

Family members of individuals suffering from mental disorders: Stress and care stressors

Famíliares de pessoa em sofrimento mental: estresse e estressores no cuidado

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Abstract

Following the reform in mental health care, the family began to assume a significant role in the psychosocial rehabilitation of individuals suffering from mental health issues, which has made family members susceptible to stress. This study evaluated the manifestation of stress, self-perception of stress, and perception of stressors in care provided by family caregivers to individuals suffering from mental disorders. Fifty-four caregivers of patients being cared for in a mental health service for at least one year participated in the study. The following were used: the Lipp Stress Symptom Inventory, and a complementary instrument. The results were analyzed through descriptive and non-parametric statistics. Half of participants manifested stress. Caregivers considered contact with patients and the caregiver role as the most stressful factors. The conclusion is that caregivers have difficulties in providing informal mental care and need support to development strategies to deal with stressful care situations.

Keywords: Caregivers; Mental health; Stress.

Resumo

Dada a reforma da assistência em saúde mental, o familiar assumiu papel significativo na reabilitação psicossocial da pessoa em sofrimento mental, cujas atribuições podem torná-lo vulnerável ao estresse. Objetivou-se avaliar manifestação de estresse, autopercepção do estresse e percepção dos estressores no cuidado entre familiares cuidadores de pessoa em sofrimento mental. Participaram do estudo 54 cuidadores de usuários em tratamento em serviço de saúde mental há pelo menos um ano. Os instrumentos aplicados foram: Inventário de Sintomas de Stress para Adultos de Lipp e Roteiro Complementar. Os resultados foram tratados por meio de estatística descritiva e estatística não-paramétrica. Metade dos participantes apresentou manifestação de estresse. O contato com o usuário e o papel de cuidador foram considerados mais estressantes entre cuidadores com estresse. Conclui-se que os cuidadores apresentam dificuldades no cuidado informal em saúde mental, necessitando de suporte para o desenvolvimento de estratégias de auxílio às situações estressantes do cuidado.

Palavras-chave: Cuidadores. Saúde mental. Estresse.

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The recent changes resulting from mental health care reform have led caregiving family members to take on several different tasks regarding the general daily care and handling of patients. According to Rosa (2005), caregiving family members, such as partners and those co-responsible for care, can be recognized as those family members who are direct caregivers of patients suffering from mental disorders.

Within this perspective, being a caregiver is associated with burden, an impact that is often combined with stress and the stressors experienced by caregivers (Floriani, 2004; Gonçalves, Alvarez, Sena, Santana, & Vicente, 2006). In some studies, stress is referred to as a burden or emotional discomfort (Cassis et al., 2007) and it has been understood as a natural response to the impacts of overload (Borba, Schwartz, & Kantorski, 2008; Fujino & Okamura, 2009; Soares & Munari, 2007).

Conceptually, stress can be characterized as a General Adaptation Syndrome (GAS) resulting from an event that demands great effort on the part of individuals concerning their adaptation to new situations (Selye, 1956). As soon as the internal homeostasis is broken, the stressor alters the ability of the organism to maintain the equilibrium. Stress can yield both positive and negative effects on the organism. Although damaging effects (distresses) are more often highlighted, stress may act in a beneficial way (eustress), and thus become a necessary step toward preparing individuals for action.

Selye (1956) developed the following three-phase model to represent the stress process: alert, resistance, and exhaustion. These stages stand out as differentiated degrees of manifestation of stress, beginning with the preparation of an individual to either fight or escape, by the activation of homeostatic mechanisms, and to physical and psychological exhaustion, as the adaptability of organisms is a finite trait. A study conducted by Lipp (2000) identified a fourth phase between resistance and exhaustion, called almost-exhaustion, a moment when the weakened individual is no longer able to adapt to or resist the stressor and thus becomes vulnerable to the emergence of diseases.

Studies show that due to the chronic nature of mental illness, family members are exposed to a wide variety of stressing agents (Campos & Soares, 2005), a position that can affect family relationships and the caregivers' own health status (Rammohan, Rao, & Subbakrishna, 2002). In a study carried out with family members of patients in a mental health-care setting, Pereira and Bellizzoti (2004) pointed out the occurrence of health problems, such as arterial hypertension, diabetes, sadness, depression, reduced sleep, and reduction of appetite following the emergence of a mental disorder in a family member.

Möller-Leimkühler and Obermeier (2008) researched the predictors of the overload track for a period of two years among family members of patients diagnosed with schizophrenia or depression and found that negative responses to stressors and daily stress were listed among the determinants of overload. In a literature review, Saunders (2003) affirmed that caregivers, within this context, display meaningful stress, as well as moderate to high level of overload.

According to Pegoraro and Caldana (2006), the daily tension to which family members are exposed in the context of caring for individuals with mental disorders may emerge from both their empathy with the suffering of the other and from the lack of response and a sense of impotence concerning how to cope with the behaviors presented by patients in crisis. Dias and Silva (2010) affirm that the behavioral alterations of patients may cause caregivers to experience elevated levels of stress.

Experiencing stress and the powerful burden related to the caregiver role significantly impacts the family's equilibrium, affecting the caregiver's quality of life and the acceptance and care framework designed to receive the patient, thus demanding the use of effective strategies toward coping with such situations. The perception of stress, therefore, offers conditions for individuals to undertake efforts toward dealing with situations that afflict and burden them.

In this sense, the aim of the present study was to identify and assess the manifestation of stress

in caregiving family members of patients suffering from mental disorders, as well as their self-perception regarding stress and the perception of stressing factors in the caregiving process provided to people with mental disorders.

Method

Participants

The present study was carried out with 54 family members who provided care for patients in a substitutive mental health care service in a mid-sized city in the countryside of the State of *São Paulo*. The caregivers invited to participate in the study were the major caregiver for the patient, according to the opinion of either the patients or other family members. Additional inclusion criteria were as follows: to be a family member and caregiver who had attended a health-care facility for at least one year in a semi-intensive or intensive regime (directed to patients who needed frequent follow-up as the result of their clinical status); and those who lived with the patient.

Access to participants was achieved by means of the patients' medical records from the health-care facility, considering the above-mentioned inclusion criteria. Family members of all patients frequently attending the health-care facility in an intensive (n=36) and semi-intensive (n=72) care regime were invited. In order to verify the adequacy of the other criteria, family members were personally contacted, initially by phone, as this was shown to be the most effective way to contact the participants. At this moment, the researchers verified whether or not the potential participants were in compliance with the other criteria established in this study, and fully explained the objective of the research. Following the contact with 108 family members of patients in the semi-intensive and intensive regime, 12 patients were found to have abandoned the facility; three had been transferred to other facilities; and one patient had deceased. Nine patients reported to be living on their own, and six affirmed that they lived apart

from the major caregiver; therefore, they did not comply with the established criteria. One patient and 14 family members refused to participate in the study. The present study also excluded family members and caregivers who: a) had been treated at the health-care facility (n=3); b) manifested any difficulty in continuing with the data collection process (n=3); and c) presented hearing impairment (n=2).

The sample was mainly characterized by female family members (63.0%) and the mean age was 53.0. Among the participants in the research, 29.6% had either finished high school or had not finished college, followed by 27.8% who had completed elementary education. As per the marital status, 50.0% maintained a stable relationship and 50.0% reported being single. Regarding the caregivers, 40.7% were parents; mothers were more frequently identified as main caregivers (27.8%).

As for the patients receiving mental health care and whose caregiver took part in this study, it was observed that the majority were women (55.6%), with a mean age of 44.9 years. As for the educational level, 48.1% had either completed high school or incomplete college degree, followed by 24.7% with either no education at all or incomplete elementary education. As for the marital status, 75.9% did not have a spouse, meaning that 29 had never married, nine were separated/divorced, and three were widows/widowers. According to the medical records, schizophrenia (46.3%) was the most frequent disease among patients whose caregivers participated in the study.

Instruments

For the data collection process, the following instruments were used:

a) Lipp's Inventory of Stress Symptoms in Adults (ISSL), as validated by Lipp (2000). This instrument allows the identification of the presence of stress-like symptoms, as well as the stress phase and the type of symptomatology, i.e., somatic or psychological. Composed of 53 items divided into three groups, the ISSL primarily assesses physical

and psychological symptoms occurring within the previous 24 hours (15 items). In the next step, the symptoms manifested in the previous week (15 items) are assessed and, finally, the symptoms experienced during the previous month (23 items) are assessed; b) Complementary instrument: elaborated by the researcher based on the literature (Bandeira & Barroso, 2005). This instrument was divided into two parts: 1) Collection of social-demographic data related to the caregiving participants, as well as the patients whose family members took part in the study, and 2) Identification of the perception of stress subdivided into: a) self-perception of stress: composed of a closed question regarding the perception of the participant concerning his/her own stress, presented in accordance with a five-point Likert intensity scale ranging from “nothing stressing” to “very stressing”; b) perception of stressing factors in dealing with a family member suffering from mental disorder, in compliance with the five-point Likert intensity scale ranging from “nothing stressing” to “very stressing” in relation to the following aspects of the caregiving process: “the caregiver role”, “contact with the patient”, “contact with the professionals”, and “contact with the health-care service”.

Data collection and analysis procedures

The present study was approved by the Research Ethics Committee of the Philosophy, Sciences and Language School of *Ribeirão Preto, Universidade de São Paulo*, under Protocol nº 377/2008-2008.1.400.59.8. The voluntary character of the collaboration was highlighted at the beginning of the process, before the caregiving family member agreed to be part of the study and signed the form of Free and Informed Consent. The next step was the application of the complementary instrument that was answered by the individual in the presence of the researcher so that eventual clarifications could be provided, if necessary. After that, the ISSL was administered. The data collection process took place in the participants' homes at their own request. The

institution also authorized the implementation of the study following the presentation of the project and the agreement of the professionals involved.

The closed questions contained in the Complementary Instrument regarding the stressing factors in the caregiving process and the self-perception of stress were organized and treated by means of descriptive statistics. ISSL data were ranked according to their technical propositions by means of the descriptive statistics and non-parametric statistics (Chi-square test and Mann-Whitney test).

Results

As assessed by the ISSL, it was observed that half of the participants presented manifestation of stress indicators (Table 1). Among those who presented stress (n=27), 74.1% were found to be in the resistance phase (n=20), with a predominance of psychological symptoms (63.0%; n=17).

The stress self-perception assessment showed that 46.3% of participants perceived themselves to be stressed or very stressed; 40.7% acknowledged having little or no stress; and 13.0% showed a moderate level of stress.

The participants who perceived themselves to be under any degree of stress associated such frequent condition with the situation of living with a family member suffering from mental disorder.

Table 1

Frequency (f) and percentage (%) of participants who presented stress indicators, the phase in which they were, and the predominant areas of symptomatic manifestations, according to the criteria proposed by the normative data of the Lipp's Inventory of Stress Symptoms

Stress	f	%
Presence	27	50.0
Absence	27	50.0
Alert phase	3	11.1
Resistance phase	20	74.1
Almost exhaustion phase	3	11.1
Exhaustion phase	1	3.7
Physical symptoms	9	33.3
Psychological symptoms	17	63.0
Physical and psychological symptoms	1	3.7

Table 2

Personal assessment concerning the perception of stress in relation to the following factors: caregiver role; contact with the patient; contact with the professionals, and contact with the service in terms of frequency (*f*) and percentage (%)

Factors	Level of stress	<i>f</i>	%
Caregiver role	Stressing/Very	22	40.7
	Moderate	9	16.7
	Nothing/Little	23	42.6
Contact with the patient	Stressing/Very	14	25.9
	Moderate	14	25.9
	Nothing/Little	26	48.2
Contact with the professionals	Stressing/Very	8	14.8
	Moderate	0	-
	Nothing/Little	46	85.2
Contact with the service	Stressing/Very	8	14.8
	Moderate	3	5.6
	Nothing/Little	43	79.6

Table 2 presents descriptive data concerning the perception that caregivers had of the stress factors involved in caring for a person with a mental disorder.

Table 2 shows that the caregiving role toward the patient suffering from a mental disorder was deemed to be “not stressing or little stressing” by 42.6% of the family members, followed by 40.7% of participants who considered it “stressing or very stressing”. The contact with the patient was assessed as “not stressing or little stressing” by 48.2% of family members. With regard to the contact with the professionals at the health-care facility of the patients, 85.2% of the family members deemed it to be “not stressing or little stressing”. For 79.6% of family members, the contact with the health-care service was assessed as “nothing or little stressing”.

Concerning the inferential statistics, the study found a significantly higher percentage of female participants (77.8%) who were stressed in comparison with male participants (22.2%; $p=0.02$ - c Chi-square test).

Moreover, the study also observed a higher self-perception of stress among participants, which was pointed out by the presence of stress indicators in the ISSL (Mean - $M = 3.78$), when compared with caregivers with no stress at all ($M = 2.44$; $p=0.001$ - Mann-Whitney test). Additionally, it was

found that the caregiving role ($M=3.33$; $p=0.05$ - Mann-Whitney test) and contact with the patient ($M=3.07$; $p=0.02$ - Mann-Whitney test) were deemed to be more stressing among caregivers who had clear manifestations of stress.

Discussion

The present study observed the predominance of the participation of women, similarly to what has been verified by other studies, thus indicating that the female individual plays a major role in the caregiving process (Pegoraro & Caldana, 2006; Romagnoli, 2006; Vechia & Martins, 2006). In the sample analyzed, it was also found that the mother was considered as the main caregiver among family members, hence corroborating the literature (Campos & Soares, 2005; Estevam, Marcon, Antonio, Munari, & Waidman, 2011; Pegoraro & Caldana, 2006).

Half of the participants presented manifestation of stress indicators, according to the criteria proposed by the normative data of the ISSL, with the majority being in the second phase of the stress process - resistance. At this stage, stress has already been installed and more serious efforts for reestablishing internal equilibrium will be required. As the energy toward adaptation is a finite trait (Selye, 1983), it is important that these caregivers

come up with strategies to manage the stressors more effectively, thus preventing more intense physical weakness and the potential development of diseases.

When asked about their self-perception of stress, caregivers' assessments indicated that they were "stressed or very stressed" on a more frequent basis, although they were proportionally as stressed as those who considered themselves as "not stressed or little stressed". It is worth highlighting that a large percentage of caregivers presenting symptoms of stress also perceived that they were under stress.

Caregivers who presented stress indicators in accordance with the ISSL also showed a higher self-perception of stress. Bearing in mind that the process of coping with stressors is possible through the individual's interpretation of reality (Lazarus & Folkman, 1984), a strong relevance may be assigned to the self-perception of stress as a trigger of strategies aimed at dealing with self-imposed burdening situations. Self-perception should be understood in association with feelings of discomfort whenever signals of distress and/or alterations in the emotional status are reported. As such, it is important to recognize that people are capable of identifying situations, behaviors, or feelings that generate the sensation of being under stress.

An analysis of the factors assigned by participants to the perception of being stressed, at any degree, led us to verify the predominance of caregivers who considered aspects related to the experience of living with the person suffering from a mental disorder to be a strong contributor to such condition. As many caregivers are found to be under stress (ISSL), they perceive themselves as being stressed; in addition, as they frequently point to caregiving factors in their list of stressors, it may be presupposed that the manifestations of stress in the participants might be both associated with their condition of caring for the patient suffering from a mental disorder and the difficulties family members find in coping with health care. A study conducted by Osinaga, Furegato, and Santos (2007) showed that family members are in complete agreement

that tension and conflicts produced by the experience of living with a person suffering from mental disorder may negatively affect the equilibrium and the health status of the family members.

Within the same perspective, the present sample showed that the stress indicators displayed by caregivers were predominantly based on psychological grounds and manifested as irritability, anxiety, depression, and emotional hypersensitivity, among others. Such symptomatology may generate negative impacts on the quality of life of these caregivers, as well as their capacity and availability to embrace and care for the needs of the person with a mental disorder.

It must be pointed out that these symptoms may also produce a negative impact on the caregiver's health status. Similarly to burden, the caregiving process should be a factor of high concern, as it may affect both the caregiver's and the patient's health status, thus influencing the treatment process. Jorge, Ramirez, Lopes, Queiroz, and Bastos (2008) point out the emotional distress of a family member as a result of the experience of living with a person suffering from mental disorder. In Cavalheri's research (2010), feelings such as sadness, anguish, and depression were reported by the vast majority of participants who provided care for patients suffering from mental disorders.

Studies assessing the presence of stress in caregiving family members in different contexts have found similar data regarding the presence of stress in both the resistance phase and in the psychological symptomatology, such as those observed in patients with the Alzheimer's disease (Lawal & Rezende, 2008) and mothers of autistic patients (Schmidt, Dell'Aglio, & Bosa, 2007). In the mental health area, studies indicate that family members do experience stress and emotional distress as a result of living with a person suffering from mental disorders (Barroso, Bandeira, & Nascimento, 2009; Rammohan et al., 2002).

The experience of stress as well as the self-perception of stress mainly related to the experience of living with the suffering of another person, indicate the need to provide more focused care for

the caregiving family members. Following the alterations produced by the mental health-care reform, family members have been assigned a crucial role concerning the care and the treatment of patients. According to Cavalheri (2010), the new caregiving process toward people suffering from mental disorders has created several difficulties for family members. Such impact, therefore, points to the need on the part of health-care services and teams to provide support and work in partnership for the development of caregiving actions. Waidman (2004) rightly affirms that, more than simply being collaborators, the family must be considered as a unit that requires care. Severo, Dimenstein, Brito, Cabral, and Alverga (2007) conclude that the caregiving strategies should include the family as a whole, thus favoring the idea that health-care practices should pay attention and listen to the families during the health-care process, as they are allies that can help change health-care practices. The result would be therapeutic action to improve family relationships, with a special priority given to the treatment process.

Nevertheless, several difficulties in the mental health caregiving reform can still be observed. Bandeira and Barroso (2005) state that there has not been an adaptive application of sufficient community resources to meet the caregiving needs of both the patients and their families. Gonçalves and Sena (2001) recommend that the patient's return to family unit must be accompanied by mental health professionals designed to assist them to cope with the additional challenges associated with maintenance, stability and patient care. Therefore, the need to expand the proposal for a network of mental health support is the current challenge, thereby advancing the development of associations that effectively integrate families and patients and establish partnership strategies.

In this sense, it is worth highlighting the assessment of the caregivers found in the literature concerning some aspects that they have identified as stressors within the caregiving context for patients with mental disorders. According to data obtained from the complementary instrument regarding the stressing factors, the "caregiver role"

was assessed as "not stressing or little stressing" and as "stressing or very stressing" by practically the same percentage of caregivers. The "caregiver role" may include all of the activities (aid, supervision, and maintenance) and responsibilities that family members have toward the patient.

From the perspective of the participants, "contact with the patient" was more frequently considered as "not stressing or little stressing". However, the high proportion of caregivers who assessed such contact as being "stressing or very stressing" or "moderately stressing" should be taken into account. "Contact with the patient" implies each and every existing relationship between the caregiver and the patient, revealing the daily experience of living together. As the daily relationship with the patient go hand in hand with the caregiving process, it may be inferred that these are the activities that intensify the level of stress in the relationship, similarly to what was pointed out by the self-perception analysis of stress. It might also be observed that acknowledging the contact with the patient as a stressing factor may impact the caregiver, thus generating the need to alleviate the situation. It could be said that the experience of living with the patient establishes life boundaries generated by the caregiver role and its resulting difficulties. On the other hand, "contact with professionals" and "contact with services" were not pointed out by the participants as having strong stressing potential.

Furthermore, "contact with the user" and the "caregiver role" were considered as being more stressing to participants who presented indicators of stress. The existence of feedback processes that creates a cycle in which caregiving tasks are stressing factors for caregivers can be a red flag; on the other hand, caregivers indicating the existence of stress show a decreased chance of committing to being caregivers. Such difficulties undermine the relationship between the caregiver and the patient, which in their turn may negatively reflect upon the family dynamics and quality of life.

Caregiving-related stressors have been widely discussed in the literature. Due to the chronic nature of the mental disease, daily caregiving-based

stress factors acquire a prolonged effect, which may affect the mental health of caregiving family members (Rammohan et al., 2002). Severo et al. (2007) affirm that, in face of the difficulties caregivers have with patients and their perception of low level of problem solving, the experience of living with the person suffering from mental disorders imposes behavior control, particularly regarding the patient's medication issue. In addition, the impact on the family life due to the caregiver role corroborates the data in the literature regarding the role of family constraints in determining overloads (Barroso et al., 2007). The evidence showed here points out the dimensions of stress to which mental health-care services should direct their actions.

Taking into account the manifestation of stress indicators with the predominance of psychological symptomatology and the assignment of some aspects of the experience of living with the patient as contributors toward the self-perception of stress, it may be concluded that caregiving family members present difficulties in providing informal mental health care. This suggests that there may be a lack of supportive strategies in the home environment.

Guided actions toward family care have been a constant issue in the discussions and proposals of services. Nonetheless, strategies that go beyond the presence of the family in meetings and that enable further reflection and new ways of implementing health care should be carried out. Getting to know the family's routines as well as the difficulties and stressors caregiving family members face may provide new ways of understanding how people relate to each other within the family realm. Such action should also question patterns that have already been established and reproduced by families on a daily basis. A deep reflection on the repetitions that lead to stress may positively favor new attitudes in the family's daily environment, as these difficulties can then be coped with from a different standpoint. Intervention strategies that may provide support to family caregivers, meeting thus their needs and proposing a place for reflection and learning, can encourage the emergence of other resources to deal with patients and their mental disorders.

One of the limitations of this study was the realization that examining a single health facility with family caregivers of patients who had potentially different problems and presented different levels of severity may have influenced the degree of stress in this particular group of caregivers. As for the set of instruments used, we consider that they allowed a thorough understanding of the manifestations of stress and the perception of stressing factors in the caregiving process. Further studies using cross-sectional follow-ups must be conducted to deepen the understanding of the caregiving family members of patients suffering from mental disorders with the purpose of contributing to the identification of difficulties experienced by the family members and patients and their potential resources. Such practice would also offer support the development of new strategies directed toward the care of caregivers, which would be reflected directly on the patient care practices.

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