional facing such hard times, and here the social assistant also appeared in two statements, as a professional that helps in providing counseling to the members of the family and directing the services for assistance. The HCA was also appointed and the nurse was mentioned in one statement, for the administration of the medicine. The ones who answered never having looked for help from health professional reported that they knew about the inexistency of qualified personnel for the assistance or they didn't look because the family member didn't take medicine: *sometimes we need a doctor. Many times I was assisted by the doctor, sometimes he helps, sometimes he doesn't, right? Even so, thank God I was helped* (S2 Jericó). *But the nurse, for some medication my mother needed to take, especially the injections in the period she had an outbreak, I needed him* (S14 Jericó).

It can be seen that, in the imaginary of these subjects, the doctor´s centered model still exists, where the doctor is the person who prescribes the medicine, that is, the one who provides the solution of the problem. With this, the attention is concentrated in the biological care in detriment of the therapeutical possibilities related to link and reception in and with the community.

Difficulties and challenges of the care

As results of the questioning if the family members faced difficulties in the care of these family members with mental disorder in the county, a significant part showed to have difficulties in the care in their counties once they felt alone, not having the support of other members of the family, politicians or health professionals, facing the care with the food, medication, hospitalization, among others. Besides that, they reported the need of qualified personnel to listen and provide counseling from their family members, as it is shown in the following statements: *There is difficulty, a person like him needs more than one person to talk to, to make the stories healthier, it helps. For me is good too because outside nobody knows about my life inside the house, then when you talk to me you understand, anything I say you understand* (S3 Jericó). *I cope with it, because I have nobody´s help it is just me alone, and I am the one to take him to the doctor, to provide him medicine, to buy the food, to fix her* (S10 Jericó). *I face difficulties because I don't have how to take him to another place, because it is just me and I don't have transportation* (S8 Mato Grosso).

Other difficulties were pointed out such as the lack of specialized medical assistance, the difficulty to get a transport to other counties, to have a private assistance, spending with transportation and even medicine: *The trip was very tiring, when we have to go I set the appointment, my mother stops sleeping because she became apprehensive, because she thought it was too tiring and she got to sleep during the trip, and couldn't relax, she was very tense….then for me, taking her to another town is very difficult* (S14 *Jericó). The difficulty is precisely this, because there is not a professional of the area, the access is very difficult, because if there is the professional of the area, if there is a psychiatrist here, you wouldn't have to go Sousa, nor to Caicó, nor to any other places we go. Then comes the question, this doctor, the one from Souza is right, it was a public doctor. But the one from Caicó is private, the appointment is always expensive, we pay the for the second appointment, we pay for everything and there is the matter of transportation, by car, all of this is difficult, the cost is high, the medication too and there is no medication in the public health, there is no medication* (S9 Jericó).

So, the family members are in a situation of overload, once they suffer with the expenses, with the time to get assistance in these services, for the tiredness caused by the amount of trips and distance, or even for leaving his relative hospitalized in such a distant place.

Besides that, other problems are shown regarding the confrontation of situation of prejudice of the population with the patient in mental suffering, as it can be seen in the following statement: *but I don't allow him out of the house because I see what people does with others who had mental problems, they curse, they play jokes* (S8 Mato Grosso).

Only three people in the county of Mato Grosso and one from Jericó showed to have no difficulty, once they said they never needed any service or received any help from the family members or medical assistance or from any other health professionals, as shown in the following statements: there are *no difficulties, I don't leave the house with her, when I do this, it is to my family´s house. She goes to her family´s house, she dances with everybody, but I, the meeting is for me but she said that I can take her too* (S11 Mato Grosso). *No, on the contrary, they help, they help in whatever I need (S12 Mato Grosso). No, because I never looked for anything here, I don't even know how it is, if I look for it Iwill have this help* (S13 Jericó).

This implies that other members of the family developed a fundamental role providing support and company to people with mental disorder and their caregivers. The attention turned to these subjects, by the health professionals such as nurses, doctor or HCA can be some information, a simple assistance or a conversation, which is recognized as of great importance, offering support and relief, facing the situations they experience.

Discussion

According to similar findings in other studies, the women are shown as main caregivers, once they incorporate the task of providing care to the family and to needy ones[15]. It is still noticed that some caregivers, due to their age, should be in the position of being take care of, and many times presented difficulties in their daily lives and however they assume the role of caregivers that is imposed to them[16].

The family is the organ that welcomes and helps the patient in mental suffering and, therefore, is exposed to the challenge of dealing with the unforeseen happenings and experience with their own prejudice concerning such disorder. So, it is up to the family to try to harmonize the environment, once living as a group requires the recognition of each one´s singularities. In this sense, a great difficulty in living with a patient in mental suffering is many times due to the aggressive attitudes, the social isolation, the unpredictability of the actions and the lack of affection.

The suffering which attacks the family is linked to the adversities of living with a family member with mental disorder, they are behavior and symptoms which drag, unbalance, misguide and makes the familiar relation difficult. Besides that, the family is many times without information concerning the best way to care of the relative, feeling insecure, afraid and unprotected[16].

The feelings of difficulties are expressed by the family members by several factors such as watching the patient all the time, taking care of the food, the bath, the medication, the impossibility of leisure of having a work which may result in emotional, social and financial overload for the family. It also shows that these subjects, facing so many attributions, without psychic and physical resources, live in a situation of alert, causing nervousness, anguish and stress[11].

So, based on the overload brought to the family nuclei by the people with mental disorder, the services of health must elaborate and develop programs that aim at assisting the needs of the family members whether facing the first episode of mental suffering or those patients with several psychiatric hospitalizations. So, the Health Department, with Administrative Rule No. 224 of the Mental Health guidelines, propose that the family must be assisted in all the services, whichever they might be[17].

Despite these orientations, it is noticed that in many part of the cases, the basic attention does not plan assistance which completely assists the matters of health, many times just aiming at the biological manifestation, once the actions of mental health are absent once the user with psychic suffering is a destabilizing element in the assistential routine of the professionals[16].

Another characteristic shown in the studies was the doctor-centered assistance as strategy of team work[9]. The nurse, in term, appears in the development of basic interventions, not performing the role of care

to the subject and his family member, through the knowledge of these problems, embracing, listening, inclusion in collective activities or even intervention which minimize conflicting situations thus forming a link and a commitment with the subjects or even sending them to specialized services[18].

Facing the scenario of the changes which guide the policies and practices in health, it is necessary to offer whole time attention to the subjects, using new practices of care aiming at autonomy and integrality. So, the formation of new knowledge and practices is essential, especially to the nurse, who is present in the several scenarios and teams of attention to health[18].

The health professional, form an idealist vision that the family is always ready to take care, protect, build an identity and relational links of belonging, providing the subject with the better quality of life and social insertion. However, they must consider that the family lives in a specific context and at a time in which their potentialities may be jeopardized and, therefore, difficulties and need of support emerge[19].

Keeping in mind the difficulties and challenges for these subjects, the counties must, together with the population, the health professionals, users and family members, develop actions of health which make the attention in mental health feasible, and therefore require an effort of the managers in order to have a greater investment in resources for the team of Family Health, so that a net of care and social inclusion can be built[9,20].

Researches in this field have shown little investment in training the FHS professionals for the assistance in mental health[21]. The nurses, e.g., are aware of the work they should to attend to this demand, however, they feel difficulties and do not have enough training, besides mentioning the lack of a multidisciplinary team for performance of the care[22].

The county can still count on reference services on mental health, which freely assist the population not bringing so much distress to the subjects. Therefore, besides producing a greater comfort, it decreases the economic overload brought to the family that will have to cope with the expenses with private services and no contribution from the sick family member.

A stereotype concerning madness was created as a burden for the society for considering the mad one a dirty, strange person, who acts differently from the ordinary people and because of that they were excluded. So, a standard was instituted between what is adequate or not. For such, the population has to be oriented and clarified concerning the mental disorders, aiming at decreasing prejudice and stigmas, once these actions can lead to social isolation of the subject and family member[21].

For that it is necessary to have the increase of the partnerships which strengthen the relations of the other members of the family, Microsystems or Macro systems such as the net of social support and partners in the confrontation of experience of people with mental disorder, besides that, the professionals must also be a part of this net of support, forming links with the subjects and making these services of health a point of listening, embracement, affect and liberty[3].

Final Considerations

The research provided the knowledge of the feeling of the family members of the small-sizes counties concerning the experience with subjects with mental disorders, presenting as results expressive tiredness, anguish and suffering. Aspects of physical, psychic and financial overload were common, made evident by the use of medicine which induces to sleeping or even by the disorganization of the routine and of the family experience.

Regarding the actions in mental health in basic attention of the counties, there is frailty, once they do not develop the role of assistance to the subject in mental suffering and his family effectively, so, the use of private services in distant counties is frequent, which caused expression of lack of support and expenditures with transportation, medical appointments and medicine. So it is worth emphasizing that the FHS, once located near the population, has the condition

of recognizing the suffering of these families and from that develop actions of embracing and listening, as well as minimize situation of stress and send the patient to services specialized in more complex occurrences. All of these through the assistance of doctors, nurses and psychologists.

The health professional, in turn, has the responsibility to develop actions which help the family member in the care thus generating his autonomy. In this case, it becomes necessary to empower the family members in the care to the relative with mental suffering, emphasizing that it requires detachment, strength, courage and recognition of these singularities, so that all his needs are assisted.

So, the study presents the evaluation of the subjects on the assistance in mental health offered in small-sized counties, showing the need of attention turned to those families that suffer so much, provided by the managers and FHS team. Therefore an improvement of the existing services of health, in the formulation of county policies is proposed in order to fill the need of this demand and promote a better quality of life of these subjects.

Collaborations

Silva LI contributed for the conception of the work, data collection, analysis, interpretation of the data, writing of the article and review of the version to be published. Maia KKO contributed for the writing of the article. Martins AKL contributed in the orientation of the research, writing of the article, review and final approval of the version to the published. Oliveira FB and Souza AMA contributed with the review of the article.

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