

Feelings of nurses who work with cancer patients in terminal phase

Sentimentos de enfermeiros que atuam junto a pacientes com câncer em fase terminal

Sentimientos de enfermeros que trabajan con pacientes con cáncer en fase terminal

Delmo de Carvalho Alencar¹, Antonia Taísa de Carvalho², Rejane Lopes de Macedo³, Ana Maria Neiva Eulálio Amorim⁴, Álissan Karine Lima Martins⁵, Marcia Teles de Oliveira Gouveia⁶

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ABSTRACT

Objective: To identify the feelings of nurses who work with cancer patients in terminal phase. **Methods:** It is a qualitative research conducted with 10 nurses from the oncology department of a hospital in Teresina, Piauí, Brazil. Data collection occurred through semi-structured interviews submitted to thematic analysis. The Research Ethics Committee of the Santo Agostinho College approved the study under protocol No. 350/10. **Results:** One of the biggest anxieties nurses face is dealing with death, seen as a painful phenomenon and difficult to accept. Most professionals admitted not being prepared to manage and cope with this condition, experiencing it in a conflicting, bitter, and cruel way. **Conclusion:** Given the fragility of nurses' feelings, there is a urgent need to aid oncology professionals by creating professional support groups in order to share experiences and minimize the emotional distress.

Descriptors: Nursing; Medical Oncology; Mental Health.

RESUMO

Objetivo: Identificar os sentimentos de enfermeiros que atuam junto a pacientes com câncer em fase terminal. **Métodos:** Pesquisa qualitativa, realizada com dez enfermeiros do setor de oncologia de um hospital de Teresina, Piauí, Brasil. Coleta de dados realizada por meio de entrevista semiestruturada, submetida à análise temática. Obtenção de parecer favorável pelo Comitê de Ética em Pesquisa da Faculdade Santo Agostinho, conforme Parecer nº 350/2010. **Resultados:** Para os enfermeiros, uma das maiores ansiedades enfrentadas é lidar com a morte, vista como fenômeno doloroso e de difícil aceitação. A maioria dos profissionais admitiu o despreparo no manejo

¹ Master in Nursing from the Federal University of Piauí (UFPI). Nurse of the Family Health Strategy of Pio IX, Piauí, Brazil. E-mail: delmo-carvalho@hotmail.com

² Nurse of the Hospital of Urgencies Prof. Zenon Rocha (HUT), Teresina, Piauí, Brazil. E-mail: taisacarvalho7@hotmail.com

³ Nurse from the Faculdade Santo Agostinho (FSA), Teresina, Piauí, Brazil. E-mail: rejane_252@hotmail.com

⁴ Psychologist. Master in Public Policy from the Federal University of Piauí (UFPI). Lecturer at the Teresina Unified Education Center, Teresina, Piauí, Brazil. E-mail: ana.eulalio@uol.com.br

⁵ Nurse. PhD in Nursing from the Federal University of Ceará (UFC); Professor of Nursing Graduation, Regional University of Cariri, URCA, Ceará, Brazil. E-mail: alissankarine@gmail.com

⁶ Nurse. PhD in Fundamental Nursing, School of Nursing, Ribeirão Preto / USP; Professor of the Graduate and Post-graduation in Nursing, Federal University of Piauí, UFPI, Piauí, Brazil. E-mail: marcia06@gmail.com

e enfrentamento desta condição, experienciando de forma conflituosa, amarga e cruel tal vivência. **Conclusão:** Mediante a fragilidade dos sentimentos dos enfermeiros, urge apoio ao profissional da área oncológica com formações de grupos de apoio ao profissional, a fim de compartilhar experiências e minimizar o sofrimento emocional.

Descritores: Enfermagem, Oncologia, Saúde mental.

RESUMEN

Objetivo: Identificar los sentimientos de enfermeros que trabajan con pacientes con cáncer terminal. **Métodos:** Investigación cualitativa, con 10 enfermeros del departamento de oncología de un hospital de Teresina, Piauí, Brasil. Recogida de datos realizada a través de entrevistas semiestructuradas sometidas a análisis temático. Obtención de dictamen favorable del Comité de Ética de la Facultad de San Agustín, según parecer N° 350/10. **Resultados:** Para los enfermeros, una de las mayores preocupaciones se fue con la muerte, vista como dolorosa y difícil de aceptar. La mayoría de los profesionales admitió falta de preparación en la gestión y hacer frente a esta condición, experimentando una forma de confrontación, amarga y cruel esta experiencia. **Conclusión:** Por la fragilidad de los sentimientos de los enfermeros, insta apoyar la oncología profesional con la formación de grupos profesionales con el fin de compartir experiencias y minimizar el estrés emocional.

Descritores: Enfermería, Oncología, Salud mental.

INTRODUCTION

Despite the progress of science in the treatment of terminal illnesses, cancer is still a stigma-laden pathology, which may occur unexpectedly at some point in the life of a person who is hardly prepared to receive a diagnosis that will interfere in its habits, customs, physical integrity and biological cycle.¹

The disease has been seen as an irreversible and meaningful process for the patient and the health team, which are established based on socio-cultural experiences, myths, fears and uncertainties formed from the moment they recognize the possibility, even if remote, of its diagnosis because it is a pathology that covers itself with unknowns, causes future predictions, which are constituted of an infinity of sufferings, comings and goings to the hospitals. Such experiences may produce paralysis of professional activities, distress, despair and extreme negativism in families and individuals, with fear and emotional discontent predominating because the patient has an intense impact and a sense of imminent death.²

In Brazil, neoplasias occupy second place in causes of death due to illness, according to the Mortality Information System, and are recognized as a public health problem.³ It is estimated that in the year 2030, 27 million new cases of cancer will be registered worldwide, 75 million people will live with the disease annually and 17 million will die,⁴ which reflects the need for qualified professionals to subsidize treatment, rehabilitation, cure and palliative care, when establishing the terminal condition.

Currently, a health care model called palliative care is used, which, according to the World Health Organization, is defined as those who value the lives of patients and their families, helping them to live with the disease in its

final phase through the prevention and relief of suffering, identified early. It also establishes wide assistance, focused on the treatment of pain and other physical, psychosocial and spiritual problems.⁵

Faced with a diagnosis of cancer, each individual responds singularly, but reactions such as fear, anxiety, denial, hopelessness and loss of control are common. In this scenario, the health team, especially the nursing team, is the one that is closest to the patient and for a longer period, which makes it apt to provide humanized care, understanding and supporting them in all their needs in the course of the illness process.⁶

Due to this constant contact with the patient, the nursing team, most of the time, establishes affective bonds with these and their relatives, being able to suffer with the losses and to express feelings of hope, as well as to have the sensation of incapacity, of not have done enough and cannot repair life, especially for the family.⁷

With the technological advances, there has been a great increase in the life expectancy of individuals with cancer, however, as long as it is possible to prolong it, there is a basic cycle common to all living beings. It is necessary that the nursing professional who works with patients in terminal stages of cancer learns to live with the proximity of death, which is a stage of the development process of being, even if, often, feelings of anguish and impotence are present, otherwise, promoting broad and unique care to soften and transform the vital process, controlling suffering.⁸

The emotional problems caused by the patient in terminal conditions and the network of social relations that bind him, in addition to feelings such as depression and anxiety, both of patients and relatives, are naturally projected in the hospital through elements of mediation, that is, professionals, especially nurses, who often feel confused and distressed, since the care needs presented by patients and their families go beyond simple physical care, pressure and temperature, therapeutic applications or even hygiene and comfort, requiring differentiated preparation of nurses who are responsible for deciding important issues and assuming responsibilities in an integral manner.⁹

Recent studies show that feelings of fear and insecurity on many occasions are referred to as a gap in undergraduate education, which often does not prepare the professional for the arduous routine of hospitals, a place where one constantly lives with the suffering of others, making the nurse stop taking a therapeutic stance in these situations, being rare to find in hospitals nurses able to dialogue with the family and the dying patient, assisting them in their psychological needs in the moments before death.^{8,10}

Thus, this study is considered significant, given that, during nursing graduation, the approach to the subject of death can be limited, often, to the technical character, with an appreciation of the maintenance of life, and can thus generate uncertainties regarding the preparation of the future nurses in dealing with the termination process of their patients.

Learning how to deal with losses in a disease context, such as cancer in the terminal stage, is a challenge that few people propose to discuss, much less to confront. In this context, the objective was to identify the feelings of nurses who work with patients with end-stage cancer.

METHOD

This is a descriptive and exploratory study of a qualitative approach carried out with nurses from the oncology sector of a Hospital of Teresina, capital of Piauí, Brazil.

The subjects of the study were nurses who composed the nursing team in the morning and afternoon shifts and who provided care to the terminal cancer patient. Ten nurses were interviewed, characterized by the following aspects: gender, graduation time and working time with the terminal cancer patient. Inclusion criteria were: nurses who worked at the site providing care to the terminal cancer patient for at least one year.

Data collection was performed through a semi-structured interview composed of two parts: the first one consisted of characterization data of the participants, and the second with questions that enabled the subjects to discuss the proposed topic without the submission of pre-set conditions. To record the speech, a digital recorder was used in MP4 media format; and in order to preserve the anonymity of the subjects, an enumeration of interviews was used.

The data were analyzed as follows: ordering, classification of the data and final analysis, followed, also, the recommended steps for thematic analysis.¹¹

The study complied with ethical and legal aspects as provided by Resolution 466/12 of the National Health Council, which approves guidelines and regulatory norms for research involving human beings.¹² For that, it was submitted to the Center for Research and Development of the Research Site and to the Research Ethics Committee of the Santo Agostinho Faculty (SAF), obtaining a favorable opinion for the study, under the opinion 350/10. The participation of the subjects counted on the signing of the Term of Free and Informed Consent in two ways, offering the guarantee of anonymity, the confidentiality of information, the right of privacy, access to data, as well as freedom to withdraw of the study.

RESULTS AND DISCUSSION

The study sample consisted of ten nurses. From these, eight were female and two were male, ranging in age from 22 to 33 years and graduation time from 1 year and 6 months to 10 years. Working time with the terminal cancer patient also ranged from 1 year and 6 months to 10 years.

From the subjects' speeches, the following categories were created: Positive feelings influencing nurses' practice of care and Negative feelings influencing the management of care by nurses.

These categories express the nurses' feelings towards the terminal cancer patient, since, during the routine work with these patients, the nurse has been confronted with situations in which care must be provided and emotional involvement,

such as attachment, sadness, feelings of helplessness and frustration should be avoided.

Initiating the analysis of the speeches, it was verified that the subjects reported positive feelings related to the nurses' performance before the patient with cancer under palliative care, such as: bonding and attachment.

Positive feelings influencing nurses' practice of care

Bonding and attachment arose in the subjects' speeches due to the fact that the patients remained hospitalized for a long period of time, predominating feelings resulting from this frequent contact with the patient and the family, making them perceive themselves as family members.

Sometimes we get very sensitized and there was a patient that I could not take care of because I was very emotional, sometimes I left quickly, I was almost crying, and there are people who say that we are cold, but I have not yet reached this stage. (E07)

We do not stop getting involved, I get very involved. They are patients who are here almost every month, who have many hospitalizations and are always here. When the patient dies, I cry, I get emotional, but I try to work so I do not stay that way. But there is no way you cannot get attached. (E02)

Patients who come to us well, talking, walking, smiling, joyful, satisfied and starts languishing and getting to the end of everything that happened, the way he got here to the way he left us, we get very emotional. We are sad. (E03)

So we end up clinging even if we do not want to. We cling to the patient, have a special affection [...] because they spend a lot of time with us, because they almost do not leave here. They go home, but the hospitalizations are constant. And the closer it gets [to death], the closer the hospitalizations are. So we end up sticking. (E01)

The death of the patient who is given continuous care over a long period without therapeutic perspectives can sometimes be seen by the nurse as a relief for the suffering of the patient.

The relief I wanted to say is that sometimes we have patients who experience three ... four months of hospitalization, suffering ... without much improvement ... sometimes it does not react to the treatment, it has several complications. Complication upon complication [...] and sometimes we even conform to that [...]. (E05)

[...]For me the terminal condition has a positive meaning in some situations, when all that suffering comes to an end, when the person cared for dies without pain, dies accompanied by those they love, when it gave meaning to their existence and that of their relatives. (E08)

Negative feelings influencing the management of care by nurses

In the statements that can be verified next, the subjects of the research reported that the worst feelings towards the terminal patient were impotence and frustration.

The worst feeling is that you cannot do anything to bring back your health. You can do to minimize discomfort, but not to rehabilitate the patient to get him back to his health condition, I think this is the most frustrating feeling, the sadness of losing the patient, although I already expected it and for me today the biggest feeling is this, of impotence in the face of the disease itself, of having nothing more to offer to the treatment to rehabilitate the patient. (E06)

So we see that there is not much we can do to improve it, at least to have a better quality of life. It is so, impotence, we would like to do something, but unfortunately this is not possible, it gives us sadness. (E03)

We feel powerless about this patient, because it is the end of life, whether this patient is new, old, oncological or not. It would always be the only certainty that we have, that life will come to an end. (E04)

The feeling of loss towards the patient becomes deeper when it comes to a child, in whom there is greater involvement with the nurse, perhaps because of the very uniqueness of childhood, or because it is considered as an untimely death. The greatest anguish manifested by nurses in the face of the death of the child happens, almost always, because the child is in the beginning of life, by interrupting his life cycle still in childhood, not participating in the changes that involve life. This fact was proven during the speeches, in which there was a greater emphasis on the suffering faced by the professionals who already accompanied children with cancer in the terminal phase.

As a professional, we always try to be impartial! Because if we get very emotional, it interferes a lot in the care. Here was a child that, when she passed away, was very painful for the whole team, it was a child who came here conscious, talking, saying that he wanted to see the little brothers. So that there, especially when the professional is already a mother, then this impacts directly, we get more shaken by it, but we try as much as possible not to get too involved because otherwise it also hampers professional interaction. (E08)

What I find even more difficulty dealing with is a child, because a child affects us deeply. The children are very destructive to the whole team, like one recently, the girl was already a third recurrence and she moved with everyone because she stayed all day contemplating the parents, saying goodbye, in a way that left everyone very touched. This is something that still hurts me, which still

gives me a feeling of sadness, to the point of getting to cry and all. (E09)

The nurse is the professional who is always present next to the patient, giving him direct care, which can trigger affective involvement. This is conceived as a form of behavior whose person maintains closeness to another, which is different and preferred. It is considered as a basis of security and when, for some reason, it is interrupted, like what happens with death, it generates suffering and feeling of loss, that is, causes mourning which is an expected response to separation.¹³

In assisting the cancer patient in his/her death and dying process, the nurse experiences situations permeated by suffering, anguish, fear, pain and revolt on the part of the patient and family, and as a human being endowed with emotions and feelings, one manifests in some moments these same reactions to this process.¹⁴

Care is essential for all clients, regardless of their clinical condition, but an emotional nurse - patient - family connection is observed in relation to patients without conditions of a good therapeutic result, which is often the case in the oncology specialty.¹⁵

There are health professionals, especially nurses, who come to affirm that there may be patients with whom a differentiated and singular relationship is established, and when they experience the death process, feelings of sadness and a sensation of emptiness emerge, as the preservation and extension of the life are their goals, therefore they may feel incapable or frustrated when they do not succeed in their attempts.¹⁶

Impotence towards the terminal patient, the feeling of inadequacy, the expectation of death, the lack of belief in the available therapeutic measures, reflect in a kind of paralysis in the face of the situation and the demands. Such behavior stems from the anguish of the perception that cancer can lead to death, regardless of the efforts. This perception entails difficulties of confrontation that can affect the specific activities of the professionals.¹⁷

It can be seen that the involvement in the process of death and dying is closely related to the patient's length of stay during hospitalization, which contributes to the fact that the suffering of nurses becomes more intense with the death of patients who remain hospitalized, with which, consequently, a stronger link is formed.

Thus, there is suffering arising from the involvement with the child and his family and the impotence in the negative evolution of the disease. The limitations and the need to deal with children in some way result in feelings of helplessness and inadequacy.¹⁸

The nurse, when caring for a child with cancer in the terminal phase, faces the anguish and pain of family members, as well as their own difficulty in dealing with this situation. Particularly because it is a child, in which one has the image of a being who jumps, jokes and moves, to another who feels nauseated, weak, restricted to the bed, are the determinants of the stigmatization suffered. Faced with this, emotional involvement and pain are

frequently caused by the loss of the patient.⁷ Creating a bond with the terminal child generates emotional exhaustion, as often the professional ends up getting very involved with it, even comparing it with someone in his own family.¹⁸

The greatest anguish manifested by nurses in the face of a child's death is almost always because the child is at the beginning of his life, interrupting his life cycle in his childhood, not participating in the changes that involve growing and developing, not through stage of work, marriage, children, and not being able to enjoy a good old age. Anyway, not enjoying a life full of dreams and hopes.¹⁹

However, on the other hand, because it is intimately involved with the patient to whom care is given, death can sometimes be seen as a relief from suffering, since no matter how much the nurse suffers with the patient's death, he/she also does not feel at ease when visualizing the suffering of the oncologic patient out of therapeutic possibilities.¹

In this study, nurses' experience in the death and dying process of these oncological patients was understood as a difficult process and without many expectations on the part of the nurses interviewed, which creates in these professionals anguish that, consequently, provides escape from the true role of professional responsible for caring.

By becoming aware of its fundamental importance in the development of activities that provide comfort and physical and mental well-being to patients beyond therapeutic possibilities, nurses are faced with the paradox between caring in a humanized way and their socio-cultural convictions involving the fear, the anguish and the difficulties with the prognosis of the cancer patient.

It was possible to perceive that the nurses manifested emotional difficulties in working with the patients in their process of death and dying. In addition, the training of these professionals is often focused on technical and practical actions, and while they are aware of the real needs of the patient and the family, they try to perform their tasks in the best possible way, presenting difficulties to support and comfort this nucleus.

Because nursing professionals spend long periods of time in contact with the terminal cancer patient, be it child, adult or elderly, and their family, they often feel the loss of the patient as if it were from someone in their own family. As a consequence, the suffering experienced by them is similar to the loss of someone they love very much.¹⁸

The aforementioned categories expressed the feeling of nurses facing the terminal cancer patient, which has been a challenge for these professionals since, during the routine work with these patients, nursing has been faced with situations in which care must be provided and emotional attachment, such as attachment, sadness, feelings of helplessness and frustration that most often occur when dealing with this patient should be avoided.

CONCLUSION

For the nurse, one of the greatest anxieties faced is dealing with death, because it appears, in most cases, as a painful phenomenon and difficult to accept, especially when it comes to a child, in which most professionals admit the unpreparedness in dealing with this condition and who, surrounded by stigmas, experience this situation in a bitter and cruel way, provoking conflicting reactions and imposing certain limits on those who struggle for life.

The nursing experience is then marked by conflicting situations, exposing the nursing professional to an atmosphere of feelings, mainly negative, that can cause damages that are reflected in both the emotional and the professional aspects of this individual, and can induce the nurse to withdrawal from direct patient care or even abandonment of professional duties in this area.

Therefore, there should be support for the oncology professional on the part of the institution, such as the formation of support groups for professionals with the purpose of sharing experiences and minimizing emotional distress. The institution could also provide the opportunity for professionals to participate in specialization courses and improvement of knowledge, since there is constant technological update of the therapeutic modalities. Moreover, knowledge favors the proper handling of the patient under critical conditions and reduces the grief of the caregiver by making him aware that he has used the skills available and possible in the care of the patient in question.

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Contact of the corresponding author:

Delmo de Carvalho Alencar
Universidade Federal do Piauí
Rua Josias Antão de Carvalho, 103, Centro
ZIP-code: 64049-550
Teresina - PI
E-mail: <delmo-carvalho@hotmail.com>