

CAREGIVING FOR A FAMILY MEMBER WITH HEAD AND NECK CANCER

Ser cuidador de familiar com câncer de cabeça e pescoço

Ser cuidador de un familiar con cáncer de cabeza y cuello

Original Article

ABSTRACT

Objective: To know the perception of informal caregivers regarding the care for a family member with head and neck cancer. **Methods:** Qualitative study conducted between March and May 2014 in the radiotherapy outpatient center of the Centro de Alta Complexidade em Oncologia – CACON (Oncology High Complexity Center) of the Hospital Universitário de Brasília – HUB (University Hospital of Brasília) using semi-structured interviews with nine caregivers about the experience of caring for family members. Data underwent Content Analysis and four units of meaning were identified: “Representation of cancer in the Family”, “The care as debt, individual reward or reconstruction of family ties”, “Repercussions of cancer on the caregiver’s personal life” and “Social support and network used by caregivers”. **Results:** Feelings of sadness and surprise at the moment of diagnosis were attributed to cancer, as well as the idea of punishment. The care was seen as personal satisfaction, accomplishment and opportunity for family rapprochement. Work overload and change in routine were altered functions. Religiosity, exchange of experience in the waiting room and institutional support appeared as coping strategies. **Conclusion:** The experience of caring for family members with head and neck cancer directly interferes in the lives of caregivers. Pointing out the institutional embracement as a strategy within the social network reinforces the importance of integrating the caregivers as a significant part of the health care plan developed by the health team.

Descriptors: Neoplasms; Head and Neck Neoplasms; Caregivers; Oncology Nursing; Family Relations.

RESUMO

Objetivo: Conhecer a percepção de cuidadores informais sobre o cuidar de um familiar acometido por neoplasia maligna de cabeça e pescoço. **Métodos:** Estudo qualitativo realizado no período de março a maio de 2014, no ambulatório de radioterapia do Centro de Alta Complexidade em Oncologia (CACON) do Hospital Universitário de Brasília (HUB)-Brasil, baseado em entrevista semiestruturada com nove cuidadores. Os dados foram submetidos à Análise de Conteúdo, sendo identificadas quatro unidades de significado: “Representação do câncer na família”, “O cuidado visto como dívida, recompensa individual ou reconstituição do elo familiar”, “Repercussões do câncer na vida pessoal do cuidador” e “Rede e apoio sociais utilizados pelos cuidadores”. **Resultados:** Foram atribuídos ao câncer sentimentos de tristeza e surpresa diante do diagnóstico, bem como a ideia de castigo. O cuidar foi visto como satisfação pessoal, dever cumprido e oportunidade de reaproximação familiar. Sobrecarga e mudança na rotina foram funções alteradas. Religiosidade, troca de experiência na sala de espera e apoio institucional apareceram como estratégias de enfrentamento. **Conclusão:** A experiência de cuidar de familiar com câncer de cabeça e pescoço tem interferência direta na vida dos cuidadores. O acolhimento institucional ser apontado como uma estratégia dentro da rede social reforça a importância de integrar os cuidadores como parte significativa do plano de cuidados traçado pela equipe de saúde.

Descritores: Neoplasias; Neoplasias de Cabeça e Pescoço; Cuidadores; Enfermagem Oncológica; Relações Familiares.

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Received on: 04/27/2015

Revised on: 07/04/2015

Accepted on: 09/04/2015

RESUMEN

Objetivo: Conocer la percepción de cuidadores informales sobre el cuidar de un familiar con neoplasia maligna de cabeza y cuello. **Métodos:** Estudio cualitativo realizado en el período entre marzo y mayo de 2014 en el ambulatorio de radioterapia del Centro de Alta Complejidad de Oncología (CACON) del Hospital Universitario de Brasilia (HUB)-Brasil, basado en una entrevista semiestructurada con nueve cuidadores. Los datos fueron sometidos al Análisis de Contenido e identificadas cuatro unidades de significado: "Representación del cáncer en la familia", "El cuidado visto como deuda, recompensa individual o reconstitución de la relación familiar", "Repercusiones del cáncer en la vida personal del cuidador" y "Red y apoyo sociales utilizados por los cuidadores". **Resultados:** Fueron atribuidos al cáncer los sentimientos de tristeza y sorpresa frente al diagnóstico así como la idea de punición. El cuidar ha sido visto como una satisfacción personal, el deber cumplido y la oportunidad de proximidad familiar. La sobrecarga y el cambio de rutina fueron alterados. La religiosidad, el intercambio de experiencia en la sala de espera y el apoyo institucional surgen como estrategias de afrontamiento. **Conclusión:** La experiencia de cuidar de un familiar con cáncer de cabeza y cuello influye directamente en la vida de los cuidadores. El hecho de que la acogida institucional es considerada una estrategia de la red social refuerza la importancia de integrar los cuidadores como parte significativa del plan de cuidados elaborado por el equipo de salud.

Descriptor: Neoplasias; Neoplasias de Cabeza y Cuello; Cuidadores; Enfermería Oncológica; Relaciones Familiares.

INTRODUCTION

The head and neck cancer affects different anatomical regions, specially the oropharynx, oral cavity, hypopharynx or larynx⁽¹⁾. It is one of the most prevalent types of cancer, particularly among men. It is estimated that in 2015 circa 22,930 new cases of this type of cancer are diagnosed in Brazil⁽²⁾.

The cancer diagnosis brings changes not only to the life of the individual but to the whole family of an individual diagnosed with this disease. Despite advances in treatment methods, cancer is still associated with an ideology of death, religious discrimination, pain and fear of treatments, which undermines family relationships and dialogue about the disease. Family members are affected by the disease, and the way they react to it directly influences the patient's treatment^(3,4). Depending on the structure prior to the disease, cancer can affect family dynamics, leading the individuals and their caregivers to rearrange their daily activities and the roles performed, and also review their values⁽⁵⁾.

The main caregiver, usually someone in the nuclear family, takes various care responsibilities, such as having to make decisions, performing the activities of daily living, responding to emergency care and providing emotional support. Taking responsibility over the feeding, hygiene and medication can lead to significant physical, psychological and social consequences. These consequences can be linked to increased stress, less satisfaction with life, job loss, depression, deprivation of liberty, broken relationships, isolation and decreased social participation. Moreover, there is the fear of dealing with death and loss of the beloved one (3,6,7). A study conducted with patients with head and neck cancer identified the caregiver roles: to provide emotional support, take the patient to health facilities, clean the house, do the shopping, cook, and provide hygiene and night care⁽⁸⁾. Noteworthy, these caregivers have multiple roles that require time and dedication. In addition to these responsibilities and the psychosocial effects related to cancer diagnosis, they must learn to deal with the nutrition of patients, who are often fed via feeding tubes, special hygiene care, tracheostomy care and communication, which can be impaired^(6,9,10).

Anxiety, fear of losing control and uncertainty are constant feelings in the diagnosis and treatment of cancer. Added to this, the high mortality rate of the disease feeds the imagination of the individual and his family with the fear of death, which is often underrated by health professionals. The impact of disease on patient's life, associated with the routine and side effects of treatment, has important consequences for the family, especially for the primary caregiver⁽¹¹⁾.

The World Health Organization calls attention to the importance of health professionals who are also able to deal with the needs of caregivers⁽⁴⁾.

Thus, the present study is of utmost importance because knowing the implications of caregivers' experience allows the development of interventions to meet their psychosocial needs. The nurse, as the professional that is the closest to the patient and family has an important role in the preparation, counseling and support to this group.

Given the above, the present study aimed to know the perception of informal caregivers regarding the care for a family member with head and neck cancer.

METHODS

This is a qualitative descriptive study conducted between March and May 2014 in the radiotherapy outpatient center of the *Centro de Alta Complexidade em Oncologia - CACON* (Oncology High Complexity Center)

of the *Hospital Universitário de Brasília – HUB* (University Hospital of Brasília).

The study included nine (n=9) caregivers of patients with cancer of the oral cavity, pharynx and larynx submitted to radiotherapy. The selection criteria included primary caregivers over the age of 18 who were part of the patient's family. Caregivers - including the ones who were part of the family - who received money for the job were excluded from the study.

Participants were contacted in the waiting room of the radiotherapy outpatient center and then invited to participate in the study while waiting for the family member to return from the radiotherapy session. At that moment, they were explained about the nature of the research, its objectives, methods and implications. Those who showed interest in participating in the research were sent to a reserved space where they read and signed the free informed consent (IC) form in accordance with the ethical aspects of research with human beings according to the guidelines of the National Health Council Resolution No. 466/12⁽¹²⁾.

Data were collected using semi-structured interviews in order to allow the interviewee to talk about the issues addressed. Interviews were recorded by a digital recorder and then transcribed and analyzed. In order to preserve the identity of the participants, they were given fictitious names.

Closed-ended questions sought to obtain participant's sociodemographic data, such as age, gender, origin, place of birth, education, profession, and the medical diagnosis of the patient they cared for. Open-ended questions included the following questions: "What is the meaning of your family member's cancer for you", "Can you explain in details how you experience being a caregiver?", "What strategies do you use to get strength during this care process?", "In your opinion, what is the good side of caregiving for a family member?", "What is the biggest difficulty you encounter during this process?", "Is there any support in the service that is important to you right now?".

For data analysis, we used the systematization of the thematic-categorical content analysis⁽¹³⁾ that took place in three stages: pre-analysis; exploration of the material or encoding; and treatment of results, inference and interpretation. The first stage aims to organize ideas for further analysis. The encoding process refers to the grouping of the collected material into units of meaning. The last step is the description and interpretation of the categories identified. In the present study, four units of meaning emerged: "Representation of cancer in the Family", "The care as debt, individual reward or reconstruction of family ties", "Repercussions of cancer on the caregiver's personal life" and "Social support and network used by caregivers", and their respective subcategories: religiosity, experience

exchange in the waiting room, and the importance of institutional care.

This study was approved by the Research Ethics Committee of the *Faculdade de Ciências da Saúde da Universidade de Brasília - UnB* (Faculty of Health Sciences of the University of Brasília) under Opinion No. 493.456.

RESULTS AND DISCUSSION

In this section it is presented the sociodemographic data of the participants and then the units of meaning that emerged from the study.

Sociodemographic data of participants

Participants were seven women and two men aged 32-80 years. Regarding marital status, most respondents were married (n=6), followed by single (n=1), widowed (n=1) and divorced (n=1). The degree of relationship between caregiver and patient was as follows: spouses (n=3), siblings (n=3), children (n=2) or parents (n=1). Five respondents had completed secondary education; one had not completed primary education; and two had completed higher education.

The predominance of women as primary caregivers is in line with other studies. Historically, women have been placed in activities involving the care for children, parents and family, as well as professions related to care^(7,14-16).

Representation of cancer in the family

This category defines the meaning given to cancer based on the experience of caring for a family member with cancer.

The speeches reveal feelings of sadness and surprise in face of the diagnosis within the family.

"We hear about cancer and we see it as something distant from us. In fact, when you have someone very close to you with this problem, it looks like cancer showed up."
(Fernanda)

Cancer and its chronicity lead to a series of events that have not been previously experienced by family members, such as anxiety, fear, anguish and distress. Moreover, the fear of losing a loved one, due to the possibility of imminent death, may trigger feelings of helplessness for not knowing how to help this person, apparent frustration and the need for total devotion to the other person as a compensatory mechanism^(4, 5,17). When confirmation of the diagnosis of cancer is experienced as an interruption in the history of life, both the patient and their family unit may be affected⁽¹⁸⁾. The stigma of cancer may affect family

relationships, making it difficult to address issues related to the disease and preventing any talks about it. People commonly avoid talking about the diagnosis with the most fragile individuals, limiting the expression of the feelings of both the patient and the family⁽¹⁹⁾.

Some participants referred to the head and neck cancer as a punishment for the consequences of bad attitudes of the patient throughout life.

“My father used to be very mean to my first family, which is me and my sisters who are caring for him now. I don't know... of course anyone can develop cancer, but I think that is a way for him to think about it, you know? A way for him to see the bad things he did and that now he's got a second chance.” (Sandra)

“Maybe if he was not sick, I would probably not be talking to him today. We didn't talk because of that, 'cause he had this problem with alcoholism and drank everyday. He use to get home aggressive [...]. So, after the disease I became his real daughter, friend, companion.” (Adriana)

The way how family members relate affects the way the family faces unexpected situations such as cancer. The need to reorganize the family relationships evokes difficulties in the relationship and feelings that influence how the care will be provided.

This perception can sometimes be related to habits such as alcohol drinking and smoking. It is estimated that the majority of cases could be avoided by changing lifestyles considered risk factors⁽²⁰⁾. As alcohol and tobacco dependence is still not seen as a disease that needs to be treated, users are still stigmatized in the social sphere and do not receive proper treatment⁽²¹⁾. Excessive alcohol drinking not only harms the individual, but damages relationships directly or indirectly. The life of families living with this problem can be marked by inconsistency and weakness in emotional relationships, creating an emotional distance between family members⁽²²⁾.

The sufferings of the past are brought to the fore when there are setbacks related to the context of disease and treatment, making it more difficult the caregiver-family member relationship⁽²³⁾. Family histories marked by difficulties related to alcohol and tobacco can, therefore, negatively affect the relationship between caregivers and patients.

The perception of the individuals involved in the task of caring for others is related to one's own reward, either as a way to keep a clear conscience, to meet religious requirements or as an opportunity for family rapprochement.

“For me, it is pleasurable because I know I am doing my part, got it? Although some are not. He has seven children,

right? And it is just me and another that do something. So, as I say, I am doing my part.” (Adriana)

The possibility of caring for others and the sense of accomplishment contribute to the personal satisfaction of caregivers⁽²⁴⁾. For some people, caregiving may be seen as an obligation and a commitment in terms of family relationships that followed throughout life. In this case, feelings of love and affection are expressed and caregiving is not seen as a burden despite the difficulties and overload the family can experience.

On the other hand, caregiving can also constitute a different kind of obligation when it is perceived as something imposed and there is no option to deny it, whether because there is no one who can play that role or by considering that it is the fulfillment of a moral and social duty. In this second context, affection becomes more fragile, causing the caregiver to see its role as exhaustive. Thus, caregiving is embraced in order to keep a clear conscience, without feelings of guilt and a sense of accomplishment⁽¹⁵⁾. The results pointed out caregiving as a matter of commitment to the family relationships and a way to keep a clear conscience, with feelings of affection being reported.

As evidenced in the speech of the caregiver named Adriana, caregiving can also be seen as an opportunity for family rapprochement, corroborating that the cancer may be able to change considerably the relationship between family members and the way they communicate and solve their daily issues⁽³⁾.

Repercussions of cancer on the caregiver's personal life

This category describes the impact of being a caregiver regarding the functions that have changed and emotions triggered by caring for a family member, such as the feeling of overload and losses related to the difficulty in reconciling personal life and the role of caregiver and the changes in routine.

“I left my job to take care of her, because the others work, then it's harder. Since then, I am the one who has come here more often, who cares for her the most, because I drive and come back. So, it got me tired, it got tiresome.” (Antônio)

“You have to give up many things for you to do this treatment. All this is difficult for us. Give up your dreams. Sometimes you want to do something. I can't, because ... you're stuck in the treatment, stuck in it.” (Cristina)

Being an informal family caregiver implies sacrifices and privations that can overload and even weaken the caregiver/patient relationship. The severity and the unpredictable course of the disease, the lack of rest by the

caregiver, the inexperience, and the complexity of tasks related to care are some of the factors identified as major causes of stress in caregivers⁽²⁵⁾. Taking a caregiving role involves abandoning existing projects such as giving up on work, family and even on himself⁽¹⁷⁾. The economic difficulties generated by the costs with the treatment, the need to hide the diagnosis to minimize unwanted comments, the emergence of family conflicts and the need for adjustments and changes in lifestyle imposed by the disease are problems faced by many caregivers⁽²⁶⁾.

Being a caregiver is an unexpected event that brings the need to adapt to deal with the disease and treatment of a family member; it can lead to emotional problems such as depression, insomnia, stress, discouragement, and social and emotional isolation. Given the importance of the activities performed, it is important to note that the physical and emotional health of caregivers affects the well-being and the care for the patient. Therefore, the caregiver must receive special attention from the health team^(3,23).

Social support and network used by caregivers

This category describes both the support network and the social support used by caregivers. It portrays a group of people, activities and situations that offer social and emotional support to caregivers for them to cope with the family cancer. Given the variety in the types of social support identified, we set up subcategories to facilitate the definitions and discussions on the issues that have emerged in different speeches: religiosity, experience exchange in the waiting room, and the importance of institutional care.

The term “social network” refers to the structural and institutional dimension associated with an individual, consisting of individuals who have social ties with one another due to the spaces they share, such as neighborhood, religious organizations, health care system and school⁽²⁷⁾. On the other hand, social support implies emotional closeness and is perceived uniquely by each individual. It consists of members of the social network that became effectively important for the person - because of the the provision of material, social or psychological resources - and generate, through exchange relationships, physical, emotional and behavioral benefits. The existence of social support may help family members make decisions, manage their needs and solve problems⁽²⁷⁾.

Religiosity

The subcategory “religiosity” emerged as a strategy to deal with the diagnosis and treatment of the family member with cancer. Religiosity and faith can increase social support, as they allow access to forms of assistance provided by social networks related to the spiritual/religious practice

of the caregiver, as well as by fostering contact with people and situations that can offer spiritual support to the often experienced fears and anxiety^(27,17). Moreover, keeping a belief and/or spiritual practice that positively influences the individual also favors the acceptance of the situation in a more flexible and adapted way^(26,27).

“In the most difficult times, I believe in God and ask Him to come and give me and him strength and courage.” (Joice)

“When I’m very bad, I pray a lot, I talk a lot to God. I ask Him to give me strength, to give strength to him, too, because... (crying) there are days we think everything is wrong. But you’re all right in the hand of God.” (Cristina)

Experience exchanges in the waiting room

This subcategory shows that exchange relationships characterized by material, emotional or affective support, and even knowledge sharing regarding caregiving generate a sense of self-confidence in the individual, comforting him and demystifying the complexity of care⁽⁵⁾. The social contact that takes place in the waiting room of the radiotherapy outpatient center was pointed out as an important resource for the caregiver’s coping ability because it enables the sharing of knowledge among family members who go through the same experience. However, such place should be better used by the health team, which has the power to constructively guide the discussions and exchanges that take place in order to enjoy the beneficial content and mitigate the effect of the spread of myths and dysfunctional information.

“During the time we stay here, we talk to other patients, other caregivers, and we gain experience with the time we spend taking care of him.” (José)

Institutional care

This subcategory defines the importance of institutional care of caregivers as the focus of health care, which should take into account the essential role they play. It is important to understand that caregivers also need that their psychosocial and health needs are met, as they may hinder the care of the patient with cancer⁽²⁸⁾. In general, health actions still disregard the family dynamics and its relevance in the context of disease and treatment of cancer.

“People’s goodwill, people’s interest, the satisfaction that one has when you arrive, you know? This is very important. Oh God, you have such a problem and then get to a place and find bad grace, difficulty... that lets you down.” (Cristina)

“So, the way the staff treats you here is very important. Their support was very important.” (Antônio)

Caregivers should not be seen as a nuisance in health services; on the contrary, they must be embraced as part of the treatment plan and the care team. When received and oriented properly, family members become sources for the transformation and expansion of health care and production strategies. The individual who takes responsibility for the care of the patient needs to be integrated in the care process. While maintaining accountability for the care of the patient, the staff needs to consider their wishes and respect their autonomy, showing solidarity with their personal demands and sharing with them the responsibilities in the treatment of patient⁽²³⁾. Family members interviewed in this study highlighted the importance of being embraced by the health team as a resource that helps in coping with suffering caused by the diagnosis and subsequent treatment of cancer; thus, when properly offered, it is one more source of social support.

FINAL CONSIDERATIONS

Caregiving was identified as a source of personal satisfaction, as it represents a commitment to the loved one, a form of accomplishment, or a form of being in line with religious precepts. When associated with an obligation of commitment, i.e., when it is related to a family history marked by positive relationships and affection, caregiving is not considered a burden. However, when it is seen as an obligation because there is no other option, affection becomes fragile and caregiving can be seen as a burden. There were also reports that associated caregiving with an opportunity for family rapprochement, as the relationship between some family members had been changed by the diagnosis of cancer.

The results of this study allowed to infer that the experience of caring for a family member with head and neck cancer has a direct influence on the quality of life of caregivers. Changes in family roles and emotions triggered by such condition were dysfunctional in the life of the caregiver - for instance, the feeling of overload and the difficulty in reconciling personal life with routine changes made to take care of the family member. Religiosity appeared as the main coping strategy - when it positively influences the individual, it may favor the acceptance of the patient's condition. Within the health service, the exchange of experiences in the waiting room and the embracement by health professionals were pointed out as forms of social support that significantly impact the care process carried out by the interviewees.

Institutional care has been identified as an important resource within the social network and confirmed the relevance of integrating the family as a significant part of the care plan by developed by the health team. When this

care is effectively provided, both the patient and the health team are benefited, as family members can work as partners and contribute effectively to the health care process.

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