

Health workers coping with having a relative in palliative care for cancer

Profissional da saúde frente a situação de ter um familiar em cuidados paliativos por câncer

Profesional de la salud ante la situación de tener un familiar en cuidados paliativos por cancer



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ABSTRACT

Objective: To know the experience of health workers who are coping with having a relative in palliative care for cancer.

Methodology: A qualitative study conducted with four family members of cancer patients in palliative care. Data were collected by means of semi-structured interviews from November to December, 2014, at the home of the participants. The data were analysed using the operative proposal of Minayo.

Results: Two themes emerged, Health worker and family member coping with a cancer diagnosis and Health worker and family member coping with the proximity of death.

Conclusions: Being a family member and a health professional at the same time demanded greater involvement in care and caused distress since these workers witnessed the suffering of a family member with a terminal disease. However, their professional knowledge supported decision-making during the care process.

Keywords: Palliative care. Medical oncology. Family.

RESUMO

Objetivo: Conhecer a vivência do profissional de saúde na situação de ter um familiar em cuidados paliativos por câncer.

Metodologia: Qualitativa, desenvolvido com quatro familiares de pacientes oncológicos em cuidados paliativos, por meio de entrevistas semiestruturadas, no período de novembro a dezembro de 2014, no domicílio dos participantes. Para a análise dos dados foi utilizada a proposta operativa de Minayo.

Resultados: Surgiram duas temáticas, Profissional da saúde e ser familiar frente ao diagnóstico de câncer e Profissional da saúde e Ser familiar no confronto com a proximidade com a morte.

Conclusões: Ser familiar na condição de profissional de saúde demandou maior comprometimento no cuidado, tornando-os angustiados por terem que lidar com seus sentimentos de ver seu familiar em sofrimento pela doença e terminalidade, ao mesmo tempo em que seus conhecimentos profissionais contribuíram na tomada de decisões durante este processo.

Palavras-chave: Cuidados paliativos. Oncologia. Família.

RESUMEN

Objetivo: conocer la vivencia del profesional de la salud en la situación de tener un familiar en cuidados paliativos por cáncer.

Metodología: cualitativa, desarrollada con cuatro familiares de pacientes oncológicos en cuidados paliativos, por medio de entrevistas semiestruturadas, en el periodo de noviembre a diciembre de 2014. Para el análisis de los datos fue utilizada la propuesta operativa de Minayo.

Resultados: surgieron dos temáticas, Profesional de la salud y ser familiar ante el diagnóstico del cáncer y Profesional de la salud y ser familiar en la confrontación con la proximidad de la muerte.

Conclusiones: ser familiar en la condición de profesional de salud demandó mejor comprensión en el cuidado, poniéndolos angustiados por tener que tratar con sus sentimientos al ver a su familia en sufrimiento por la enfermedad o terminalidad, al mismo tiempo que sus conocimientos profesionales contribuyeron en la toma de decisiones durante este proceso.

Palabras clave: Cuidados paliativos. Oncología médica. Familia.

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■ INTRODUCTION

According to the Humanistic Nursing Theory of Paterson and Zderad, health is understood as a matter of personal survival, quality of life and death. Disease, the medical diagnosis or any form of denomination do little to determine the capacity of a person for health. This capacity can only be found in a person's will to remain open to the experiences of life, regardless of physical, social, spiritual, cognitive or emotional state. The experience of a disease and the subsequent changes can impel people to search for the meaning of life⁽¹⁾.

Thus, admitting that the resources for finding a cure have been exhausted and that a person is reaching the end of life does not mean that nothing else can be done. On the contrary, care continues to be a way to ensure the comfort and dignity of patients beyond any therapeutic possibilities and the family⁽²⁾.

Palliative care includes these considerations and defends death as a natural process. This form of care aims to control and reduce the symptoms of a disease through prevention and to alleviate the physical, psychological, spiritual and social suffering by including family support and the consideration of grief⁽³⁾.

When confronted with the end of life, health workers must acknowledge the defence mechanisms of patients and their families. Similarly, it is important to value and understand the feelings of the workers who provide care for people at this terminal stage. Many feel unprepared to provide the care, or they do not know what to do (other than technical care) or what to say. They find it hard to engage with the patient and the family because they were trained not to show emotion, like crying; they trivialise death; and, as a method of confrontation or defence, they fantasise that death will not occur or act as if the patient will recover⁽³⁾. One of the reasons for these attitudes is the absence of serious thought on palliative care and the death process in the education of health professionals, which forces patients and families to carry an avoidable burden of suffering⁽⁴⁾.

It is therefore assumed that when the family member of health workers is approaching death, these professionals will use their technical training to distance themselves from common suffering and the pain of loss. In addition, it is assumed that they will act in a similar manner to that of lay family members, who provide a humanised care and the required affection and comfort. Consequently, the fol-

lowing guiding question was drafted for the study: How do health workers experience having a relative in palliative care?

The considerations of the data were based on the Humanistic Nursing Theory of Paterson and Zderad. Humanistic nursing care is concerned with the phenomenological experiences of individuals and the exploration of human experiences. It is rooted in existential thinking and a philosophical approach to understanding life, where individuals face the possibilities of choice and attribute meaning to their existence⁽¹⁾.

This study is justified by the scarcity of national and international studies and the need to expand and respond to a knowledge gap on this subject. Most importantly, this study can help alleviate the suffering and qualify the health professionals who must cope with terminal disease in the family. Consequently, this study is based on the following question: How do health workers experience having a relative in palliative care? The objective is to know how health-care professionals cope with the experience of having a relative in palliative care.

■ METHODOLOGY

The study refers to the final course work of a residency in oncologic care and it was conducted in a city of southern Brazil. The adopted research framework was the qualitative approach with an exploratory and descriptive purpose. Data were collected by means of interviews with four health workers whose relatives received palliative care for cancer until the end of their lives. These relatives were all attended by the multidisciplinary team of the interdisciplinary home care programme (PIDI) in a hospital of southern Brazil.

The participants were selected according to the following inclusion criterion: healthcare worker, family member diagnosed with cancer who received palliative care from the PIDI and who is deceased. The exclusion criterion was individuals who were not professional health worker and who had a family member at the final stage of life. The participants were selected according to the identification data stored at the PIDI. The possible participants totalled five, although telephone contact with one of these participants was not possible.

After the participants signed the informed consent statement, the data were collected at the homes of the participants in November and December 2014 by means

of semi-structured interviews of around 30 minutes with each participant. The interviews were recorded and transcribed in full. The participants answered the following questions: How did you experience the terminal illness of your family member? When did your family member initiate palliative care? How did you cope with the end-of-life of your family member? What difficulties/conveniences did you encounter during disease progression? Did your personal experience differ from your professional experience? The anonymity of the participants was guaranteed by assigning colours to the statements.

Research complied with the requirements for research with human beings established in Resolution 466/12 of the national health council, of the ministry of health⁽⁵⁾, and the code of ethics of nursing professionals chapter III, concerning the duties in articles 89, 90 and 91 and prohibitions in articles 94 and 98⁽⁶⁾. The research project was registered at Plataforma Brasil and approved by the research ethics committee of the Faculdade de Medicina of the UFPel under decision 573.610.

The data analysis process occurred in stages, based on the operative proposal of Minayo. The first stage was data ordering, which included the transcription of the interviews and observations in order to review the material in an orderly manner. The second stage consisted of data classification and the theoretical basis. The last stage consisted of a final analysis, which included reflection, comprehension and interpretation of the material⁽⁷⁾ based on the Humanistic Nursing Theory of Paterson and Zderad.

■ RESULTS AND DISCUSSION

Four subjects between the ages of 24 and 58 participated in the study. Of these subjects two were nurses, one was a dentist and one was a nursing technician. Data analysis led to the following themes:

THEME 1: Health worker and family member coping with a cancer diagnosis

According to Paterson and Zderad⁽⁸⁾, humans are singular and unique and they are related to others in time and space. They are characterised as being capable, open to opinions and as being the bearers of values. They are the sole manifestations of their past, present and future and are aware of themselves, that is, they are aware of their human responses and the meaning that each of these responses

offers to the world in which they live. Human beings are the product of their decisions and have the capacity to relate and to acknowledge themselves and the world around them.

Thus, the discovery of a cancer diagnosis causes a succession of changes in individuals and their families due to the stigma associated with this disease and the fact that accepting death is strongly linked to beliefs, values and adaptive choices according to the internalisation of each individual. Consequently, the patients and their families require the qualified assistance of a palliative care team that helps them diminish the impact of disease and ensure dignity during the dying process⁽⁹⁾. When these measures or strategies are successful, they create a sense of security and confidence that helps people live with disease⁽¹⁰⁾.

The moment of the diagnosis, seven years ago, since the diagnosis to death, caused some [...] anyway, fears, anyway, because I couldn't really cope with that function of the cancer universe itself, so you still see cancer as a death sentence [...] (RED)

Well, my mom was diagnosed with melanoma and there, of course [...] in the beginning you're scared [...] (YELLOW)

The suffering comes from the anguish of the suffering that the patient may feel, that's what tormented me the most [...] (RED)

Being the family member of a patient with a disease like cancer is linked to the knowledge of the disease and fear of the uncertainties of disease progression, which can lead to suffering due to internal and external injuries and the relationship with death.

The relationship of cancer with pain, suffering, self-deterioration and the sense of finitude demand care that can go beyond the illness and its physical manifestations. The family must be prepared to understand, offer emotional support and meet the care requirements of family members with cancer due to the conflicts and difficulties they encounter⁽¹¹⁾.

The experiences of a disease like cancer affect the sufferers and their entire families due to the interconnection of family members. This interconnection often implies the need for change and personal and family reorganisation in the social, emotional, psychological and organic aspects of life⁽¹²⁾.

[...] it's just that all this contains a family context, a social context, an economic context, so I was also going through a period of ... I was being qualified, with my activities. And they always had their own business, my father had to stop working for almost a year, and my mother ran the business on her own. So, at that time we all went through changes, we moved house, there were financial changes, and my mother had to stop working because of this process of his illness and the care, she was the primary caregiver [...] (WHITE)

My mother was mine, I was hers when I was a child and when she got old she was mine. (BLUE) (referring to the daily care)

I remember something that struck me, because I had never seen my mother naked, ever... There was this one day, I think it was the Monday before she died, it was just me and her, and the poor thing soiled herself. And I thought, gee, I can't leave you like that, mum. And I remember how difficult that was [...] (RED)

WHITE mentions role reversal when the role of the patient as head of the family and breadwinner is assumed by the mother. For BLUE and RED, role reversal is related to care, where the caregiver becomes the patient due to the fragility caused by the terminal illness.

The experience of cancer triggers a new reflection on life since the patients must change their routine and now require the strict monitoring of their health status due to the inevitable relapses and progression of the disease⁽¹³⁾.

The interviewees were the primary caregivers of their family members and they were healthcare workers, which created a greater burden of commitment and decision-making in relation to other family caregivers.

One of the things that, like, even knowing about this field of health [...], there comes a time when you can no longer bear the burden of having to decide so many things alone, in the sense that, as we were six sisters, we always decided things together and together with him and with mum, so if we have to do tests or not, because if we are, how we are going to do them [...] only the burden of knowing, like oh no, now it's diarrhoea, now it was an obstruction [...] (YELLOW)

My brothers and sisters always supported me when I needed them, because I was working. In her last few days, we prayed, they stayed overnight, I accompanied them, but the primary care was mine, I don't know if it was because I work in the area of health or what [...] (BLUE)

[...] it was my dad, my mum and my sister, and of the four I was the only one with the knowledge, I had to remain calm and organize the whole family in the sense of [...], so that, in a way, that responsibility of looking for a diagnosis, treatment [...] (RED)

With the intensification of symptoms and disease progression, the respondents saw themselves as the family member with the scientific knowledge to make decisions in relation to the care and therapy of their relatives, and often abdicated their own lives to live with their loved one during the short time he or she still had left.

Even when all the possibilities of recovering the patients' health are exhausted and imminent death seems inevitable, the patient and family should receive continued support and palliative care. Dialogue is critical for the planning of care based on listening and appreciating the desires, feelings, behaviour and needs of patients in order to understand the meaning that others attribute to the experience⁽¹⁴⁾.

THEME 2: Health workers and family member coping with the proximity of death

Death is a phenomenon with multiple interpretations that differ across societies, cultures and historic moments. It can be understood as an integral part of human life or as a hideous circumstance that unavoidably and definitively terminates existence⁽¹⁵⁾.

And when death becomes something concrete to a family, its members often feel immersed in feelings of anguish and pain with psychological, existential and spiritual effects. This condition does not merely affect the patients, but also the families who experience these vicissitudes⁽¹⁶⁾.

The context in which the relatives were inserted helped them accept the final stage of the lives of their family members, as they, being health workers, had confronted death in other situations.

So, my anxieties were not about her reaching the end of her cycle, but about losing my mother as it were, because

we will meet very soon, which is something I believe in, right, and we interact in another form, although it's not the same, whether through our dreams or thoughts, whether through intuition or spiritually, anyway we interact and that's how it always was, but it was the fear of suffering [...] (RED)

[...] you have this preparation, because we had a religion, right, there was a pastor who went there, the actual pastor of the PIDI I think was once there, the people from the church went there a lot, of the elderly group, right. So I think there is, it was not unknown to us the end-of-life issue, we knew that was going to happen one day and that day was approaching [...] Because there were signs, right, in the sense that he no longer wanted to live in that situation, he looked in the mirror and said: "I'm disappearing..." But we dealt with it in a sense that we were talking about it a lot, but it's not easy to accept. (YELLOW)

Maybe, I don't know, yes, it's harder, because sometimes being the layperson is better, because you know it's going to end. Or maybe it's best that you know too, because then you do everything at the right moment for that person, than pretending it's going to get better. Right... but for me it was much better, very good, very gratifying to have the care that I had for my mom. (BLUE)

The process of dying can be experienced in different ways depending on the shared meanings of this experience and whether they are influenced by socio-cultural contexts. The family can consider death as resting, a passage or a natural fact of life, and the adopted coping strategy makes the experience of dealing with a family member in palliative care less painful and exhausting⁽¹⁷⁾. It is observed that this line of thought usually occurs when the family member feels powerless in relation to the suffering of another family member.

[...] I am not ashamed to say that in many of my prayers, between delaying the death of my mother and allowing the suffering to continue, I asked God to abbreviate as quickly as possible [...] (RED)

So it's a very painful process, and sometimes you think that death is the only remedy. When the time really comes, right, when the suffering stops for the patient and for our family member and for the entire family. (WHITE)

Thinking about death makes us individually reflect on our own lives and how we are living. To accompany a loved one during their final stage forces people to reflect on their own finitude and discover that they will also die, which makes them rethink their existence, review their values and priorities and seek a balance between themselves and others⁽¹⁸⁾.

We think about our end-of-life, too, because I also have melanoma, my mom also has melanoma, so many, many times, when I was looking after him, I was thinking, what will happen to me? Will I be like this, too [...] we also think about our end-of-life, how we will deal with it is another matter, I sometimes wondered: will I face death like my father is facing it, how am I going to do that, what am I going to do? (YELLOW)

The proximity of the death of a loved one forced the family members to think about their own deaths and reflect on their personal and professional lives.

I don't know if it's because we've already had some, for example, I already had experience in the field of oncology, and we always bet on a different type of care [...] so I think it contributes toward what you think is right [...] And so the professional issue I think contributed because it reinforced what I believe to be care for cancer patients during the end of their lives, in terms of family, in terms of patient. (YELLOW)

[...] we have to live our lives according to what we see when we look back on our lives regardless of whether you are looking at the first or last 24 hours, or, I don't know, 10 years, 30 years, in my case 38 years, and that you are proud and did not overlook this process. So, you try to change the reality around you, what you do not agree with, even if this causes conflicts, but that you're trying to improve things [...] (RED)

Because when we are faced with a case of illness in the family, with someone very close to you and you have to experience all of this, I think you start looking at the world and at people differently, too. I think we are easily moved, I think we put ourselves in the place of others, I think that creates maturity, makes you rethink things, value things, value existence, your parents, your family, the people who are by our side. And even when we posi-

tion ourselves as professionals, I think we become more sensitive, I think it causes lot of changes, and they are positive for us as people, as nurses. (WHITE)

Thus, when providing care for human beings who are experiencing the end of their lives, it is important to consider the communication strategies and interrelations with the terminal patient. These experiences are a challenge to all the people involved since confronting an individual who is near death refers to the human finitude of all individuals⁽¹⁹⁾.

■ FINAL CONSIDERATIONS

This study reveals a number of changes in the context of family, life, routine and role reversal that caused discomfort within the family. Therefore, it was necessary to establish coping strategies and make changes in order to adapt to the new situations.

This study shows that being a family member and a health professional at the same time demands greater involvement in care and decision-making regarding treatment since these workers have the scientific and technical knowledge that the other family members do not have. The participants of this study claimed that witnessing a family member suffering from a disease and the final stage of their lives caused distress, whereas their professional knowledge helped them make decisions during this process.

The life prospects of the patients were shattered with the diagnosis and progression of the disease, forcing the interviewed family members to think about the end of the life of a loved one, about their own personal and professional lives, and about their own finitude and death.

The proximity of death and the fear of suffering of a loved one led the interviewed family members to feel some ambivalence toward the final stage of life since death was sometimes considered a way to stop the suffering. Death was probably accepted by the interviewed family members because they were forced to confront death during their professional practice and because of the fear of extending the suffering of a loved one. The statements shed light on the experience of health professionals with a family member in palliative care.

This study may contribute to education and professional practice in the areas of healthcare and, above all, nursing,

during the provision of care for patients at the final stage of life, and may encourage further reflection on the experiences of cancer patients and healthcare professionals during this stage, which is still rarely discussed in academia and in health practices.

The limitation of this study was the reduced number of participants. However, the statements are considered significant and may contribute to professionals and academics interested in the field of oncology. We suggest further research to extend the results of this study.

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