REVISTA
UNIMONTES CIENTÍFICA
(ISSN 2236-5257)

DEATH PERCEPTION BY THE ONCOLOGY NURSES

A vivência da morte pelo enfermeiro que atua no setor de oncologia

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Abstract: Objective: to understand how death is perceived by nurses working in the oncology sector of a hospital in the Northern Region of Minas Gerais. **Methodology:** this is a qualitative, field study. Four nurses working in the oncology sector of a hospital located in Montes Claros, Minas Gerais, Brazil, took part in this study. The semi-structured interview was the instrument for data collection and the analysis was performed using the methodology of Discourse Analysis. **Results:** the speeches revealed that suffering is present in the death perception of nurses who takes care of cancer patients, expressed in the form of sadness, anguish, frustration, and emotional feelings. Their discourses indicated two thematic axes: religiosity/spirituality as a source of preparation before death; and suffering before death and dying, which showed their ways of dealing with their personal suffering and that from the patients and their families, while recognizing it as part of the process of elaboration about the situation. **Conclusions:** death is a topic that causes concern, involving fright and denial, yielding feelings of fear and insecurity for nurses caring for cancer patients. Such feelings are due to limitations in their training, which does not promote the adequate preparation of nurses to work in adverse situations such as death.

Keywords: Death; Nurses; Attitudes;before death; Cancer patients.

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Resumo: Objetivo: Compreender como se dá a vivência da morte pelos enfermeiros que atuam no setor oncológico de um hospital da Região norte de Minas Gerais. **Metodologia:** trata-se de estudo qualitativo e de campo. Participaram quatro enfermeiros lotados no setor de oncologia de um hospital situado em Montes Claros, Minas Gerais. Foi utilizada a entrevista semiestruturada como instrumento de coleta de dados e a análise foi realizada por meio da técnica de análise do discurso. **Resultados:** os discursos demonstraram que o sofrimento se faz presente na vivência de morte dos pacientes oncológicos, sob a forma de tristeza, angústia, frustração e abalo. Seus discursos indicaram dois eixos temáticos: A religiosidade/espiritualidade como recurso de preparo diante da morte; e, o sofrimento diante da morte e do morrer, os quais mostraram as formas de lidar com o sofrimento pessoal, dos pacientes e seus familiares, sem deixar de reconhecê-lo como parte do processo de elaboração da situação. **Conclusões:** a morte é um tema que causa receio, cercado de pavor e negação gerando sentimentos de medo e insegurança aos enfermeiros cuidadores de pacientes oncológicos. Tais sentimentos são consequentes de limitações na formação, que não promove o preparo adequado do enfermeiro para a atuação em situações adversas como a morte.

Palavras-chave: Morte; Enfermeiros; Atitude frente à morte; Paciente oncológico.

INTRODUCTION

Death can be defined by the ontological features of living beings. Every living creature is subjected to an irreversible process that comprises birth, growing, decline, and death.[1-3] The human being is, therefore, a being programed to death. In that sense, it is assigned, since the beginning, to its own finitude. Despite the great advances of civilization and its conquests, humans are still not capable of controlling or stopping it.[4]

Currently, due to the scientific advances, especially those in the field of Medicine, the levels of sickness and mortality have dropped sharply, as well as the increase in the number of live births.[5,6] If previously death could be experienced socially, since it was regarded as a natural fact, with the technological advances life was extended, and Science has provided the cure for many diseases.[7]

Therefore, death became a synonym of failure and error. Becoming sick now means stop producing and working, which is shameful.[8] Death is the result of the failure of the therapeutic process and of the effort for the cure.[9,10]

In the 20th century there was a shift of care for the chronic patients from home to the clinical institutions and hospitals. With this change came the institutionalization of the process of hospital death.[11] Hospitals and health care facilities became the main setting for death, apart from the population in general, becoming part of the routine of many healthcare professionals such as physicians, nurses, psychologists, and technicians that deal with its presence in their daily lives.[12]

Data from the Worlds Health Organization estimate that, until the year 2030, the most frequent death causes will be the result of non-transmissible chronic diseases (NTCD), such as malignant neoplasia. These diseases, by their chronic nature, demand intense care in the admission regimen.[10,13]

Along the therapeutic process, the nurse is the practitioner with the highest contact with the cancer patient, and for an extended period. They provide cares that exceed those purely technical, since they are those with the highest access to the reports of the personal life of the patients they follow up..[12,14]

It is not unusual for these professionals to feel and to report their inability to deal with the death of their patients. Without a proper space to deal with their own pain, they get sick due to the lack of elaboration of the emotional load that follows a non-elaborated mourning.[15]

In this way, this study aims to understand how death is perceived by the nurses that work in the oncology sector of a hospital in the Norther Region of Minas Gerais, Brazil.

METHODOLOGY

The data collection was performed in April 2016, in the healthcare facility where the interviewed nurses worked, for the sake of convenience. At the time of the interviews the hospital had four nurses that interacted directly with the oncological, which were invited to take part in this investigation. The sampling group was defined by convenience and availability in order to attend the purpose of a qualitative survey, considering the interest in the depth of information and the time available for the data collection and analysis.

This study opted for a qualitative design, with the use of a semi-structured interview, containing questions about the identification of the

sociodemographic profile and those related to the perception of death by the nurses that work in the oncology sector.

Previously to the investigation, the project has been approved by the Ethical Committee in Research – CEP, associated to the National Commission of Ethics in Research – CONEP, and by the Hospital Ethical Committee, being approved by the Report nº 577.545.

Later, the data collection was conducted by individual interviews, with an average time of 30 minutes per respondent, and their answers were recorded and concurrently transcribed.

The data related to the death perception by nurses were analyzed the methodology of Discourse Analysis, considering the connections between objects, strategies, concepts, and the types of asserions.[16]

RESULTS AND DISCUSSION

Four nurses took part in this study – three females and one male, with ages ranging from 23 to 33 years, with the time of graduation varying from 1 to 12 years.

The process of interview analysis allowed the elaboration of two thematic axes: a) the religiosity/spirituality as a source of preparation before death and, b) the suffering reported before death and the dying process. For the data presentation, in order to preserve the confidentiality of the respondents, each subject was identified with the letter "I" (for interviewed) and a number, followed by the order of the interviews performed.

A) The religiosity/spirituality as a source of preparation before death

The clash between Religion and Science date back to centuries, beginning in the 16th century, due to the overvaluation of physical-biological causes, and extending later to the health sphere. However, along the 20th century, the confirmation of the influence of psychological determinants over health has yielded several transformations, being currently accepted that the spiritual dimension is part of the health concept proposed by the World Health Organization.[2,3,10,15,17,18]

The experience of practices that help the individual to get in contact with the transcendent and keep connected to it characterizes religiosity. In order for it to exist, there must be a relationship with somebody, or something, that humans recognize as bigger than themselves, and to which they pay reverence. Differently than what happens in the development of the spirituality, there must be a superior being to whom they are connected, beyond the personal integration and the integration with other people.[2,3,17,18,19] The following discourses depict this reality:

> *I talk to the patients about God and about the need to trust in God. [...] God knows the right moment in the life of everybody (...) God knows the right moment (...) God knows the right moment for the patient, and the right moment that he is going to stay here (...)* (I1)
>
> *I prepare the patients and the family spiritually and psychologically [...] it is necessary because the cancer patient is at home (...)* (I4)

The perception of the nurses that took part in the study is confirmed by the literature, since a study performed with 85 healthcare professionals found that for 85% of them the issues related to religion and spirituality are frequent in the attendances. Such study reported a higher positive influence of religiosity and spirituality for the perception of improvement during the process of treatment.[18]

Situations with patients with severe diseases such as cancer and the feelings presented by them and their families, such as distress, fear, and suffering were described by the nurses as capable of facilitating the introduction of religious/spiritual issues in the routine work of the nurses. They

report their mutual benefits both because of their own effect and due to their consequences upon the professional performance[20], a situation present in the discourses of the interviewed nurses:

> *As I said, since I am very religious, I do not believe that death is the end.* (I2)
> *Most of the patients become calmer when we listen to them... They ask us to pray with them ... and they feel more reassured...I am evangelical you know? But I do not think it is bad to pray with the patients, even when it is different from the way I do, because it comforts them... (...) and creates a bond between us.* (I3)

In some cases a close relation between nurses and spirituality might be noted, whether as a spiritual preparation or as system of beliefs before the imminent death of oncological patients[21-23] and this can be observed in the fragments of the discourse of I1, which shows the trust in a "God" as a superior entity that regulates the life and death processes in each individual; or in the interview of I2 believing that "death is not the end", and basing such belief in religiosity; or yet, as stated by I3, which assumes the religious identity and follow the prayers of the patients since this reassures them.

Frequently, the nurses face death situations, especially those that work in the oncology sector of hospitals. The death, in this context, is seen as the result of therapeutic failure. Among the nurses that have a more constant presence taking care of the patient, potential conflicting feelings are present. Many times they search for spirituality to deal with their experiences of loss, consoling themselves with the recognition that they have provided the best support to the patients and family regarding the death.[9,10,20,24,25,26]

The creation of bonds is also an important element in the improvement of the condition of the patients. They might develop due to the elements of identification between nurses-patients and the spiritual beliefs are one of these bonds. Besides religious thoughts, it is well acknowledged that the humanization of treatment, as well as the social and professional commitments promote the development of interpersonal links.[24,27]

Self-awareness, as an expression of the care for the self, should take into account the daily spiritual practices of the nurses. Such dimension should not be disregarded since it is capable of increasing the consciousness of the individual , besides enabling the reintegration with the self.[24,25,28-30]

The literature points out that nurses assign feelings such as fear and instability to a gap in their academic training, that does not provide the proper formation to act in adverse situations such as the death.[15] During their training there is an effort to hide it, and an endless effort to postpone its arrival indefinitely or, at least, to delay it as much as possible, with the aid of clinical procedures.[31-33]

B) Suffering before death and dying

Death, as an uncontrolled event, might be called "Destiny", exposing completely to everyone the vulnerability and limitations of the human condition, despite all the efforts spent by humans in order to avoid helplessness and weakness.[26,34]

Historically, in the Middle Ages, death was faced as a natural everyday fact, with the dying person surrounded by family members and other people from the community. Death was fast and, with the limited resources available to confront it, little could be done in order to avoid it or fight against it, which made death more present. There was a space for its ritualization, mourning, and acceptance of the loss.[5,8] With the advent of Modernity, the advances of the medical sciences removes death from the daily life and from the conscience of people. The processes of sickening start to be regarded as controllable facts.[5,6,35]

In the 21st century, in a paradoxical way, death returns to be close to people. Death scenes,

violence, accidents, and diseases are exposed by TV and other media, without a possible elaboration of them. The death issue is invoked all the time by the communication media, in a large and superficial way, without a proper discussion, trivializing this topic. Death became treated as a commodity, exposed aggressively and only with the purpose of attracting a higher number of viewers, hence the need to treat death in a more compassionate way.[22,36]

Healthcare professionals use different terms to conceptualize death: death as an end, passage, mystery, loss, sleep, cut, return, as a scary, natural, and abstract experience, and finally, as an encounter with truth. The diversity of connotations for death should be remarked[17]:

> *We get much shaken! It is impossible not to be. Sad, really sad. For the family, for everybody, we try not to show, but it is difficult, very difficult for everybody. [...] It is a lot of suffering. Working in the oncology is a lot of suffering.* (I1)
> *It is very hard to deal with death, you know? It affects us too much (...) We cry, whoever thinks we do not cry ... (...) We get frustrated, you know (...)* (I1)
> *Incapable (...) I know it does not depend only on me, but from all the team (...)* (I3)

The statements of the interviewed nurses reveal they have difficulty to deal with death and face the reality of finiteness. There is a relentless effort to move away the final moment, avoiding it by any means. However, this is a useless fight, since death is implacable, putting an end to the lives of everybody. Cancer, as a disease associated to the idea of death, is capable of raising reflections, both in the affected patient, as in all health professionals that treat him, about the meaning of life.[17,18,20]

For healthcare professionals death, as a part of their daily work, stresses even more the perception of finiteness, including that of their own, yielding feelings like sadness and distress when dealing with dying patients or those with an advanced age of chronic illness, such as in the case of cancer. In this way, nurses are not free from these feelings.[6,9,10,12,17,21,36]

Such findings matches the type of formation provided to these professionals, focused mainly in the cure and in the avoidance of death. The death of the patient leads to an impact and unleash mourning, an expected response when there is a separation, especially when closeness is developed between two people.[6,9,17,18,20]

During their work in the hospital, professionals that deal with the suffering of patients might be affected by psychological illnesses. Generally, these result from bad elaborated mourning that activate psychological defenses when the nurses face terminal patients. The most common defenses, denial, somatization, pain hiding, and trivialization of suffering, act only to buffer them. When the enclosed emotions are poured out, these can interfere with the relation professional-patient.[22]

The work with cancer patients shows its complexity by requiring considerations that go beyond the therapeutics, demanding psychological, social, cultural, and economic cares.[21]

CONCLUDING REMARKS

Death is an issue that causes concern, especially for being apart from the daily life and restricted to the hospital environment. The nursing professional stands out in this setting, especially for taking care of the patients, not only medically, but also in the psychological, emotional, and spiritual dimensions.

The results herein presented show that the suffering is part of the death perception by nurses, in the form of sadness, distress, frustration, and shock. The professionals interviewed use their spirituality/religiosity as a tool to prepare themselves for the death of the patients. The same tool is used to prepare those that are under their cares and are about to die, as well as dealing with their relatives. Issue about the spirituality/religiosity of the nurses might be important to capacitate the professional to take care of the patient in a contextualized way, considering all the aspects of his personality and helping him to develop resilience in the face of despair and discomfort, so common in the oncological treatment.

We understand that the creation of spaces that enable the discussion about the suffering experienced in the hospital facing death or an impossible cure, might contribute to a better elaboration of the losses by the healthcare professionals. In the same way, the academic training of the nurses should be reconsidered by the educational institutions in order to prepare these professionals to deal with death.

CONFLICTING INTERESTS

The authors of this work report the absence of any conflicting interests with the present study.

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