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Emotional stress between informal caregivers of patients in palliative care

Estresse emocional entre cuidadores informais de pacientes em cuidados paliativos

Estrés emocional entre los cuidadores informales de pacientes en cuidados paliativos

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ABSTRACT

Objective: to analyze emotional stress among informal caregivers of patients in palliative care. **Method:** this exploratory, qualitative field study was conducted with 10 informal caregivers from a philanthropic hospital in João Pessoa, Paraíba, Brazil. Data were collected between April and May 2021, through online questionnaire and virtual semi-structured interview, and then submitted to thematic content analysis, after approval by the human research ethics committee. **Results:** the thematic categories obtained were: physical and emotional fatigue in the informal caregiver; care as a form of duty and retribution for affection; care and the need for a social support network and spirituality; and caregivers' difficulties in adapting to palliative care in the hospital. **Final considerations:** care responsibilities must be divided among informal and family caregivers. Also stressed is the importance of the health team's stimulating caregivers spiritually and socially.

Descriptors: Mental Health; Palliative Care; Caregivers; Emotional, Psychological.

RESUMO

Objetivo: analisar o estresse emocional de cuidadores informais de pacientes em Cuidados Paliativos. **Método:** pesquisa de campo, exploratória, com abordagem qualitativa, realizada com 10 cuidadores informais de um hospital filantrópico em João Pessoa, Paraíba, Brasil. Os dados foram coletados entre abril e maio de 2021, mediante questionário *online* e entrevista semiestruturada virtual, e então, submetidos à análise de conteúdo temática, após aprovação do Comitê de Ética em Pesquisa com Seres Humanos. **Resultados:** foram obtidas as categorias temáticas: Cansaço físico e emocional do cuidador informal; Cuidado como forma de dever e retribuição do afeto; O cuidado e a necessidade de rede de apoio social e da espiritualidade; Dificuldades na adaptação do cuidador aos Cuidados Paliativos na instituição hospitalar. **Considerações finais:** é necessária a divisão das responsabilidades do cuidado entre cuidadores informais e outros familiares. Salienta-se a importância da equipe de saúde estimular a dimensão espiritual e social do cuidador.

Descritores: Saúde Mental; Cuidados Paliativos; Cuidadores; Estresse Psicológico.

RESUMEN

Objetivo: analizar el estrés emocional de cuidadores informales de pacientes en Cuidados Paliativos. **Método:** investigación de campo, exploratoria, con enfoque cualitativo, realizada junto a 10 cuidadores informales de un hospital filantrópico en João Pessoa, Paraíba, Brasil. Los datos se recogieron entre abril y mayo de 2021, mediante un cuestionario *online* y una entrevista semiestructurada virtual, y luego se sometieron a un análisis de contenido temático, tras la aprobación del Comité de Ética en Investigación con Seres Humanos. **Resultados:** Se obtuvieron las siguientes categorías temáticas: Fatiga física y emocional del cuidador informal; Cuidado como forma de deber y retribución del afecto; El cuidado y la necesidad de red de apoyo social y espiritualidad; Dificultades de adaptación del cuidador a los Cuidados Paliativos en la institución hospitalaria. **Consideraciones finales:** es necesario repartir las responsabilidades de los cuidados entre los cuidadores informales y otros miembros de la familia. Así mismo, se destaca la importancia de que el equipo de salud estimule la dimensión espiritual y social del cuidador.

Descriptores: Salud Mental; Cuidados Paliativos; Cuidadores; Estrés Psicológico.

INTRODUCTION

Palliative Care (PC) is an active holistic care approach to individuals, in all age groups, who have some health-related ailment due to life-threatening diseases. Its objective is to prevent and alleviate suffering and improve the quality of life of patients with potentially fatal diseases, as well as of their family members and caregivers[1,2] through the performance of an interdisciplinary team with specialized training and emphasis on compassionate communication, family care and knowledge in management of the symptoms[3].

In view of the broad approach to the aspects inherent to the patient, informal caregivers are included in this palliative care network, considered a fundamental element in this process[4]. This figure of the informal caregiver is characterized by the preexisting bond with the person cared for[5], and presents two essential aspects, such as not having any paid employment relationship or specific training in the area of care provision[6]. In addition to that, it is common for a single person and in a self-attributed manner to assume this role[7].

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Becoming a caregiver can be a slow or abrupt process, starting from the diagnosis of a given disease, whose treatment and evolution trigger a dependence condition[8]. The demand for care responsibilities evidences the accentuated burden on informal caregivers, expressed by the stress signs involved in situations of change and adaptation to the routine and deprivation of freedom and leisure, in addition to performing care measures without techniques, knowledge or guidance[9].

Among the new experiences for caregivers, often previously unknown to them, are drug administration, bed hygiene, food preparation, and handling of drains, tubes and dressings; in addition to dealing with progression of the symptoms and with the possibility of imminent death of the family member[10].

Some psychosomatic disorders are related to emotional stress, characterized by symptoms such as mental fatigue, low concentration, impaired memory, apathy and emotional indifference, which are also common in anxiety or depression conditions, and health professionals should be aware of emotional changes in the caregiver[11].

Regarding these aspects, a number of national and international studies show that these caregivers become more vulnerable to stressful events due to the interaction and activities required by their role, mainly in relation to chronic patients[11-15], which makes it necessary to investigate the occurrence of emotional stress in informal caregivers in the context of PC.

In addition to that, a number of studies on the topic may contribute to the planning and implementation of prevention, self-care and identification strategies corresponding to the phenomenon, resulting in beneficial effects on quality of life and prevention of potential mental illness in this group. Thus, this research was carried out, with the following guiding question: Which are the factors associated with the occurrence of emotional stress in informal caregivers of patients in Palliative Care?

To answer the question, the research aimed at analyzing emotional stress in informal caregivers of patients in PC; as well as at identifying factors related to emotional stress in informal caregivers of patients in PC.

METHOD

A field and exploratory research with a qualitative approach was conducted, in which the Consolidated Criteria for Reporting Qualitative Research (COREQ)[16] were considered. Data collection took place in a virtual environment with informal caregivers from the Palliative Care Units of a philanthropic hospital located in João Pessoa, Paraíba, Brazil, from April to May 2021.

Informal caregivers of patients in PC who met the following criteria were included in the study: age between 18 and 65 years old; no remuneration; having cared for the patient during a period of at least six months; and having a digital device with an available Internet network. Caregivers who were in the study locus only for care shift exchanges and who expressed difficulty using the digital device were excluded from the study.

In the first stage, an online questionnaire was applied using a form in the Google Forms® platform to obtain the participants' sociodemographic data.

The second stage corresponded to a semi-structured interview conducted through an audiovisual call app, in order to analyze emotional stress in the informal caregiver based on the following subjective questions: How do you feel performing the care actions with the patient? Do you think that you are able to do most of the things you need to do? How do you get organized and make plans for the future? Do you feel that what you do for the patient is enough? What difficulties do you face in this care relationship? Do you feel overloaded due to the care provided to the patient? Do you think that your own health is being impaired? If so, what do you do to improve it? Would you like to find a way out of this situation? Do you feel valued by the patient's family members? How would you feel if another person shared the care with you?

The candidates were approached in person by means of a visit to the locus for the researcher to introduce herself and the Free and Informed Consent Form (FICF). After this moment, appointment of the day and time available by the caregiver for virtual collection was carried out, which lasted a maximum of 30 minutes, as well as the recommendation of using an appropriate and private place to conduct the study. The interview audios were recorded and later transcribed in full.

A total of 15 participants were approached; however, five of them were not included in the sample due to refusal. Consequently, the sample size was defined at ten informal caregivers of patients hospitalized in the study locus. A non-probabilistic convenience sample was used, in which the most accessible members of the population were selected, seeking quality of the actions and interactions throughout the process[17].

The data were analyzed grounded on the thematic content analysis methodology, based on the following phases: pre-analysis, coding, categorization and inference[18]. In the pre-analysis phase, the previously transcribed empirical data were subjected to floating reading, with systematization of the initial ideas. Coding of these data was performed through aggregation of the registration units into cores, followed by the categorization phase. Finally, analysis and discussion of these categories were performed in the inference phase.

The study was approved by the Committee of Ethics in Research with Human Beings, in accordance with the precepts set forth in the General Law for the Protection of Personal Data (*Lei Geral de Proteção de Dados Pessoais*, LGPD) No. 13,709/18[19] and with measures of protection, safety and guarantee of the participants' rights in a virtual environment[20]. Once the FICF was signed by all participants, and in order to guarantee their anonymity, names of butterfly species were used referring to the symbology of Palliative Care, as follows: *Ascia monuste (B1), Caligo (B2), Danaus (B3), Dryas julia (B4), Hamadryas (B5), Methona (B6), Morpho (B7), Panacea prola (B8), Phoebis (B9)* and *Siproeta stelenes (B10).*

RESULTS AND DISCUSSION

Of the research participants, most were female, a factor socially recognized as a historical construction of the female figure intrinsic to the care practices, as also observed in some studies[3,21], and the age group varied between 18 and 55 years old. Most of them were single, married or divorced: 30% each. Eight had children (80%), seven (70%) self-declared as brown-skinned and six (60%) had completed High School. In relation to their personal clinical history, the main finding was presence of musculoskeletal disorders (33.3%), anxiety (27.8%) and sleep disorders (11.1%).

Six (60%) participants reported not having any employment contract, being susceptible to losing their autonomy, contracting debts, and even losing their social support[22]. Their occupations were varied, with two (20%) farmers among the participants. Kinship between the caregivers and the patients was mostly characterized as children (30%) and grandchildren (30%). None of them received remuneration for the care provided; in six of them (60%) there was predominance of between six months and one year of care time, while the others were distributed over a variable period of over a year.

Four thematic categories were identified from data analysis, namely: Physical and emotional wear out in the informal caregiver; Care as a form of duty and affective retribution; Care and the need of a social support network and spirituality; Difficulties in the caregiver's adaptation to Palliative Care in the hospital institution.

Physical and emotional wear out in the informal caregiver

From the participants' statements, physical and emotional signs and symptoms were verified, such as problems related to sleep and rest, diet, signs of impaired immune system, anxiety, emotional exhaustion, desire to escape and irritability as factors related to physical and emotional wear out, characterized by the high demand in relation to the daily care routine, mentioned in the following excerpts:

> *[...] I don't sleep at night because he (stepfather) has prostate cancer so he pees every ten minutes, this leaves the body very tired [...] the impression it gives is that I'm sick, but it's just being tired from not sleeping well. (B2)*
>
> *I feel very overloaded, you see?… I spend eigth full days there (hospital), then I come home and spend only two or three days here. (B3)*
>
> *It's a difficult situation, I know that it's a hard situation that he (father) is going through, and it gets a little tiresome due to the work-related stress and everything else. (B5)*
>
> *My emotional health has certainly been harmed, I feel more nervous, with itching on the skin, every now and then I get somewhat cold, nervous… (B6)*
>
> *[...] I started to feel insomnia, on the days in the hospital too, there comes a certain time when I'm so exhausted that sometimes I feel like running out of the hospital [...] The feeling I have is that I'm going to have an anxiety crisis, [...] this wear out is really affecting me, I feel that my immunity is dropping, because sores start to appear in my mouth [...] (B7)*
>
> *I certainly feel physically impaired, for not being able to eat properly, without sleeping, and also emotionally, for stopping my life, right…? (B8)*

In the study, it was verified that emotional stress is related to burden, presenting itself as a risk factor for emotional distress[23]. The statements also evidenced that the caregivers show that they are distressed when they notice that the patient in PC does not present significant improvements. However, when the caregiver perceives the process of alleviating the patient's suffering due to symptom control, this process of multidimensional suffering becomes less painful for both[21]:

> *I really wanted to do something for him to grow, to improve, but he's paralyzed, stuck in time… (B4)*

> *I doubt if what I do for him is enough because he doesn't speak, I wanted him to speak, so that I knew what I'm doing, right? (B6)*
>
> *[...] Her suffering is so big that it's no use telling her that she can't eat or drink water but, at the same time, I can't control my despair distress either. [...] it's distress for her and distress for me too. (B7)*
>
> *My biggest difficulty is seeing her in that situation [...]. (B9)*
>
> *[...] It's no use just wanting her to live, she also needs to want to live [...]-when we're talking she says "I'm gonna be fine, you see?, let's go home later on". I share her same thought, of wanting to live, seeing her hopeful also gives me hope. (B10)*

Thus, it is possible to analyze that the feelings experienced by the patient are directly linked to those of the caregivers, allowing for an intense, interpersonal and affective connection among those involved, showing that they are active in the caregiver's emotional oscillation process in the context of PC, mediated by the feelings of the person cared for, both positive and negative.

Care as a form of duty and affective retribution

When asked about the feeling they have when providing care to their family member in PC, despite the physical and emotional wear out, nine of them expressed themselves in a positive way. Family caregivers share affections, feelings of trust, comfort and meeting the other's needs, who express feelings of personal satisfaction and gratitude for assuming the caregiver role with care focused on the sick family member receiving it with a feeling of devotion, love and affection[12,24-26]. In this context, it was possible to highlight the following excerpts:

> *I feel good taking care of him, because I'm very fond of him. [...] all my life I owe first to God and then to him, he was the one who raised me, he educated me, and today I am who I am thanks to him, so I do my part. (B1)*
>
> *I try to give my best, right?, because he needs me to take care of him, right?, I try to be there giving my best. (B3)*
>
> *I feel very good taking care of him, I'm doing good to my fellow, I'd do it for any human being in such need. (B4)*
>
> *It's good because he's my father, right?, the sooner he gets out of this, the better. (B5)*
>
> *I feel good taking care of him, because he's my blood, part of my family [...] I feel pleasure taking care of him. If I could make him get better, I would. (B6)*
>
> *I feel as if I'm doing my part, that I'm giving the love my grandmother needs right now, the care she needs, I'm by her side at the most difficult moment in her life. (B7)*
>
> *In the future, I imagine myself taking care of him, with him living in my house. Me struggling to take care of him and also pursue my own future. (B8)*
>
> *[...] He's my father, right?, I have to do this for him. I don't like being in the hospital, it's just that I have a duty to go and I go, isn't it so? [...] then I have to take care of him and that's what I'm doing. (B9)*
>
> *I feel good, it's the care we need to offer our parents. It's the children's duty to take care of their parents. It's tiring, but it's for my mother [...] if I don't take care of my mother, who will? She gave me life, if I were the one who was sick, she'd do the same, she'd be by my side. (B10)*

Care is usually defined by relationships of affection and commitment that unite the family member, friends or neighbors to the dependent person, calling them informal caregivers[24]. Although the care practice involves feelings of satisfaction, personal fulfillment and pride, it is possible to notice the presence of emotional wear out, stress and even health problems as a result of this service in a hospital environment and even in the context of PC[8].

It is important to emphasize that this compatibility becomes fearful for the caregivers regarding the risk of neglecting their own health in order to dedicate themselves only to the patient. Such issues may affect their emotional dimensions, in addition to generating changes and deprivations of personal lifestyle activities to include the needs of their sick family member[27].

Care and the need of a social support network and spirituality

In this category, it was possible to analyze the positive effects that social support and spirituality can add in improving the well-being of the main caregivers through a palliative approach, showing that it is necessary to take care of other family members[22], as well as stimulate the caregiver's spiritual dimension, in order to alleviate the emotional stress caused and allow them to go through this process in a less painful way, providing comfort and better acceptance[28]. Revealing through the statements feelings of abandonment, burden and emotional wear out, in addition to highlighting the physical affections that limit them:

> *[...] I'd feel valued if the other family members helped, visited him, saw what we need, if everything is OK, if there's anything missing, and they don't ask about that. It would ease a little [burden and care] for me and my mother. (B1)*
>
> *[...] Nobody says "go home and rest, I'll stay here with so-and-so, for at least three days here for you" nobody says that… I'd feel better if I got any help, I wouldn't be so overloaded. (B3)*
>
> *[...] It's very difficult to be stuck here inside the hospital all the time, not having someone to switch with. [...] if I had someone else to share with me, it would be much better, to solve my life problems, to relax a little [...] because here in the hospital, it's not easy... (B4)*
>
> *It would be better for me if I had someone who could share it with me, I'd share a weight with someone else, I feel a little suffocated. (B6)*
>
> *I needed to set my personal life and my own duties aside at that moment. I need someone to come and say: listen, I'm here with you, everything's going to be fine, I'm going to help you, stay home, have a little rest… (B7)*
>
> *[...] I think that the family should be more available to help, spend a few days here so I could go home, take turns… and not throw everything [care responsibility] on me. Then I'd feel a little less overloaded. (B8)*

In addition to emphasizing social support, the caregivers also cited faith as a comfort support that gives meaning to the care provided, in which meaning is sought in life, through a personal, collective and divine relationship[29], behaving as a method to cope with their distress[30]:

> *It is God who will give me even more strength to take care of my child, whether he's getting out of bed or not… I need to have a lot of faith and a lot of love in my heart. (B3)*
>
> *The medication is there, but there are some things that only God can do. (B5)*
>
> *I have faith in God that my mom is going to recover. (B10)*

It is also added that the possibility of spaces for dialog about God and spirituality and prayer establishes a feeling of peace, health, happiness and protection, in addition to offering understanding and coherence in disease and death situations[31-34].

Difficulties in the caregiver's adaptation to Palliative Care in the hospital institution

Social isolation, lack of socialization with other people and absence of activities not linked to care favor the emergence of depressive symptoms among caregivers[35]. Consequently, it is necessary to emphasize the caregivers' institutionalization, regarding their insertion in the routine of the family member in PC. These approaches are described in the following reports:

> *It's not easy to sleep in an armchair, spending several days and nights like that, it's not easy. To improve this situation only when he comes home, right? (B1)*
>
> *[...] I don't eat well [...] I sometimes fall asleep without having dinner, because I haven't adapted yet. It's not very comfortable to sleep in a chair [...] I'd really love to bring him home, because at home I'd be taking care both of him and of myself. (B3)*
>
> *The emotions get all messed up, it's not even about taking care of him here or at home, it's about being inside a hospital [...] Here you see many situations with other patients, and you can't do anything… (B4)*
>
> *[...] Although the hospital wants to offer us maximum comfort, the chair is still really uncomfortable. [...] Staying 24 hours there in the hospital, a time comes that you are already stressed, irritated, with the lights, with everything (B7)*
>
> *I feel a little sad for being in a hospital. (B9)*

It is also possible to notice the reinforcement of the home care premises in PCs, commonly indicated to meet the needs of people with chronic and dependent diseases[36], requiring family reorganization to enable the inclusion of other relatives in this process[37], as a possibility to alleviate these problems for the caregiver, making some of their activities more flexible. In addition to that, it contributes to the caregiver's socialization, which allows for the development of a diversity of roles, change and balance of power, conjunction of views and physical contact, as well as mutual respect[38].

The research provides a scientific contribution to Health and Nursing professionals, influencing the planning and implementation of prevention strategies for emotional stress, inserting the caregiver in the active practice of Palliative

Care, as well as for the development of coping measures, through practices with a palliative approach based on scientific evidence that, especially in the Nursing context, include the stages of the Systematization of Nursing Care.

There are also limitations regarding the current pandemic scenario, referring to the restrictive measures and online data collection, due to Internet unavailability and lack of skills with digital resources in the participants.

FINAL CONSIDERATIONS

The study allowed analyzing emotional stress in informal caregivers of patients in PC in the hospital environment, based on aspects related to physical and emotional wear out, affective care, the need for a social support network and spirituality and adaptation to institutional PC.

From this perspective, the need for caregivers to understand their social role was noticed, as well as to seek ways to strengthen their self-care and encourage their sources of coping, either for social aspects, through family member turnovers in order to segment the responsibilities with the sick family member's needs, or by spiritual aspects. For this, it is indispensable that the team knows the caregivers' spiritual beliefs, promotes spaces for dialog with effective communication between the team, caregivers and patients, as these conditions ease the PC process.

The scarcity of studies focused on the theme reveals the need for more research studies aimed at informal caregivers of patients in PC and that investigate the finitude of life, seeking to expand care multidimensionality. Therefore, this research enables a contribution not only for professionals, but also for health institutions and family members.

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