

BURDEN EXPERIENCED BY THE COMPANIONS OF PSYCHIATRIC PATIENTS HOSPITALIZED IN A GENERAL HOSPITAL

SOBRECARGA EM ACOMPANHANTES DE PACIENTES PSIQUIÁTRICOS INTERNADOS EM HOSPITAL GERAL

SOBRECARGA PARA ACOMPAÑANTES DE PACIENTES PSIQUIÁTRICOS INTERNADOS EN UN HOSPITAL GENERAL

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ABSTRACT

With the objective to identify indicators of burden among the caregivers of psychiatric patients hospitalized at a general hospital in the interior of Minas Gerais, Brazil, this qualitative and descriptive study was conducted over a period of three months in 2016 and addressed a convenience sample of 10 family caregivers of individuals hospitalized in a psychiatric unit. Data were collected through a semi-structured interview and analyzed using content analysis. Results show that providing care to a family member with a mental disorder may physically and emotionally affect the health of caregivers as well as impose changes in their routines during hospitalization. The experiences of caregivers include a desire for the condition of the mental patient to improve or heal completely, a feeling of guilt, and a desire to share the responsibility of caring for a family member with a mental disorder. The results indicate that these caregivers experienced burden and that families need interventions intended to minimize distress.

Keywords: Mental Disorders; Caregivers; Family.

RESUMO

Com o objetivo de identificar indicadores de sobrecarga referidos por cuidadores de pacientes psiquiátricos hospitalizados em um hospital geral do interior de Minas Gerais, desenvolveu-se este estudo qualitativo e descritivo, realizado durante três meses do ano de 2016, com amostra por conveniência de 10 familiares de pessoas hospitalizadas em leitos psiquiátricos. Para a coleta de dados utilizou-se a entrevista semiestruturada e os dados foram analisados por meio da análise de conteúdo. Evidenciou-se que cuidar de um familiar com transtorno mental pode desencadear abalos físicos e emocionais, bem como gerar alterações na rotina dos cuidadores durante o período de internação. Entre as perspectivas diante do cuidar de uma pessoa adoecida, destacam-se o desejo de melhora ou mesmo cura do transtorno mental, sentimento de culpa e o desejo de compartilhamento de responsabilidades na lida com o familiar com transtorno mental. Os dados obtidos indicam sobrecarga e demonstram que a família necessita de intervenções que contribuam para minimizar seu sofrimento.

Palavras-chave: Transtornos Mentais; Cuidadores; Família.

RESUMEN

El objeto del presente estudio fue identificar los indicadores de sobrecarga mencionados por los cuidadores de pacientes psiquiátricos internados en un hospital general del interior del estado de Minas Gerais. Se trata de un estudio cualitativo y descriptivo realizado durante tres meses de 2016, con una muestra por conveniencia de 10 familiares de pacientes. Se utilizó la entrevista semi-estructurada para la recogida de datos y el análisis de contenido como método de investigación. Se observó que el cuidar de un familiar con trastorno mental puede causar daños físicos y emocionales, además de generar alteraciones en la rutina de los cuidados durante el período de internación. Entre las perspectivas que generan dichos cuidados se destacan el anhelo de que el paciente mejore o que se cure del trastorno mental, sentimientos de culpa y deseos de compartir las responsabilidades de atender al familiar internado. Los datos obtenidos indican la presencia de sobrecarga y que la familia necesita intervenciones que contribuyan a minimizar su sufrimiento.

Palabras clave: Transtornos Mentales; Cuidadores; Familia.

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INTRODUCTION

The word “hospital”, from Latin, means lodging, hostel and hospitality. This institution was created in the Middle Ages, with the initial purpose of performing acts of charity and providing shelter to beggars and the sick. Beginning in the 17th century, the conception of hospital was reinterpreted and it was no longer seen as an exclusively philanthropic and religious institution, but it also started fulfilling a social and political role, that is, hospitalizations started occurring according to royal and judicial orders. At the beginning of the 18th century, the purpose of hospitals underwent transformations until it became to be understood as a medical institution, a place to run analyzes, implement treatments and reproduce knowledge.¹

During this period, the French physician Philippe Pinel (1745-1826), while studying and recognizing illnesses, conceived madness – which assumed different meanings over the course of history – as an illness susceptible to medical intervention. The treatment he proposed was based on social isolation, that is, patients were committed to a hospital for observing, treating and healing them. Pinel’s proposal was acknowledged at the time and resulted in the creation of specific facilities for the treatment of mental disorders. A structural and nosographic separation was then established between General Hospitals (GH) and specialized centers. General hospitals focused on the treatment of physical diseases while asylums focused on the treatment of mental diseases.¹

In Brazil, the first psychiatric facilities were established in mid 19th century, both in São Paulo and Rio de Janeiro. Afterwards, psychiatric hospitals were established in other Brazilian states. The therapy proposed, however, negatively affected patients’ physical, psychological and social well-being. Many never left because their illnesses became chronic, other diseases emerged, they lost ties with their families, or experienced sequelae caused by the treatments imposed.^{1,2} The conditions of these psychiatric facilities were unhealthy and precarious as they lacked food, sanitation, and even clothing.^{3,4}

Based on negative experiences of treatments, a movement in favor of the psychiatric reform in Brazil advocated for changes in the prevailing care model at the time. The primary purpose was deinstitutionalization and consequent deconstruction of asylums, accompanied by the creation of new and effective therapeutic practices. The movement identified the inconveniences of a model that supported the classic psychiatric paradigm, which considered the institutionalization the only form of treatment, favoring social exclusion, the worsening of diseases, and the loss of family bonds.⁵

Some care devices are gradually implemented in Brazil in order to revert the model of asylum treatment. The emphasis of this study is on the psychiatric units available in general

hospitals, the regulation of which was established by Ministerial Order No. 224, 1992. According to this law, the hospitalization of people with mental disorders when experiencing acute episodes (crises) should occur after unsuccessful attempts of community mental health services to control the condition. The number of beds available in a psychiatric unit is limited to 10% of a hospital’s capacity and is restricted to 30 beds while a multidisciplinary team monitors inpatients. In addition to drug treatment, patients also receive psychological support along with social assessment, and families receive orientations regarding the patients’ diagnoses, and also in regard the treatment to be implemented in the hospital and by community mental health services. Patients are also prepared for hospital discharge, and healthcare services are contacted to ensure the treatment continues to meet the needs of patients.⁶

These psychiatric units treat patients with mental disorders in a facility also occupied by people affected by different clinical diseases, which reduces stigma and prejudice, still present in society and which are sources of distress and impede individuals from realizing life projects. Social image may reduce an individual to violent characteristics, unpredictable behavior, or even blame him/her for the illness. From this perspective, this inclusive proposal, in addition to favor decreased prejudice, enable people to access other therapeutic resources that are essential for receiving integral care such as clinical exams and multidisciplinary care.^{7,8} Therefore, effectively meeting the objectives of psychiatric units in general hospitals is directly related to the grounds of the psychosocial model that takes into account the multidimensionality of individuals, that is, integrality considering individuals’ biological, psychosocial, and cultural dimensions, which are inherent to the process of becoming ill.⁹

Considering this new perspective of treatment and understanding psychological illness as a multi-determined process, the context in which an individual is inserted and the people with whom s/he lives with play equally relevant roles for one’s psychosocial rehabilitation.¹⁰ Family life can be very beneficial, as well as shortened periods of hospitalization, strengthened bonds, and social activities. Thus, in many cases, the caregiver is a family member who meets the needs of an individual with mental disorders.¹¹

As an individual with mental disorders remains with family, the caregiver becomes responsible for assisting with daily activities, administering medication, accompanying the patient to health services, dealing with unstable behavior and crises, handling expenses, providing emotional support, and accompanying during hospitalizations, among others. Note that these demands can lead to caregiver burden.¹² According to a recent study,¹³ the psychological illness of a family member strongly impacts the remaining family members and for this reason, families often experience feelings of anguish, guilt, and sorrow.

Considering that these new existing treatments are a consequence of the deinstitutionalization process, the responsibility to provide care is transferred to the family, who plays an essential role in the treatment and quality of life of those with mental disorders. Thus, it is important to also pay attention to this group of people who often spend many daily hours assisting and caring for the patient in times of crises and even hospitalizations. In this sense, it is relevant to investigate caregivers' physical and emotional burden. This study's objective was to identify burden indicators reported by the caregivers of psychiatric patients hospitalized in a general hospital in the interior of Minas Gerais, Brazil.

METHOD

This descriptive study is based on a qualitative approach and was conducted in a mid-sized town in the interior of Minas Gerais, Brazil with approximately 300,000 inhabitants. The study setting is a hospital of medium and high complexity that provides care to the macro region of Triângulo Sul. This facility has six beds available for psychiatric patients equally divided between female and male patients.

PARTICIPANTS

Ten family members of psychiatric patients participated in this study, composing a convenience sample. All the participants met the inclusion criteria: being 18 years old or older, considering themselves the primary caregivers (those primarily responsible for providing care) or secondary caregivers (those who occasionally provide assistance and support) of the hospitalized individuals, living in the same home as that of the patient, and being the main companion during hospitalization.

We consulted the electronic file of the patients hospitalized in the psychiatric unit and verified whether they had a companion and what their relationship to the patient was. All those who met the inclusion criteria agreed to participate.

INSTRUMENTS

The authors developed the instrument used to collect data, a semi-structured script addressing the participants' characteristics (i.e., age, marital status, religion, income, and diagnosed diseases) and including questions, which were based on the literature, addressing potential indicators of burden such as: engagement in leisure activities, perception of quality of life, responsibilities as caregiver, the patient's level of dependency, burden, and self-perception of health status. Two pilot interviews were conducted to test the script.

DATA COLLECTION

A semi-structured interview was used to collect objective and subjective aspects related to the act of providing care to a family member affected by a mental disorder. The interviews were performed by one of the researchers over the course of three months in 2016 within the hospital's premises; answers were recorded and later transcribed for analysis.

DATA ANALYSIS

Descriptive analysis was used to characterize the participants and their daily tasks as well as the patients' diseases. Data were interpreted using content analysis according to the procedures recommended by Bardin¹⁴. First, the report of each participant was analyzed for later identifying similarities and differences among the reports, as well as content that was relevant for the study's objectives. The results were grouped into categories and discussed based on a literature review.

ETHICAL CONSIDERATIONS

This paper was based on a larger project titled "Nursing care provided to individuals with mental disorder hospitalized in a medical clinic due to a clinical intercurrent", which was approved according to Opinion Report No. 447.029. All the participants received clarification regarding the study's objectives and signed free and informed consent forms.

RESULTS

Most of the 10 family caregivers were male (70%), the patients' parents (50%), primary caregivers (80%), aged 58.8 years old on average, married (60%), retired or on-leave (60%), with an income of approximately two times the minimum wage (50%), and had zero to eight years of schooling (60%). The diseases affecting the individuals accompanied by these caregivers were: depression (30%), schizophrenia (60%), and drug abuse (10%).

The perception of most (50%) regarding their own health conditions was regular, 60% reported having health problems. In regard to burden, 70% denied it, reporting the patient demanded care only in a time of crisis and/or hospitalization (70%). Most reported leisure activities (70%), having a religion (90%) and being a regular practitioner (70%).

Data analysis enabled identifying the difficulties family caregivers faced by having a family member with a mental disease, resulting in the following thematic categories: "routine changed during the period of crisis or hospitalization"; "physical and emotional health affected by having a family member with a mental disorder"; "prospects for improvement"; and "feelings toward the family member with a mental disease"

ROUTINE CHANGED DURING THE PERIOD OF CRISIS OR HOSPITALIZATION

A hospitalization affects the routine of families and requires that caregivers renounce their personal responsibilities to care for a family member with a mental disorder.

"You have to leave everything behind (my chickens, my dive bar) to stay here in the hospital with him" (F1).

"I had to stop working to stay as a companion during hospitalization. I'm also away from the children. When the girls get sick, she won't take them to see a doctor, I have to do it. She doesn't support the kids at school either or take care of things at home" (F2).

But it is not only during hospitalizations that families experience the reflexes of psychological illnesses. Changes are also experienced in the daily routine of caregivers providing care to individuals with mental disorders.

"Tiredness, few financial resources, I'd rather to meet her needs; much emotional distress" (F5).

"It disrupts my work, much concern" (F7).

These reports reveal that changes accruing from the role played by these caregivers are perceived as situations that negatively affect their jobs, as well as social and family relationships, also affecting the health of family members/caregivers.

PHYSICAL AND EMOTIONAL HEALTH AFFECTED BY HAVING A FAMILY MEMBER WITH A MENTAL DISORDER

Caring for a family member with a mental disorder may trigger physical and emotional problems. Among the emotional issues reported by the participants, tension, concern, and sadness stood out.

"I more frequently feel sad, worried" (F8).

"I'm concerned with what is happening. It's bad, we get sad, we know he'll get sick if he continues messing up with it" (F10).

The caregivers also reported physical harm, which reflects the negative effects of fatigue and of not having much time to self-care.

"I'm really tired, don't sleep well, I have no peace of mind. She wanted to go out all the time and I had to go with her" (F2).

"I feel I'm getting worse, no time for self-care, no time for me, I'm tired" (F5).

Some participants identified emotional harm involving stress and concern along with physical problems caused by fatigue and the emergence of diseases.

"I think my health suffered, it's too much concern" (F3).

"When he is in crisis, he gets nervous and talks to himself. I feel alone, sometimes it's hard taking care of him, I get afraid during crises. I avoid telling him things, so he won't get more nervous. His problems drain my energy" (F4).

"My health used to be better. Nowadays, I get concerned a lot, stressed, tired, have family problems and other diseases" (F6).

Most participants complained of having their emotional health compromised due to recurrent concern and feelings such as fear and anxiety, while physical problems also derive from the caregiver role. Note that these individuals are mentally and physically affected. The participants expressed they very much desired the illnesses of their family members were healed, which would alleviate the burden, as the following thematic category shows.

PROSPECTS FOR IMPROVEMENT

The behavioral problems of an individual with mental disorders greatly impact the lives of family caregivers. The desire to change the health condition of their family members reveals the difficulties and responsibilities caregivers must deal with because of the transformations caused by a mental disease.

"I wanted him to get well, it'd be great if he'd find a girlfriend to take care of him" (F1).

"It would be good if there was an effective treatment for her to go back to what she used to be, affectionate, polite, active" (F5).

"I wish God prepared a medication to heal this depression" (F8).

"Taking the treatment so he'd go back to what he used to be" (F10).

These reports show that the family caregivers continue expecting the mental disease will improve or even get healed, which reveals the impact of behavioral changes. The caregivers also have feelings that accrue from the responsibility they assumed, as the following excerpts show.

FEELINGS TOWARD THE FAMILY MEMBER WITH A MENTAL DISEASE

The caregivers' reports also reveal a desire to support their family members with mental disorder, which may trigger anxiety given the demands presented, such as ability or availability to provide care.

"I should have taken better care of her (not having lied to the doctors), because she'd be better now" (F2).

"I'd like to have other people helping me" (F4).

"I'd like to spend more time with him" (F9).

Feelings inherent to the caregiver role were identified such as feelings of guilt, self-criticism, and a desire to share responsibilities.

DISCUSSION

The psychiatric reform brought with it advancements in terms of mental health care; especially in regard to replacing long-stay institutionalized care to community mental health services and to the patients' home. This new way of understanding mental disease values deinstitutionalization and social inclusion and reintegration. The family plays an essential role in this new context, assuming responsibilities that concern the care provided to the family member with a mental disorder. Even though hospitalization is not a therapeutic measure prescribed often, it is sometimes necessary and plays a complementary role in situations of psychiatric emergence.^{9,15}

The psychosocial care network includes various community mental health services that collaborate with each other in addition to specialized services provided in general hospitals. Hospitalization in mental health units within general hospitals is intended to include patients, as they receive treatment within a facility in which patients have different profiles and diseases. Additionally, it allows patients to keep family bonds as they are allowed to have a full-time companion. This proposal of treatment reinforces the role of the families in the

different contexts of treatment.⁹ In this study, the interviewed caregivers had been accompanying their family members for most of the time, a situation that have affected their lives.

The reports show that because a hospitalization is an unpredictable situation, caregivers have to renounce their personal responsibilities to accommodate changes in their daily routines and professional lives in order to meet the needs of their family members affected by mental disease. From this perspective, F1 mentions potential losses for leaving his business under the responsibility of other people, while F2 reports having lost his job to accompany his wife during hospitalization. Considering that the family is a basic unit, historically configured as the core of human experiences, changes that take place within this system may rupture balance and affect different spheres of life. Situations in which a mental disease demands hospitalization does not allow for preparing in advance.

Changes in daily routine often lead to burden, which is seen as the experience of problems, difficulties and adverse events accruing from living with a family member with a mental disorder.¹⁶ Responses to one of the interview structured questions show that some participants did not recognize burden in their lives, though their reports revealed that most did experienced burden at some degree. Their reports list the negative consequences of providing care to a family member with a mental disease. The consequences seem to affect at an emotional level and are manifested as concern, stress, sorrow and anguish. Studies show that such feelings are an expression of distress and reflect how challenging the role of caregivers is. Having the responsibility to care for a family member with a disease is an extra role added to the other role(s) an individual plays within the family. The individual requiring care is considered to be fragile and vulnerable and for this reason demand support and assistance to perform the functions of adult life.¹⁷

Analysis of the pair family caregiver/recipient of care with a mental disorder reveals how insufficient and superficial is the knowledge of caregivers concerning the specificities of the patients' mental disorders, such as signs, symptoms or prognoses, which make them feel insecure and face difficulties to provide proper care, especially at a time of crisis. Such a context may lead to subjective burden from the perception of caregivers in regard to their daily experiences due to distress and feelings they experience.^{16,17}

There are also reports of physical and social losses, reflection of objective burden that is a concrete consequence of having an individual with mental disorder in the family and related situations.¹⁵ In this sense, having to abandon one's job, reducing working hours, dealing with financial expenses, having to provide support, and dealing with changes in life are some of the situations reported. Burden can affect the physical and psycho-

logical health of caregivers, interfering in their well-being and quality of life. Therefore, caregivers often lack time to perform self-care, experience fatigue, tension and stress, becoming vulnerable to diseases.¹⁸ Restricted social life and leisure are permanent changes that harms quality of life and increase the burden of family caregivers.¹⁶

Even though this study's participants face different challenges due to the patients' different diagnoses, the impact they experience and their coping strategies are similar. Due to the breadth and multidimensional nature of burden, the symptoms and behaviors of the family member affected by mental diseases harm the family structure¹⁸. Some aspects that hinder relationships and disorganize routines were reported. Such aspects lead caregivers to longing for reverting the situation, hoping to help the patient and also alleviate the burden imposed by their role. Some reports also express an expectation that symptoms will improve or even that the disorder will heal so that the patient will go back to at stage prior to the emergency of disease or before it worsened, which reveals the transformation patients undergo. This may be a factor motivating caregivers to keep caring, accompanying hospitalizations, or putting the patients' needs first. The possibility of healing, however, is a distant reality for some, which reinforces the need of caregivers to acquire a greater understanding of the mental disorder affecting their family members and of potential interventions that can be implemented through the mental health service network.¹⁹

Because of their responsibility as caregivers, these individuals experience diverse feelings. Some family caregivers assume, without any assistance, full responsibility for providing care, revealing a lack of social support, which results in burden. These caregivers wish they had more time to spend with their family members affected by disease and feel guilty for the patient's current health condition. Caregivers often assume this responsibility for not having the option to share tasks with some other family member. Prejudice, stigma, and lack of information regarding mental disorders may lead some family members to distance themselves from the patient, directly affecting the lives of family caregivers.^{18,20}

FINAL CONSIDERATIONS

The important role families play in the therapeutic process of patients, which includes from providing care at home to accompanying them during hospitalizations reinforce their level of involvement and responsibility. This study's results emphasize the burden experienced by family caregivers of individuals hospitalized in the psychiatric unit of a general hospital. Some of the situations reported by caregivers included changes in the domestic and work routines, changes in social life, and situations in which other family members distance themselves

from the patient, together with the caregivers' affected physical and emotional health. Results obtained here show that families need interventions intended to alleviate burden.

From this perspective and attempting to better understand the impact of deinstitutionalization in the dynamics of families, future studies are needed to address the process of transition that accrues from deinstitutionalization as well as the context of family caregivers of psychiatric patients hospitalized in general hospitals, where hospitalizations are shorter and there is a less stigmatizing context.

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