

EXPERIENCE OF FAMILIES FACING THE REVELATION OF THE CANCER DIAGNOSIS IN ONE OF ITS INTEGRANTS

EXPERIÊNCIA DE FAMÍLIAS FRENTE À REVELAÇÃO DO DIAGNÓSTICO DE CÂNCER EM UM DE SEUS INTEGRANTES

EXPERIENCIA DE FAMILIAS ANTE LA REVELACIÓN DEL DIAGNÓSTICO DE CÁNCER EN UNO DE SUS MIEMBROS

Michele Carvalho Karkow ¹
Nara Marilene Oliveira Girardon-Perlini ²
Bruna Stamm ³
Silviamar Camponogara ²
Marlene Gomes Terra ²
Viviani Viero ⁴

¹ RN student at the Universidade Federal de Santa Maria-UFSM. Santa Maria, RS – Brazil.

² RN. PhD in Nursing. Adjunct professor at the Nursing Department and the Postgraduate Program in Nursing PPGEnf/UFSM. Tutor at the Multiprofessional Residency Program in Health: emphasis in Hematooncology at UFSM. Santa Maria, RS – Brazil.

³ RN. Master student in Nursing at the PPGEnf/UFSM. Santa Maria, RS – Brazil.

⁴ RN. MS in Nursing. Nurse at the UFSM. Enfermeira no Hospital Universitário de Santa Maria. Tutor at the Multiprofessional Residency Program in Health: emphasis in Hematooncology at UFSM. Santa Maria, RS – Brazil.

Corresponding Author: Nara Marilene Oliveira Girardon-Perlini. E-mail: nara.girardon@gmail.com

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ABSTRACT

This study aimed to understand the experience of families facing a diagnosis of cancer among one of the family members. This was a field research, descriptive and qualitative, involving twelve family of ten patients who were undergoing treatment in the outpatient chemotherapy section of a teaching hospital in Rio Grande do Sul, Brazil. Data were collected through semi-structured interviews and analyzed using content analysis. Based on the results, data were organized two thematic categories: the impact of being given the diagnosis of cancer, and the feelings it provoked. We concluded that a diagnosis of cancer is a difficult experience, and not always unexpected by families.

Keywords: Neoplasms/diagnosis; Truth Disclosure; Professional-Family Relations; Nursing.

RESUMO

O estudo objetivou conhecer a experiência das famílias frente à revelação do diagnóstico de câncer em um de seus integrantes. Tratou-se de uma pesquisa de campo do tipo descritiva e de abordagem qualitativa, envolvendo 12 familiares de 10 pacientes que estavam realizando tratamento no ambulatório de quimioterapia de um hospital de ensino do estado do Rio Grande do Sul, Brasil. Os dados foram coletados por meio de entrevista semiestruturada e avaliados a partir da análise de conteúdo. Com base nos resultados, organizaram-se duas categorias temáticas: o impacto da revelação do diagnóstico de câncer e sentimentos frente à revelação do diagnóstico. Concluiu-se que a revelação do diagnóstico de câncer é uma experiência difícil e nem sempre inesperada pelas famílias.

Palavras-chave: Neoplasias/diagnóstico; Revelação da Verdade; Relações Profissional-Família; Enfermagem.

RESUMEN

Este estudio tuvo como objetivo conocer la experiencia de las familias ante la revelación del diagnóstico de cáncer en uno de sus miembros. Se trata de una investigación de campo, tipo descriptiva y de enfoque cualitativo, con la participación de doce familiares de diez pacientes que estaban realizando tratamiento de quimioterapia ambulatoria en un hospital universitario del estado de Río Grande do Sul, Brasil. Los datos fueron recogidos a través de entrevistas semiestructuradas y analizados mediante análisis de contenido. En base a los resultados se organizaron dos categorías temáticas: impacto de la revelación del diagnóstico de cáncer y sentimientos ante la revelación del diagnóstico. Se concluyó que la revelación del diagnóstico de cáncer es una experiencia difícil y no siempre inesperada para las familias.

Palabras clave: Neoplasias/diagnóstico; Revelación de la Verdad; Relaciones Profesional-Familia; Enfermería.

INTRODUCTION

Cancer is frequently perceived as a life-threatening disease, and is thus culturally feared.¹ The diagnosis of cancer is often seen as bad news, because of the stigma associated with the disease. Being given such bad news can lead to situations that can threaten life and personal, familiar, and social well-being because of the physical, social, and emotional repercussions they bring.²

Facing a cancer diagnosis, as well as any potentially fatal disease, the patient's family will suffer more or less significant changes. This is because the family is a strong circle in which all group relations are very intense, both relations between the patient and the disease and relations that involve sharing information and feelings that will, in turn, affect personal relationships.³ Therefore, at the same time the family's support is one of the patient's main recourses to cope with the disease,⁴ family members can also suffer. Because of its group impact, cancer can be considered a family disease.⁵

There have been a growing number of studies investigating the impact on the family when one of its members is diagnosed with cancer. In such studies, we see that families also need to be cared for, both in a general emotional way but also each member individually.^{5,6}

Nursing plays a key role in the moment of disclosing the cancer diagnosis, and has the opportunity to provide a holistic therapeutic relationship, caring for the needs of the patient and their family. Nursing can also develop an encouraging stance, which can be vital in the process of adapting to the changing circumstances.⁶

Families are usually taken aback by the diagnosis but can experience the process in different ways. The aim of the present study is to understand the experience of the family facing a cancer diagnosis for one of its members.

METHODOLOGY

This is a field study, descriptive and qualitative, carried out in the outpatient chemotherapy section of a teaching hospital in the state of Rio Grande do Sul, Brazil. Twelve family members of ten patients undergoing treatment took part in the study. The participants were approached in the waiting room. Both patients and family members were over the age of 18, and we selected family members with the physical and psychocognitive abilities to provide the data we required.

For data collection, we adopted a semistructured recorded interview, planned with the following questions: "How was it like to know your relative's diagnostic of cancer? What did you think, and how did you feel? How did your family organize itself after the diagnosis?" Interviews were conducted in April and May 2014 in a private room.

We adopted thematic content analysis⁷ for the data, in three stages. On the first, interviews were transcribed, organized, and then read. On the second stage, we grouped interview extracts according to theme, and developed thematic categories. Finally, results were analyzed, interpreted, and discussed within the context of the literature.

The research protocol was approved by the Ethics Committee according to report 29863514.3.0000.5346 and followed the directives and guidelines of resolution 466/2012 of the National Health Council. Participants signed a free informed consent form. To preserve anonymity, participants were coded with the letter I for interviewee and a number that reflected the interview order.

RESULTS AND DISCUSSION

Twelve family members of ten patients diagnosed with cancer were interviewed. All participants were females (mother, sister, aunt, granddaughter, niece, daughters, and wives of patients) with ages from 19 to 78 years. Six had the schooling level of incomplete primary school and the other six, complete primary school. As for their occupation, one was an elderly caretaker, one salesperson, one cook, one student, two farmers, two teachers, and four housewives. Concerning the type of cancer, five were lung cancer, two breast cancer, one stomach cancer, one colorectal, one testicular, and one lymphoma.

From the analysis of the interview, two thematic categories emerged: the impact of the revelation of the diagnosis, and the feelings the diagnosis provoked.

THE IMPACT OF THE REVELATION OF THE CANCER DIAGNOSIS

The news of the diagnosis, according to the data, is surprising and unexpected, as the families considered the patient to be healthy.

It hit like a bomb. What were we to do? [The patient] is a person who had never needed medicine for anything. She had no high blood pressure, nothing. (12)

We didn't expect something like this. You don't expect that your niece is going to have this... or a son. It's hard! (110)

In the interviews, the notion that the diagnosis is an unexpected and disturbing event is reinforced. A similar result was found in a study describing the life experience of women with ovarian cancer. The diagnosis was often "shocking," as those women considered themselves to be healthy before the diagnosis.⁸

For some participants, whoever, the diagnosis was somewhat expected, due to the patient's lifestyle, unhealthy habits and

the use of substances containing carcinogens. There were also cases in which the patient had been delaying seeking a diagnosis.

Deep inside, I felt something was going to turn up, because of [the patient's] smoking and drinking. [The patient] has had a lung problem for years, and is a smoker. So, it wasn't a surprise. (I3)

My father wasn't well. He went to see the doctor when he was already in bad shape. I'd say this has been going on for quite a while. He was putting it off... So we were already more or less prepared for bad news. (I6)

A retrospective study that aimed to identify factors leading to late diagnosis of neoplasias showed that a delay in diagnosis implies putting off the specialized treatment. The study also verified that in advanced diseases, this delay does not correlate with a worse prognosis, but for patients in poor health, the time between diagnosis and treatment should be the shortest possible, so that a potentially curable disease does not become incurable.⁹

Facing the impossibility of altering the diagnosis, the family feels devastated and question why did the disease appear in their family. During this period, these questionings stem from feelings of hopelessness.

Her mother aged years. We see that, that the person suffered so much from knowing it. [The daughter] always wonders why not her instead. (I10)

We stopped everything. My daughters thought this could not be! [...] Even know, it doesn't feel it's real... It makes me so sad. (I12)

In the interview extracts, the feelings of apprehension and disbelief that arise can be related to difficulties in accepting the disease, a common manifestation in these situations.¹⁰ Normally, the family goes through several stages of adaptation after the diagnosis. The grief stages, proposed by Kübler-Ross, can be used for chronic illnesses: denial and isolation, anger, bargaining, depression, and acceptance. Denial can be seen in the present study, manifesting in almost all of the interviewees as a temporary defense that can soon be replaced for partial acceptance.¹⁰

Another aspect that can trigger difficulties in accepting the disease is the relative's closeness to the patient.

It was very hard for me, because I was very close to him. (I9)

It has been very hard for me, because we've been together for 18 years. (I11)

The revelation of the diagnosis brought pain and suffering to the families, especially when the patient was close to them. Studies show that families, when close to the patient, require social support, as they suffer a blow when they learn someone close to them has a terminal disease.¹¹ In addition, families consider the disease to be more acceptable in older patients.

We've never lived with this disease. We've gone through other diseases in the family, but nothing this severe. For our parents who are older, [it is easier to accept], but less so in a young person. (I10)

He thinks his father is too young to have a disease like this. (I12)

From the interview extracts we see an association between youth and vitality. Thus, when the patient is young, expectations for their future turn into frustration. The death of an old person from cancer is, generally, much better tolerated than the death of a young person of the same family. The participants see death as a concrete possibility when the diagnosis is confirmed, because of the previous negative experiences they had with the disease.

I don't know if I was being negative, but I've had other experiences [with cancer] in the family... Blood relatives, many of them had cancer and died. (I7)

My mother also died of cancer. When I found out [about the patient's diagnosis] I thought: will it be like my mother? Will I lose him this early? (I11)

The interviews show that the families project the possibility of reliving experiences from previous losses of relatives to cancer. Thus, they have the expectation of finality for their current situation. Adaptation, both for individuals and as a group, will depend from the quality of the interactions between the family members and the meanings associated with the disease,⁶ which are uniquely constructed.

In this sense, family members try not to talk about or think about the disease, using denial as a coping mechanism.

We try not to talk about it, because [the patient] doesn't like talking about it. (I1)

I made it talking about it taboo. I said, I forbid it! There were neighbors who came to visit and all they talked about was death, of people who died from cancer. I said, there will be no talk of disease in this house! There will be only happiness here. We're not to talk about it near him! (I8)

News of the diagnosis causes a disturbance in the family, and motivates them to protect the patient and keeping harmonious relationships. The family tries to avoid comments that can bring out the patients' fears and suffering, and also to avoid unpleasant discussion among the family members. For this reason, they prefer to hide or avoid talking about the disease at all.¹²

On the other hand, the diagnosis can bring positive elements to the family, such as strengthening affective bonds, bringing siblings closer, and galvanize the family into taking care of the patient and preserving their well-being. The disease itself demands physical, emotional, and financial resources that can emerge from the support system created by the family.¹³

We never leave him alone. We always give him all the attention we can give so he won't be so upset. (I9)

He is the priority now. Do things for him, to be with him. And he feels well when everyone is together. (I12)

The family that seeks a healthy relationship manifests the desire to tend to, in the best possible way, all the needs of the patient. They express love and care and are even able to share their doubts and knowledge about what's around them.¹⁴

FEELINGS PROVOKED BY THE DIAGNOSIS

This category was designed from themes related to the feelings the family members experienced after they heard the news of the diagnosis. The word most used to describe the way the family received the news was "impact," which can be defined as an intense sensation, provoking emotion and moral setback, caused by a shocking event, a strong, deep impression, and diverse effects.¹⁶ The interviewees associated the impact of the diagnosis to feelings of sadness, suffering, and fears of loss and loneliness.

It is quite an impact! I felt despair. I was crying all the time... [...] I said, what if I get sick too? I need to take care of her. (I1)

I was very sad. My son and I felt extreme sadness. We were knocked down. (I2)

We suffered as hell. The whole family was taken aback, not just [the patient]. (I5)

From the interviews, we can notice that the diagnosis affects the entire family. This is also made clear in other studies about diagnosis disclosure, and shows that the people involved experience psychic and behavioral manifestations, such as fear, anxiety, disquiet, frustration, and despair.^{16,17} However, despite the impact

of the diagnosis, some family members are able to conjure up the strength to minimize their unhappiness and suffering, and try to control themselves so they can be able to help the patient.

He didn't want me crying next to him, so he wouldn't cry too. So I don't. (I4)

I'm still bracing myself, because it's going to be hard. I need to be stronger than all my children, and stronger than [the patient] too (cries). I need to be strong. (I12)

Even though they feel disconsolate and fragile, some family members tend to assume a strong stance, to help the patient and support the family as a whole. We can infer that the diagnosis leads to ambivalent feelings. Despite the negative aspects, after the initial impact, or even simultaneously, the family starts to feel hope, faith, and optimism, feelings that help lessen the negative feelings of uncertainty and weakness.

But it will pass. God willing, [the patient] will get better! (I4)

We will win! Come what may, we will face it. Everything that comes, comes for us to learn and grow, even pain. (I6)

[...] I think that whatever comes to you, you have to endure it. You have to have faith. (I8)

Facing the uncertainties of the patient's health and the prospect of their death, the family turns to their beliefs for elements to give them strength and identify resources that can lead them to security, hope, and endurance. Thus, driven by these positive feelings the family feels able to overcome the suffering caused by the disease, and to face what is to come.¹⁸

Families who can foster these positive feelings are able to reorganize their lives to cope with the disease. Even if cancer presents adverse situations, the strength of the group contributes to overcome them, fostering love, respect, and gratitude.¹⁷ The family can be, therefore, a solid foundation for the patient, without which they would have a harder time coping with the disease and the treatment.¹²

The diagnosis can lead to questions that reveal the family's need to understand rationally what is happening. We noted that some of the interviewees were not clear about the situation of their sick relative. These participants were anxious and worried about the future because they had no prior experience with cancer, and knew little about it, its severity and treatment.

I was nervous because I didn't know anything about it. Later on, I talked to the doctors and nurses. (I2)

I've never had contact with sick people, with this disease. I didn't understand why the chemotherapy was done before the surgery. I thought it was the other way around. (110)

The lack of knowledge about the disease and the forms of treatment is one dimension of the experience that is gradually mitigated as family members talk to health professionals. Some family members recognize the stigma of cancer and how that plays a part in raising fear and doubt. This idea, still alive today, associates cancer to the belief that the patient is doomed to die. This is a historical stigma, attributed to the small chances of cure cancer patients had in other times.¹⁹

A study describing the representation of people dying of cancer in American movies showed that characters with cancer die in almost every situation, and those who survive are often believed that they will soon die.²⁰ This stigmatization of cancer, still strong nowadays, biases how people perceive conversations, images, and life situations. This can be seen among the participants of our study.

The word "cancer" is the hardest to hear, worse than "tumor." It is harsher, strikes faster those who are around it. It is a very strong word. (13)

Why is cancer so taboo? Each cancer is a cancer, but the taboo of cancer is heavy. (16)

The meanings attributed to cancer, socially and culturally transmitted, influence directly the way people and families receive, interpret, and project the revelation of the diagnosis into their daily lives. The history of cancer is filled with fear and shame, feelings that echo in the present and negatively, even after technical and scientific advancements.

FINAL CONSIDERATIONS

In the present study, family members perceived the disclosure of a cancer diagnosis as something not always unexpected, but an event that is still difficult and causes feelings of deep sadness. From the experience, each member reacted in a different way, with shock, fear, anxiety, sadness, and worry, because of the stigma associated with cancer as a painful and incurable disease.

We believe that the nursing professional, being close to the patient's family, can develop an active and helpful listening, offering immediate emotional support to the family at a time of moment of fear and uncertainty. It is also up to the nurses to value and encourage the family's participation in the treatment, working towards a more efficient care.

We hope that this study can lead nursing professionals to reflect on the importance of the family in the treatment of cancer patients, taking into consideration that assistance must be given not only to the patient, but to their families as well, who have their own emotional, individual, and collective needs. Finally, we hope that our results can give a better understanding of the family experience and dynamics when treating a relative with cancer, and encourage health professionals to further humanize the assistance to the cancer patient and their families.

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