

Stress on families living with the reality of mental disorder*

A sobrecarga da família que convive com a realidade do transtorno mental

La sobrecarga de la familia que convive con la realidad del trastorno mental

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ABSTRACT

Objective: To be acquainted with the stress over families living with psychic disorder. **Methods:** This is a qualitative research, with a hermeneutic-dialectic approach. Data was collected through semi-structured interviews with ten family members of mentally ill persons in a Psychosocial Attention center and on their homes. Gathered data was grouped in themes for later analysis. **Results:** We identified the presence of three overload types: financial overload, related to medicine and consultation spending; attention overload, because it's the responsibility of a single individual; physical and emotional overload, represented by tension and anxiety. **Conclusion:** The need for attention of the family of the mentally ill is evidenced. Once the the coping strategies are grasped, it can become a therapeutical and resocializing space.

Keywords: Family relations; Family; Mental disorders; Mental health

RESUMO

Objetivo: Conhecer a sobrecarga da família que convive com o sofrimento psíquico. **Métodos:** Trata-se de uma pesquisa qualitativa, com abordagem hermenêutico-dialética. Os dados foram coletados por meio de entrevista semi-estruturada, com dez familiares de portadores de transtorno mental em um Centro de Atenção Psicossocial e no domicílio dos sujeitos. Os dados coletados foram agrupados em temáticas para posterior análise. **Resultados:** Identificamos a presença de três tipos de sobrecarga: a sobrecarga financeira, relacionada aos gastos com consultas e medicamentos; a sobrecarga do cuidado, pois este fica sob responsabilidade de uma única pessoa; a sobrecarga física, e a emocional representada pela tensão e nervosismo. **Conclusão:** Evidencia-se, a necessidade de atenção à família dos portadores de transtorno mental, uma vez que favorecidas as estratégias de enfrentamento, ela possa se constituir em um espaço terapêutico e ressocializador.

Descritores: Relações familiares; Família; Transtornos mentais; Saúde mental

RESUMEN

Objetivo: Conocer la sobrecarga de la familia que convive con el sufrimiento psíquico. **Métodos:** Se trata de una investigación cualitativa, con abordaje hermenéutico dialéctico. Los datos fueron recolectados por medio de entrevista semi-estructurada, realizada a diez familiares de portadores de trastorno mental en un Centro de Atención Psicossocial y en el domicilio de los sujetos. Los datos recolectados fueron agrupados en temáticas para un posterior análisis. **Resultados:** Identificamos la presencia de tres tipos de sobrecarga: la sobrecarga financiera, relacionada a los gastos con consultas y medicamentos; la sobrecarga del cuidado, pues éste queda bajo la responsabilidad de una sola persona; la sobrecarga física, y la emocional representada por la tensión y el nerviosismo. **Conclusión:** Se evidencia, la necesidad de atención a la familia de los portadores de trastorno mental, de tal modo que favorecidas las estrategias de enfrentamiento, ella se pueda constituir en un espacio terapéutico y resocializador.

Descriptores: Relaciones familiares; Familia; Trastornos mentales; Salud mental

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INTRODUCTION

New perspectives for healthcare, such as the creation of the Family Health Program, hospitalization reduction, home care, incentives for treatment in outpatient units, a larger social network and flexibility for patients with long-term diseases encourage the inclusion of the family in the healthcare process⁽¹⁾.

The responsibility for the care of mental patients on the context of the pre-reformist movement was given to the hospital-centered institution, with the family being responsible by identifying the disorder, bringing the family member in, visiting, as well as providing the necessary disease history and background information. The relationship between the patient and the family was mediated by medical and state agents, responsible for cure, custody and care⁽²⁾.

After the 1960s, in countries like Italy, and after the 1980s in Brazil, the need of rethinking mental health practices became evident, in face of the inhuman treatment conditions that mental patients were subjected to, kept away from society and family⁽²⁾.

The Psychiatric reform defends deinstitutionalization, with the consequent exchange of psychiatric hospitals for new forms of welcoming and treating, giving rise to: Nucleuses of Psychosocial Care – *Núcleos de Atenção Psicossocial (NAPS)*, Centers of Psychosocial Care – *Centros de Atenção Psicossocial (CAPS)*, Day Hospitals – *Hospital Dia*, Therapeutic Housing Programs – *Programa de Residência Terapêutica* and psychiatric beds at Hospital Geral. These are all treatment strategies that break away from the paradigm of the asylum-based model⁽³⁾.

The mental healthcare community services should include actions focused on the family members and be committed to building projects of social insertion, respecting individual possibilities and principles citizenship for the minimization of stigmas and the promotion of quality of life for mental patients⁽³⁾.

Observing the reformulation of the psychiatric care, the family unit plays an important role in the care and resocialization of the mental patient. Thus, it is necessary to know the family environment and how its members respond to and live with mental disorder⁽⁴⁾.

“Family is the first subject for referencing and maximizing individual protection and socialization”. Regardless of the multiple forms and shapes it can assume, learning about care and social relations start within it⁽⁵⁾.

Family is defined as a system formed by values, beliefs, knowledge and practices focused on promoting the health of its members, attention to prevention and treatment of disease. The process of caring is intrinsic to the concept of family, wherein the family defines strategies in cases of complaints or signs of discomfort⁽⁶⁾.

The presence of a mental disorder in the family

environment causes changes in the routine, habits and family habits. With the impact of the diagnosis, the necessity of adapting to the new situation, the social stigma, the dependence and the implications of the chronic clinical condition. All of it may cause overloading, conflicts, feelings of disbelief, loss of control and fear, since the family lives in a stressful situation⁽⁷⁾.

Living with mental disorder results in overloading, characterized by difficulties such as problems with family relations, stress caused by living with the unstable mood and dependence of the mental patient, as well as the fear of relapse and of the patient's behavior during a crisis⁽⁴⁾.

The overload is also considered for its objective and/or subjective dimension. The former, identified with greater intensity, perhaps because it is more concrete, is related to the real demands that are consequent of living with a mental disorder, while subjective overload is abstract, referring to the universe of sensations⁽⁸⁾.

In view of the impact of disease, the possibilities for actual emotional exchanges are reduced, imposing feelings and emotions that are difficult to elaborate and understand by the family members. This exposes the need for an intervention focused on this type of grievance, taking personal subjectivity and individuality into account⁽⁷⁾.

When the family is involved in the treatment of the mental patient and educated about dealing with the difficulties related to madness and overloading, the emotional load of both the family and patient is reduced, improving the levels of interaction and empathy between them⁽⁹⁾.

OBJECTIVE

To analyze the overload in families living with psychic suffering.

METHODS

The CAPS Qualitative Evaluation Study in Southern Brazil was developed from a constructivist, responsive evaluation, and the hermeneutic-dialectic approach. Egon Guba and Yvona Lincoln's Fourth Generation Evaluation, adapted in 2005⁽¹⁰⁾, was used in the study, and guides the theoretical-methodological process in this research.

This research project was approved by the Review Board of a public university (file #074/05); the family members agreed to participate in this study by signing a term of consent.

Five CAPS were intentionally selected, using data obtained in the quantitative epidemiological evaluation of 30 CAPS in Southern Brazil as parameters. These parameters referred to structure, processes and adequacy to the rules defined by Regulation #336/2002. The time of service, experience and availability of groups interested in participating in the study were considered.

The qualitative stage of the study focused on the Centers of Psychosocial Care I and II – *Centros de Atenção Psicossocial I and II* – in five cities of the southern region of the country.

This article analyzes data obtained at a CAPS II, specifically referring to the family members' group regarding family overload due to psychic disorder.

The practical application of the Fourth Generation Qualitative Evaluation happened by:

- Contacting the healthcare team, presenting and discussing the proposal of the research;
- Identification of the stakeholders or groups formed by people with common characteristics, interested in the performance, the product or the impact of the subject being evaluated. Three groups were included in the research: team, users and family members;
- Development and growth of joint constructions
- Application of the hermeneutic-dialectic circle;
- Presenting the questions for the groups
- Organizing the constructions of the groups, so that they could either change them or confirm their credibility.

The individuals who became members of the groups were intentionally selected during the first week, when a prior period of observation was held at the service. The second and third weeks of field work were dedicated to interviewing, with the application of the hermeneutic-dialectic circle. The inclusion of subjects in the study obeyed the following criteria: Family members with good or bad insertion in the service, being the direct caregiver, having daily contact with the mental patient, and being family members considered "difficult" by the team.

Thus, ten family members were selected for the study, two of which did not mention experiencing overload situations. In order to guarantee the ethical principals of secrecy and anonymity, the subjects were identified by the letter I (interviewee), and numbered from one to eight according to the interview order.

After reading the transcriptions carefully, guided by an analysis script, the data were classified under different themes related to overload, confronting the findings with the theoretical material, and comments were made based on the authors' reflections.

RESULTS

Analyzing the interviews, it was perceived how stressful it is for the family to live with a mental disorder, including understanding and dealing with unconventional behaviors such as speaking to oneself, inversion of the sleeping cycle, social retraction, mood swings and lack of personal hygiene. All of these bring ambiguous feelings, as seen later in this study.

Financial overload: The issue of financial burdening

for the mental patient's family is evident in the testimonials below:

"My other son had to skip his job last Friday so he could take care of him [...]" (I1)

"I'd have to stop working to take care of her [...] I need to work, my salary is obviously the only source of income at home is" (I2)

"If my husband stopped working, he would get R\$350,00 from his retirement salary and he works a lot [...] if he stops working, what are we going to eat?" (I3)

"And she can't afford to stop taking her medication [...] she takes strong drugs, so she sleeps a lot..." (I4)

"Because we used to have to pay for his medication before he started his treatment here and, in this case, it was, like, very expensive". (I5)

Drowsiness, a side effect of some types of psychiatric medicine, or part of clinical symptoms, in conjunction with changes in behavior, harms the mental patient's participation in the job market.

When we analyze the presence of financial overload in the daily context of the families, it reaches larger proportions, because, in addition to worrying about providing for the household and treatment needs, the remaining family members suffer with deprivation, caused by a tight and controlled budget.

Attention overload: The interviewed family members mention how the family builds an informal, zealous, concerned and ever-present system care.

In the mental disease context, care becomes a recurrently difficult chore, either because of lack of support and commitment from the other family members or due to the demands of the affected family member.

"Then I couldn't even go to the bathroom (patient's family member) because of her, she gets too upset, she goes out [...] there's a risk of hurting herself, pull an energy cord, whatever is in front of her [...] she becomes disoriented, goes to the street almost naked, little clothing [...] I even tied her to the bed, because I couldn't take it anymore, it was unbearable, I was forced to do it". (I2)

"She throws ashes on the floor, cigarettes on the bed can start a fire, she leaves the oven on, leaves the grill working with meat on it and goes to bed. I get scared. [...] suddenly, there's a crisis again, holding a knife at me". (I6)

"He tries to kill himself [...] we always have to be alert [...] thus, if there's any noise I wake up, you sleep worried, fearing that he would get up, fall, get hurt or that he would do something stupid". (I1)

Families living with mental disease present concerns, powerless and fear in the face of the mental patient's

inadequate and unpredictable behavior, inconstant moods and risk of suicide, sometimes acting in perplexing ways, but justifiable by the hopelessness of not knowing how to act in order to protect the family from physical damage. This is the way found by the family to take care at this moment of their history.

"Twelve nights, (the patient) wouldn't really sleep, on the other day I (family member) couldn't stand it anymore, and she wouldn't stop, she wanted to go everywhere". (I2)

"There's me to take care, only me to take care, but me alone [...] I need to take care of myself, too". (I1)

"I take them to the dentist, take them to the doctor, you know? Right now, It's all up to me". (I3)

It is possible to detect how complex and hard it is to live with mental disorder, when the family is not able to rearticulate. In addition providing care, the caregivers forfeit their commitments, voiding their desires and needs in favor of satisfying the dependence of the affected family member, making it clear that the process of deinstitutionalization is valid when the family receives care as well. The family needs to learn how to coexist with a person that needs care. However, the caregivers have their own lives to organize, their commitments, their aspirations and desires.

"But there are some days when, oh, we lose it [...] Oh, so hard, because the person gets stubborn, the person has, wants to do, she, sometimes she would run away from home, we didn't know where she had gone to, I was worried, I got home at night [...] If she's awake she eats right [...] and she has insomnia, too, she is up the whole night long". (I4)

"Yeab, but unfortunately when there's only one person it's bad too, as I said, how am I only going to take care of them and of myself? So, when I have something to do, where am I going to leave him, with whom? How?" (I1).

It is evident how the families need to receive orientation, to count on organized social aid, prepared to fulfill its demands, and to receive support, so that they can articulate their internal resources in order to bear the inadequate behavior of their member.

The insertion of the family into family support groups, where the complex factors related to this situation are discussed, is beneficial, showing them that they are not alone in the duty of providing care that the adversities are also present in other families experiencing living with psychic treatment, directly suffering with the moments of aggravation of the mental disorder symptoms.

"So she doesn't take half of the medication I give her. She puts it in her mouth. When I go away, she puts everything on the floor". (I6)

"Now his medication I put it all in his hand because I'm afraid [...] sometimes he wants to take everything at once. I hide it, he doesn't know where I put it, I just put it in the medicine cup and that's it". (I7)

"They get very sick and can't eat by themselves". (I3)

Physical and emotional overload: The presence of physical and emotional overload is identified by the onset of disorders related to the nervous system, such as gastritis and gastrointestinal problems, showing how emotional problems act on the physical health of an individual. People living with the reality of a mental disorder are emotionally exhausted, due to sleep deprivation or the fact that they cannot stand the implications caused by this type of life anymore. The presence of this overload can be recognized in the following testimonies:

"Not even at night I can sleep decently [...] I get nervous" (I1)

"I couldn't stand it anymore, I couldn't deal with him any longer [...]" (I3)

"My, I was getting crazy with him, too". (I8)

"I spent the whole day in bed with diarrhea, why? Because she got a taxi and took off, I didn't know where she was, I got nervous and then colitis and gastritis get to us. [...]" (I6)

In addition to what is presented about this theme, other factors that contribute for the caregivers' emotional stress are the perception and the dimension of the results of the disease in their lives.

We believe that physical and emotional overload reflect each other and can't be isolated. Since the human being is a biological, emotional and social creature, whatever happens in any of these spheres is reflected on the whole. Perhaps this is the most harmful type of overload for the quality of life of the family members who live with mental disorder, directly interfering and resulting in a process of falling ill and crumbling coping strategies, which need to be maintained in order to strengthen the family bonds and the ability to provide care.

DISCUSSION

Financial overload: We stress that many families live in unfavorable economical situations, which increases their vulnerability. When it comes to a family living with mental disorder, that vulnerability is intensified and financial difficulty is worsened, since the family undergoes a complex process, which demands new structures in occupational relations, inter-relations and the family budget. It is necessary to anticipate missing workdays to care and provide for the needs of the mental patient, which can harm the family's only income source.

The problems become stronger when the caregiver is young, in the productive age, and the time dedicated to

care hinders the time allotted for activities focused on earning a living⁽²⁾.

Parents and relatives of the mental patient pay for the costs related to the disorder and its consequences. The household sustenance, medication purchase, travel costs, hospital stays, physician appointments, all of these have to be paid for with the resources spent on the family needs⁽¹¹⁾.

It is hard to evaluate and quantify the overload on those who live with the mental patient, but it is certain that families suffer economical hardships for not being able to count on an entirely productive member⁽¹²⁾.

The financial overload is expressed by the patient's difficulty in keeping a job or even entering the job market after the manifestation of the disease, because many problems have to be faced in order to generate income and earn a living⁽¹³⁻¹⁴⁾.

The difficulty for the mental patient to enter the job market is closely related to prejudice. When a financial benefit is achieved, it can minimize the problems caused by the impossibility of working, and it can also improve their power of contractuality inside the family group. The importance of substitutive services is stressed, such as the CAPS and income generation workshops, since they recover the patients' self-esteem, showing that they are capable of learning and producing.

Care overload: Family care can be recognized in various attributes, like presence and protection. Presence concerns actions, interactions and interpretations through which the family demonstrates solidarity for its members, which is fundamental for an integral human growth and development. Protection guarantees measures regarding physical, emotional and social security of the family group, including also personal hygiene and health⁽⁶⁾.

The family develops strategies and has a peculiar way of taking care which, sometimes, isn't the best alternative, but is how it articulated itself in order to survive, since caring for the mental patient isn't an easy task, especially on an advanced chronic stage⁽⁴⁾.

When the clinical symptoms become more acute, the family experiences an intense suffering and, at times, a process of despair, worsened by problems that emerge during this period as consequences of the disease, such as: feelings of impotence and postponing of personal projects and expectations, which deeply affect the family universe. Hence, the caregivers organize their lives around the disease, and their personal needs tend to fade into the background⁽¹³⁾.

Life with mental disorder is considered difficult by the family, because they usually do not know what course of action to take when facing problems with the mental patient's behavior⁽¹⁵⁾.

Providing care to a relative with a mental disease

involves a relationship that, at times, is similar to the relationship with children, supported by a tolerant and patient attitude⁽¹⁶⁾.

The family members responsible for the providing care demonstrates concern and awareness about the correct administration of medication, taking the responsibility of watching the medication time and dosage upon themselves, because they are afraid that the mental patient will use it inadequately, which could put their life at risk.

Family-administered care aims at preserving the lives of its members, fully enabling them to develop, their own potentials, considering the conditions they live in. The family is the core from which care is irradiated, the space where caring is learned⁽¹⁷⁾.

Physical and emotional overload: Many symptoms presented by mental patients, when uncontrolled, like speaking to themselves, aggression, insomnia, changes in thought patterns, language and behavioral disorders and unpredictable or irresponsible behaviors can cause physical and mental stress in the caregiver⁽¹⁸⁾.

It's necessary to consider that not everybody can assimilate and understand the emotions involved in caring for individuals who are weakened by side effects of medication, removed from society and with an undefined clinical course of the disease. The characteristics of a chronic disease (permanence, relapse, need for different interventions) and of the inadequate behavior of the patient seem to favor a higher vulnerability to general losses (health, financial, physical, mental and emotional balance)⁽¹⁹⁾.

Family members perceive themselves as being more nervous, irritable, lacking appetite and with troubled sleeping habits⁽¹⁸⁾, which we consider consequences of the caregiver's anxiety, who is always alert and fearing the possible behaviors that their family member with a mental disease may adopt.

Overload observed as a physical or emotional disease is noted by changes in the family dynamics, by the increasing demands of this new situation and by the lack of resources to cope. For this reason, further problems are common, such as: spinal problems, hypertension, heart disease, stress, tension and family nervousness, after the diagnosis of mental disorder in one of its members⁽¹¹⁾.

A study analyzing 40 families found that, in 24 of them, other members had psychological problems, such as discouragement regarding self-care, depression, excessive worries about the side effects of their medication and low self-esteem caused by stigmatization⁽²⁰⁾.

Living with mental disorder involves complex issues, since it is not possible to dissociate the "sick body", i.e., the biological entity from its social dimensions which, in

this case, are represented by the family context. Both the limitations and the suffering of the mental patient are also experienced by the family, confirming the close relationship between the biological and the social⁽²¹⁾.

FINAL CONSIDERATIONS

With the implantation of substitutive mental health services, the mental patients spend part of their days at the service, and the remaining time with their families, trying to attain citizenship and reinforce the bonds that were severed and neglected by the asylum institution. However, since this experience is not always harmonious, it is therefore questioned, because not all families have the structure and coping resources to coexist with the social stigma, the temporal awkwardness and the sick relative's inadequate behavior.

This study aimed at perceiving the overload in families living with psychic disorder, finding that this reality is permeated by feelings of despair, anxiety, worry and grieving, resulting in conflicts and tension.

However, considering that even predictable events can cause a certain amount of crisis in the family core, the reality of living with a mental disorder is also mediated by the family's ability to adjust to a new situation, depending on its strengths, its solidary bonds and the possibility of counting on the support of other people and institutions.

We don't intend to expose the family as a victim of the situation, since we only interviewed those who in fact participated in the care for the mental patient. We did not address the topic of those families which abandoned their members, who by now do not even have an identity, in psychiatric institutions.

In the current context of psychiatric care, the family is a privileged space for the practice of care, and it needs to

be effectively integrated in the discussion about the new mental healthcare paradigms. It is also seen as facilitator in the mental patient's process of social reinsertion. More than an ally in the implantation of the emerging psychosocial model, the family should be seen as an focal point of intervention, so that their needs are fulfilled and their overload is minimized.

The families need to be heard, to have their reality and suffering understood and welcomed. Many times, when they request the clinical admittance of a sick family member, it is not because they do not love them, or in order to run away from their responsibilities of meeting the needs of their members as a family. This happens because they cannot stand a life that, little by little, becomes unbearable, difficult and stressful, which emphasizes the importance of being oriented and supported.

It is important to insert the families in mental health community service family groups, as well as providing clarifications about behaviors, symptoms and treatment for the disease, about the use of medication and its side effects, making home visits to become acquainted with the reality of the family and make them feel that they are not alone. Conversely, the family should feel safe and capable of acting adequately regarding the symptoms of mental patient.

The connection between the family and the mental health patient needs to be based on a sincere and respectful relationship, where the singularity and individuality of all the members are preserved, in a way that the former does not feel overloaded and the latter can effectively recover his or her citizenship and autonomy, within a therapeutic relation.

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