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THE EMOTIONAL BURDEN OF FAMILY MEMBERS OF CANCER PATIENTS: AMBIGUITY OF FEELINGS IN THE MOMENT OF CARE

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ABSTRACT
The objective of the study was to understanding the emotional aspects related to the care of a relative with cancer. This is a descriptive research of a qualitative approach, whose data were obtained together with ten family caregivers of cancer patients, assisted by a support network for cancer patients, in the northwest region of Paraná State, from September to December 2011. Through thematic discourse analysis three categories emerged: Suffering before the cruel journey: from illness to the impossibility of cure; Feeling prisoners of caregiving: the dedication to frustration; and Masking pain when offering a genuine care, which highlight the mixture of feelings experienced by caregivers. It was concluded that caring for an individual goes beyond his expression. It demands full time dedication, which most of the times imposes the abdication of their plans and desires in favor of the other.

Keywords: Family. Caregivers. Cancer. Psychological stress. Nursing.

INTRODUCTION

Caring can be understood as a science that pushes the boundaries of health services as a whole and is exercised throughout history empirically by people of diverse cultures that have applied their knowledge both within the family group and the community(1). Nevertheless, it can be configured in a gift, surrounded by bond and commitment and that allows to dedicate themselves fully to a being that is somehow significant to them(2).

In the context of care, highlight the role of the caregiver, indispensable figure when it comes to chronic diseases, degenerative, and can change with limitations in carrying out daily activities(3). Commonly, who takes that role is a family able to assist you not only in its physical health needs but also to provide affection, attention and emotional support(4).

So, in the face of care needs, is elected in the patient's family those individuals who are references in aid of daily necessities, to the accompaniment during treatment and in discussions about the disease, and often only one person in charge of providing all necessary care to the patient. Usually the family that takes care resides in the same home or the patient then goes to live with him due to the disease. This closest approach strategy for facilitating care may result in high levels of burden on the caregiver(3).

It is noteworthy that, caring for a sick person at home influences and transforms the entire system and family behavior, thus modifying these relationships, alternating roles and imposing other daily difficulties to deal with the disease(1,5). Falling ill with cancer, in particular, takes patients and families to face major conflicts, to support the loved one in this difficult time and accept cancer in their

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family environment.

So, the family caregiver, to exercise an informal role of home care to the patient with cancer, lives with difficulties imposed by his new role in the home, being evidenced the unpreparedness for the care, insecurity for its execution and personal requirements for a good care, which are reflected in the physical, emotional overload and often financial one who takes this burden(6,7).

The physical wear is mainly due to the fact that, when caring for a dependent patient, the individual becomes increasingly responsible for meeting their needs as hygiene, nutrition and comfort, making their daily delivery to other(8). In addition, the daily routine of chores in the home care includes medications with side effects, patient transportation for therapies, preparation of meals and supplies, and the coping emotionally difficult moments throughout the process(9).

In this sense, the quality of life of family caregivers suffer repercussions in different areas of your life, and the psychological sphere, often home to the greatest burdens faced by these individuals(10). The emotional stress causes situations that resonate throughout the life of the caregiver, such as decreased social life, stress, loss of self-esteem, sadness and loneliness, incorporated into the reality of having a loved one sick, and the possibility of his death(8).

Given the above, the emotional aspects experienced by caregivers requires a careful look with attention and respect, as this could impact substantially on their own health and reduce their ability to provide care to their relatives(10). The assistance to home caregivers is critical and should be mandatory in health services, especially by nursing staff, so that, given the difficulties posed by cancer, the family can be informed and prepared to offer the best to the patient(1). Moreover, knowing the feelings of those who experience the daily care to the patient with cancer is critical so that strategies of support and cooperation with the family can be implemented in care as a whole.

Therefore, this study aimed to grasp the emotional aspects related to the care of a relative with cancer.

METHODOLOGY

This is a qualitative study based in the qualitative analysis, since it enables understanding of social relations between particular groups, as well as taking into account the subjectivity of each individual(11). Thus, qualitative research allows the unveiling of meanings, beliefs, values, attitudes and aspirations, based on subjective situations where it is impossible to quantify(10).

The study was conducted in a philanthropic nonprofit institution, located in Paraná Northwest, serving patients with cancer at any age, without proven financial conditions, residents in the municipalities belonging to the 15th Regional State Health Department.

The research subjects were listed according to the following inclusion criteria: being the main caregiver of the patient with cancer for more than six months, which is registered and accompanied by the above mentioned institution, and resident in the host city of this service. Family members were excluded not found at home by change of address. The inclusion of new participants was stopped when the information became repetitive and the objective was achieved, which amounted to ten caregivers.

To obtain the speech of the family, it was employed the following question: **Tell us how do you feel emotionally to care for (name of the relative)?** From September to December 2011 interviews were conducted, which they conducted after previous contact with the family and scheduled the best time to visit his home. The speeches were recorded with the aid of a digital recorder and transcribed in full.

The discourse analysis was guided by the steps recommended by Minayo(11) for qualitative analysis, consisting in: pre-analysis, material exploration and treatment of results, inference and interpretation. The discussion of the categories found went against the current and relevant to the subject literature.

It is clarified that this study is part of a greater range of research entitled "Overload of the family of cancer patients treated at primary health care in the city of Maringa-Paraná", funded by the Araucaria Foundation. The ethical aspects were recommended in its entirety by following the resolution 196/96, in force in the data collection period and following the same prerogatives reinforced by Resolution 466/12, with approval by the Ethics Committee of the State University of Maringa under Opinion 423/2010. The call for participation was made personally, and the accepted materialized from signing the Informed Consent and Informed presented in two ways. Anonymity is preserved through the use of identification codes (S1, S2, S3... S10).

RESULTS AND DISCUSSION

Through the exploration and analysis of the speeches of the deponents interviewed three categories emerged, which will be as follows:

Suffering at the cruel journey: from the illness to the impossibility of cure

In his daily life, man faces joys and sorrows as part of the process of living in the world, but always bringing in the depths of his being the consciousness that the sick is part of human evolution. However, upon learning that a malignancy settled in a loved one, the family suffers an impact and is emotionally vulnerable, being invaded by feelings such as fear, sadness and anguish that leads to experience significant emotional burden and leads this family a need for reorganization with redefinition of roles and tasks in order to respond to this new reality(12,18).

The diagnosis of cancer arises unexpectedly, carrying with it a series of overwhelming feelings, affecting and causing changes across the nuclear family, so it is also recognized by family illness(19). Although the development of technologies for the treatment and control of disease, it is continually advancing to increase the chances of good prognosis, cancer still remains surrounded by myths and fears(13).

To be surprised by the confirmation of the disease, caregivers are significantly affected against the unimaginable, generating intense emotional disorder characterized by shock and despair present in the reports. Suddenly the life of a loved one is invaded by cancer and their families experience the pain of having him seriously ill.

> At the time of diagnosis, it was I who went to fetch the result of the biopsy, was that shock, that desperation (S5).

> Look, for me it was not easy, because from the moment I knew that my mother had cancer that for me was once a thud, [...] so I'm sure that God was the one who gave us so much strength to bear so much suffering, so much passage of unpleasant things. After all, who he gave that shock; everything was fine, everything was normal was that I felt down that then I wanted to fall into depression (S4).

In S4 language, it appears that when cancer enters a household produces feelings of pain and suffering, sometimes difficult to understand. Size is suffering against the unthinkable and emotional distress for monitoring the entire trajectory of the disease, taking care of the patient, the caregiver may have committed itself to health. The progressive accumulation of stressful events during this process eventually takes you to the limit of your balance, resulting in severe consequences to their mental health.

Thus, it is clear that the emotional state of the caregiver is achieved greatly, that when experiencing deep sadness may fall prey to psychological disorders like depression. Often, the family realizes that care is subject to develop illnesses that may be related to the function of the charges attributed to him(3). Moreover, with the onset of disease process, caregivers have experience front concerns the possibility of future difficulties arise in the course of this journey(12), as shown in the following speech:

> Look to tell you the truth, right now I'm starting to prepare myself to take care of it, because prepared, I am not prepared yet, but I'm willing to take care of it as far as he needs me, but there are times that I think it will be difficult because now even he did not operate anything and will operate, I think it will be difficult both for me and for him, because he gets nervous, he's nervous, it's like ... (S6).

In speaking of S6 caregiver, it is evident that your overhead makes glimpse the vicissitudes to come to meet him in the path of possible cure for cancer. Still, despite feeling unsafe to perform this function, it conveys a willingness to be with his family knowing that difficult times will occur.

The trajectory of cancer is permeated by stressful events and numerous challenges, which change completely the family dynamics, especially in regard to treatment, since it requires everyone involved to adapt to new needs, weakening them not only through the fear and insecurity about the future(12), but also by the feeling unprepared to play the role of caregiver(3).

Nevertheless, even greater challenge surrounding the care of a family member with cancer, without possibility of cure, setting up a hard and thankless task that can lead to emotional exhaustion(17). In this sense, the environment of care is a progressive experience of finitude, which creates enormous anxiety in the caregiver, starting to set up the existential context as an overload of living(14).

The caregiver S3 demonstrates in his speech that, witness the experiences of a sick family member, disillusioned and waiting for a miracle, it is extremely painful because you feel threatened at any time, not have it around anymore. Realizing himself unable at the merciless fate imposed by the disease, feels deprived of plan for the future alongside fellow.

> It was difficult. It's hard, you live with the person who knows ... It's not easy not, but have to touch the boat and have to do their best, battle, not dropping the ball, especially near him. [...] I think it's a mixture of feelings, at the same time you can be happy, can be sad because it's a lot of suffering. You know it's a thing that hardly turning back, only a miracle of God, then you are well known, no ... You know an hour or later ... [...] but if you put it in the head, I cannot stand not. So we live day to day, there's no use dwelling on the future and not the past, have to live the day for you to live, but not lives, not to put you on the head is crazy, but with the strength of God, we go, go touching the boat (S3).

The close care of the daily caregiver's relationship with the sick relative, enabling also to recognize positive aspects involving the care, reviving the sense of unity, compassion and solidarity on the part of caregivers and opening them the opportunity of a closer coexistence and intense with your loved one(6). So even experiencing such suffering the incurable disease of his family, we realize that the caregiver strives to live together in the best possible way, each remaining time, celebrating each new dawn as if it were unique. Each day lived to the partner side is another battle won, though war is never won.

Feeling prisoners of care: from the dedication to frustration

Choosing a caregiver is not always based on the legitimate desire for cooperation with the patient. This charge ends up being imposed by adversity occurred in the family context(3). A study that also gave focus to cancer patients of caregivers shows that the determining factor in choosing who will offer care "is loaded with values, beliefs, family histories and forms of bonds that were built over the life of these protagonists (patient and caregiver)"(4:58).

From this perspective, the need to comply with the ethical principles imposed by society brings up care only by an unconscious appreciation of itself, setting up a preservation of reputation within the family or society(14). Thus began a waiver process personal life by the caregiver who has their daily lives and their feelings severely affected, since ultimately assume a routine geared to the needs and demands triggered by continued family disease, which ultimately generate high levels of stress that person who performs care(3).

> Yeah, I had home, a husband for me to look after three children [...] My father was very nervous, had to take his side too... (S4).

> Have to take care, what will you do? There are times when anger passes, there are times that it's all good, there are times that it is that way, and we keep going, because my mother is very stubborn, huh. My mother; whenever something is because she wants is for real. Today she washed dishes, but there are days when she does not wash, there are days when she does nothing. Thankfully, now she changes her diaper, I was two years changing the diaper of her and my brother, the two, now she exchanges alone diaper ... (S8).

The statements portray an intense routine care, where the caregiver meets not only the patient and other family members who are close. With denotations to weigh in every action performed by the speaker, you can see that common tasks in a residence become one overweight before the multitude of tasks that the caregiver has to perform. It is noticeable also the physical exhaustion of S8, which should be responsible for her mother's care, carries the burden of a single focus of his life in the tread of the needs of their families.

The physical and mental stress, commonly presented by family caregivers, is directly related to the degree of patient dependency, that is, the more dependent the patient, the more likely the caregiver develop symptoms such as physical exhaustion, sadness, stress and low self-estimates(3). This thinking reinforces from the speech S1:

> I do my best to feel with courage, with ease. Sometimes you lose a little patience, but do our best to take care better. It has moments that falls a little, then there are times when you feel very sad. The most difficult, for example, now is take him to the bathroom, take a bath, feed, sometimes he did not want to eat, has to do what he wants; these things are the most difficult (S1).

The feeling of frustration during care is entangled in lines when they relate to the physical and emotional limits that individuals face when dealing with family members. The absence of positive results end up compromising the relationship with the patient, as evidenced from the perception of not valuing work and dedication dispensed. However, while the caregivers demonstrate the exhausting of their strength, value the care they are able to provide at this time, attempting to illustrate that this was the best they could do for someone.

In addition to physical and emotional exhaustion, the caregiver faces the difficult environment to see that the emotional involvement he had before the patient was harmed(15). In this context, play the role of caregiver for a loved one who suffers from a serious illness ceases to be configured in one of the biggest challenges facing the duty to give up own desires for the sake of other's needs(3). It is noteworthy that, while remaining the sexual desire of the couple on the occasion of physical, psychological or by adverse effects from cancer treatment, the act of expression itself may be unable(16), as shown S2:

> It's good to see him, I'm happy. Now I will tell you the truth, anything better I have nothing, you know. So we are not happy, that part not do what! Sick, you cannot, have to settle (S2).

In the story above, while the deponent demonstrates satisfaction with her husband's improvement, feels unhappy with the expense of the physical relationship after the diagnosis of prostate cancer, responsible for the deprivation of the couple's sexual activity. Caregivers consider the disease as an obstacle in the relationship, which causes removal, reduction of affection and touch, making the restricted relation to care(4).

The weakening of family ties can still create a barrier that prevents them from continuing their projects or even that it maintains social relationships and pleasurable activities that had previously(14). Some family members feel uncomfortable while performing leisure activities, setting aside their own needs to emphasize the care provided. The time spent with the patient does not allow sometimes that activities that offer you contentment are given due importance.

> [...] I like to travel to Brasilia, have my relatives there. To Curitiba, São Paulo, I have two children in Sao Paulo. They call "Come here mom!" I will not, because I cannot leave him. [...] Forward Eriquema live my brothers, my brother, my sister-in-law, and my nephews live all there, and I cannot, I'm afraid to go out, because at the same time it is good, it no longer is. That was what the cancer hospital doctor said... (S10).

The speech S10 meets recent studies showing that the family caregiver role brings significant changes in the daily lives of those who care, especially with regard to the reduction or even the cancellation of the performance of pleasurable activities, since the family ill need care full time, which can increase caregiver burden that has the feeling of no longer be free to live their lives(1,6).

Leisure strategies that could be used to minimize the pain and suffering experienced by the family after diagnosis, become yet another reminder of how the daily lives of these individuals was before the disease. Be next to the patient, given the uncertainty of their future, permeates a process of partial caring for the family with the patient, in which the individual surrenders to the mission of caring holistically, but reserve part of their thoughts against the desire to revive the once that it was precious.

Masking the pain when offering a genuine care

The malignancy when entering in family life predisposes to different reactions, which often express the manner in which family members are facing such a situation. The feelings aroused by the act of caring for a family member with cancer are mostly negative, and expressed as sadness, anxiety, compulsion, deprivation, physical fatigue and feelings of inadequacy.

However, in the following reports, it appears that despite the demands that care prints and feelings of pain, anguish and fatigue caused by this experience, the caregivers feel able to realize it and satisfied with the results, even aware of the limitations imposed by the disease. As such, they can overcome their own restrictions with perseverance and optimism, to be close to their loved ones at this moment of their lives.

> Oh, I took care of it with great pleasure, but with the heart hurt, hurt the heart [...], did everything with great pleasure [...] we tired, but the will was so great, that we I did not feel [...] but I was too hard on my husband, my children, my grandchildren (S7).

> It is a feeling of love and affection for him. What I feel is that inside me, take care with love, do everything I can do, how long God willing I do for him. [...] But I think the best, I believe in good, I think he recovers this problem; resist the treatment [...] So I'm trusting. Go with him everywhere when he goes, I follow. I think everything will be fine. I hope (S9).

In addition to the satisfaction of caring for sick family, the feeling of hope reflects favorably on the wear and overload faced by dedicate fully to patient needs, minimizing them.

It is clear, yet the sense of emotional comfort that is revealed in the speech of S7 because when supported by other family members feel that their suffering has been alleviated, providing him strength and security to improve coping with the disease situation her daughter. It is noteworthy that the lack of support from friends and family in the care to the patient with cancer reduces coping ability in difficult times of the disease process(3). Thus, the family sets up an important social support, that by offering some kind of aid triggers positive effects on the caregiver, minimizing the emotional overload that experiences(17).

Once the family support is a protective factor in the emotional overload, spirituality comes with the same purpose in their lives, making them feel emotionally comforting when caring for a family member with cancer. Faith serves as a comfort mechanism that strengthens the caregiver in the performance of their duties and, of overcoming suffering to accompany the loved one pain, seeing his improvement(17).

> But, as we have a lot of faith in God, in Our Lady, He protects us always felt that strength came from within, it seems that nothing is happening [...] (S7).

> Thus, a soft feeling, but I trusted in God; that God would put his hand, and would be all right and he had surgery and was fine. I was really agonized one day, because at risk, but thank God everything was ok. It did not have any problem, passed. I'm not afraid, I have is confidence. I'm ready, what God wants to happen happens, and then I am prepared to receive of His hands whatever comes [...] (S9).

The speeches show that the fact that they have significant attachment to religion and faith makes both boldly coping anxieties and uncertainties that sooner or later inevitably are forced to live. Believe in divine protection reinforces them hope and confidence in a better future. Religiosity is part of the spiritual development of each individual, because it helps you understand another's pain, to feel compassion and overcome difficult experiences without giving in to grief(8).

In this context, the caregiver faces the obstacles experienced during this journey, though more lightly, concerned to maintain the overall well-being of the patient. And in an attempt to save the greatest wear, the one providing the care seeks to demonstrate to the patient, feelings that are commonly raised when cancer is present, trying to convey to you confidence. This attempt to protect the patient raises concern that too much can cause the caregiver to experience intense overload(1), since this feels a duty to hide their desires and anxieties believing that these events may cause some discomfort to the patient(7,8).

In speech S5, it is clear that although she, along with other family members, to experience some tension before the obligations not to expose their fears, reassure and not "neglect" of treatment, for her to be next to a loved one disease situation, light up the courage to confront him with this situation, since it is strengthened by the power that emanates from the patient herself, manifesting, thus developing a sense of reciprocity to take care of, what comes to soften the challenging presence of cancer.

> Now it's quiet, my mother is very strong, so she spends a lot of confidence to us. [...] But it is like, we will not show it, let's move on trust. After the treatment was doing and we were getting more confident too, saw that she was okay and she herself is quite strong as I've said, then we do not get that concern the whole time. Of course, we try not to neglect, watch to see if she takes the right medicine, tries to keep her nerve pass, things like that, but it's quiet. Now it is very calm, we know she's right, then we are well too (S5).

Despite the emotional burden experienced by the family, you can see an intertwining of affection, in which the externalization of strength and perseverance are mutual, keeping them confident in fighting the disease. This front behavior treating the disease has an impact on the welfare of those involved, is creating in this way a reflection of the emotional state of the patient as a mirror for family. When this journey is started in a positive way, the difficulties are more easily overcome, not leaving feelings that compromise the interaction of the actors in this context. This is the manifestation of genuine care, particularly aimed at the good of others.

FINAL NOTES

With this study, it appears that the cancer experience within the family raises feelings never faced in their lives, causing significant physical and mental exhaustion, which pierces the whole treatment, to not changing and totally unpredictable reality caused by healing impossibility. To experience this unknown path, patient and family go through an emotional storm, marked by anguish, sadness, fear, uncertainty and apprehension, all expressed in its absolute form during the interviews.

Caring for an individual goes beyond its expression, requiring an unparalleled dedication, which often requires the abdication of your own plans and desires for the next. So two lives become one, as patient and caregiver experience similar mishaps that, when taxes to the individual, can bring a sense of deprivation of personal life, frustration, lack of time to carry out pleasurable activities, impatience and lack of bonding with other people of your social life, especially extolling the workload experienced at this time.

However, evidence of an ambiguity of feelings, when caregivers are shown endowed with compassion and solidarity in dealing with others. In this sense, offer an attentive care can be a way to mask the wear from the disease and care process. The comfort, from the faith in a higher being, family support, or even the patient itself, which conveys hope and strength, assists caregivers in coping with the situation. Making care a feeling of virtue for themselves is the great triumph of these subjects.

Given these considerations, it reinforces the need for professional nurse know all the feelings that emerge from care experience, as this is the action inherent in their craft. Only by knowing the mishaps of this journey, nurses will be able to mobilize in favor of all the shortcomings experienced by caregivers, becoming so a safe haven across its mandate.

SOBRECARGA EMOCIONAL DOS FAMILIARES DE PACIENTES COM CÂNCER: AMBIGUIDADE DE SENTIMENTOS AO CUIDAR

RESUMO

O objetivo do estudo foi apreender os aspectos emocionais relacionados ao cuidado de um familiar com câncer. Trata-se de uma pesquisa descritiva de abordagem qualitativa, cujos dados foram obtidos junto a dez familiares responsáveis pelo cuidado de pacientes com câncer, assistidos por uma rede de apoio a pacientes oncológicos, da região noroeste do Estado do Paraná, no período de setembro a dezembro de 2011. Através da análise temática dos discursos emergiram três categorias: Sofrendo ante a cruel jornada: do adoecimento a impossibilidade de cura; Sentindo-se prisioneiros do cuidado: da dedicação à frustração e Mascarando a dor ao ofertar um cuidado genuíno, os quais ressaltam o misto de sentimentos vivenciados pelos cuidadores. Conclui-se que cuidar de um indivíduo vai muito além de sua expressão, exigindo dedicação ímpar, que muitas vezes impõe a abdicação de seus próprios planos e desejos em favor do próximo.

Palavras-chave: Família. Cuidadores. Câncer. Estresse psicológico. Enfermagem.

SOBRECARGA EMOCIONAL DE LOS FAMILIARES DE PACIENTES CON CÁNCER: LA AMBIGÜEDAD DE LOS SENTIMIENTOS EN EL CUIDADO

RESUMEN

El propósito del estudio fue entender los aspectos emocionales relacionados con el cuidado de un familiar con cáncer. Se trata de una investigación descriptiva con un enfoque cualitativo, cuyos datos se obtuvieron a partir de diez cuidadores familiares de pacientes con cáncer, asistidos por una red de apoyo para pacientes oncológicos, en la región noroeste del Estado de Paraná, en el periodo de septiembre a diciembre de 2011. A través del análisis temático de los discursos emergieron tres categorías: El sufrimiento ante la jornada: de la enfermedad a la imposibilidad de curarse; Sintiéndose prisionero del cuidado: de la dedicación a la frustración; y Enmascarando el dolor para ofrecer un cuidado genuino; los cuales resaltan la mezcla de sentimientos que experimentan los cuidadores. Se concluye que el cuidado a una persona va más allá de su expresión, exigiendo dedicación sin igual, que a menudo requiere la abdicación de sus propios planes y deseos a favor del próximo.

Palabras clave: Familia. Cuidadores. Cáncer. Estrés psicológico. Enfermería.

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