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## PERCEPTION OF NURSING PROFESSIONALS ABOUT PATIENT CARE OF THE TERMINALLY ILL IN THE HOSPITAL ENVIRONMENT

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**ABSTRACT:** This study aimed to understand how nursing professionals perceive the care provided to patients with terminal illness in the hospital environment. This was an exploratory study with a qualitative approach, conducted with 23 professionals in the ambulatory service of a university hospital in southern Brazil. Semi-structured interviews were used for data collection, in 2011. Using discursive textual analysis, dialogue was shown to be a fundamental instrument in caring for patients in terminal illness, enabling the facilitation of the difficulties experienced by these patients and their families. The importance of family presence for these patients was identified, making it indispensable for caring for their loved one. Continuous education of the staff is necessary, using problematization of the difficulties experienced in the workplace, humanizing and qualifying the nursing care, ensuring dignity and comfort to patients and their families.

**DESCRIPTORS:** Patient terminal. Nursing. Ethics. Family.

## PERCEÇÃO DOS TRABALHADORES DE ENFERMAGEM ACERCA DO CUIDADO AO PACIENTE EM TERMINALIDADE NO AMBIENTE HOSPITALAR

**RESUMO:** Este estudo teve por objetivo compreender como os trabalhadores de enfermagem percebem o cuidado prestado ao paciente na terminalidade, em ambiente hospitalar. Trata-se de um estudo exploratório, com abordagem qualitativa, desenvolvido com 23 profissionais da clínica médica de um hospital universitário, no extremo sul do Brasil. Os dados foram coletados por meio de entrevistas semiestruturadas, em 2011. Mediante análise textual discursiva, constatou-se que o diálogo constitui-se em instrumento fundamental para o cuidado aos pacientes na terminalidade, possibilitando amenizar dificuldades vivenciadas por esses pacientes e seus familiares. Verificou-se, também, a importância da presença do familiar junto a esses pacientes, fazendo-se indispensável sua instrumentalização para cuidar do seu ente querido. Nesse sentido, ressalta-se a necessidade de permanente capacitação dos trabalhadores, a partir da problematização das dificuldades vivenciadas no ambiente de trabalho, humanizando e qualificando o cuidado de enfermagem, além de assegurar dignidade e conforto aos pacientes e seus familiares.

**DESCRIPTORIOS:** Paciente terminal. Enfermagem. Ética. Família.

## PERCEPCION DE LOS TRABAJADORES DE ENFERMERÍA SOBRE EL CUIDADO AL PACIENTE EN FASE TERMINAL EN EL AMBIENTE HOSPITALARIO

**RESUMEN:** Este estudio tuvo por objetivo comprender como los trabajadores de enfermería perciben el cuidado prestado al paciente en fase terminal, en el ambiente hospitalario. Se trata de un estudio exploratorio, con abordaje cualitativo desarrollado con 23 profesionales de la clínica médica de un hospital universitario, en el extremo sur de Brasil. Los datos fueron recolectados por medio de entrevistas semiestructuradas en 2011. Mediante análisis textual discursiva, se constató que el diálogo se constituyó en instrumento fundamental para el cuidado a los pacientes en fase terminal, posibilitando amenizar dificultades vividas por esos pacientes y sus familiares. Se verificó, también, la importancia de la presencia del familiar junto a esos pacientes, haciéndose indispensable su instrumentalización para cuidar de su ente querido. En ese sentido, se resalta la necesidad de la capacitación permanente de los trabajadores, a partir de la problematización de las dificultades vividas en el ambiente de trabajo, humanizando y calificando el cuidado de enfermería, además de garantizar dignidad y confort a los pacientes y sus familiares.

**DESCRIPTORIOS:** Paciente terminal. Enfermería. Ética. Familia.

## INTRODUCTION

With technological advances and the progressive increase in life expectancy, the perspective of incurable disease and risk of death have increased in similar proportion. On the other hand, health professionals show difficulties in managing the growing demand of patients with terminal illness, requiring strengthening their manifestation of caring in the dying process, learning to work with the thematic death, especially with its association with feeling helpless and as though nothing else could be done for these patients.<sup>1</sup>

Statistical data demonstrate that, in Brazil, the chronic noncommunicable diseases (NCDs) are the cause of approximately 74% of deaths. The NCDs with the greatest impact worldwide of are the cardiovascular, diabetes, cancer and chronic respiratory diseases. Such diseases are a major challenge for health managers. In addition to the compromise to the quality of life of affected individuals with a higher probability of premature death, the families, communities and society in general can be affected by adverse economic effects.<sup>2</sup>

Despite technological progress in medicine, especially in oncology, the impact of cancer in the world population is expected to reach 80% of the 20 million new cases estimated for 2025, especially in developing countries.<sup>2</sup>

Health professionals must be prepared to assist patients with terminal illness, which in this context highlights the relevance of nursing staff members, due to their proximity and continuous presence for provision of care activities, especially during hospitalizations. The use of an infinite number of scientific and technological resources in the hospitals promotes the illusion that a cure can be achieved at any cost, in addition to molding these professionals to the same reality.<sup>3</sup>

Thus, hospital environments have been recognized for their high scientific and technological conditions, a place to search for a cure and without an expectation of death, except in intensive care units and operating rooms. However, with the expectation of death, such as those patients with terminal illness, health professionals and families do not know how to provide care in this stage of life.<sup>4</sup>

More than 75% of deaths occur in the hospital environment. This occurs probably due to lack of conditions or knowledge of the family caregiver on how to solve the difficulties of these patients in their own home environments. Therefore, the hospital environments become the most accepted choice.<sup>5-6</sup>

The philosophy of palliative care (PC) was introduced, in Brazil in the 1960s. At that time, a hospital centered on the cure of diseases was the predominant system, with multidisciplinary care, i.e. with interventions of different professionals, but without enough communication among them about the measures to be adopted for each patient. A considerable portion of the hospitalized patients of these institutions were from oncology, who experience intense pain; commonly, they die alone, without the presence of a loved one at this time of suffering.<sup>7</sup>

Palliative care contributes a new way to view the care of these patients, in order to receive care from the diagnosis until the end of this trajectory, providing a better quality of life to them and their families, with the intention of relieving the physical, social, psychological and spiritual pain.<sup>2</sup> Many health institutions do not yet include PC, compromising the care of these patients and the performance of the staff, frequently, is not appropriate for this service.<sup>8</sup>

However, the decision process is not linear, needing to be shared by all those involved; first respecting the patients' choices, when lucid and conscious, and their families, if desired. It is necessary to look at and focus upon the uniqueness, as each one has its time and perception about the challenge of getting sick.<sup>9-10</sup>

Therefore, in addition to the need for staff members to be qualified to care for terminally ill patients, their families also require strengthening and preparation to care for their loved one, and assimilate both the discovery of a complete diagnosis, as well as to act on behalf of this patient, preserving their own health. An open and frank dialogue is necessary with the family member responsible for the patient care, as this becomes a stage where there is a hope for healing, hindering the acceptance of the reality of death and the sense of loss.<sup>11</sup>

However, the nursing staff members often are assigned a secondary role in the care provided to the patient by family members, overburdening their own care. In parallel, when these professionals do not listen to the family members, neglecting their grievances and desires, and do not understand their potential care, contradictorily, they may question the lack of involvement of this family in the care of their loved one in the hospital setting.<sup>4</sup> Finitude is still considered taboo and discussion of it is difficult. Some professionals, who cannot cope with terminal illness, often do not visualize gaps in the guidelines to be offered in the care of this patients.<sup>12</sup>

Accordingly, how do nursing staff members understand the care of patients with terminal illness in hospital setting? Thus, the study aimed to identify how the nursing staff members perceive the care provided to patients in terminal illness in hospital. This research is justified by the need to cause a reflection by nursing staff members on this issue, as well as on the development of strategies for their work with patients with terminal illness and their families.

## METHOD

This was an exploratory study with a qualitative approach, conducted in a public general federal university hospital, located in the extreme south of Brazil, with 183 beds distributed across its different units. The data were collected, specifically, in the 49 bed clinical unit (CU), which was intentionally selected because it covered a large number of chronic patients, and many of those with life-threatening conditions without a prospect of cure. The nursing team\* was composed of eight nurses and 33 mid-level workers (17 nursing assistants and 16 nursing technicians), as well as relief staff, distributed in four shifts (morning, afternoon, night one and night two),

According to the following inclusion criteria, 23 nursing workers participated in the survey: working in the CU for a period greater than six months, and signed the Terms of Free and Informed Consent form. The subjects were identified in the study as nursing workers (N), followed by the number corresponding to the order of completing the interviews (N1, N2, ..., N23). The study was approved by the Ethics and Research Committee (protocol no: 43/2011).

Data collection occurred during 2011, by means of a semi-structured interview, recorded and with an average time of 25 minutes, focusing on the subjects' characteristics and their perceptions about the care provided to terminally ill patients, both by the workers as well as by relatives of the patients in the hospital environment.

After the interviews were transcribed, the discursive textual data analysis was performed through rigorous and in-depth reading, followed by the deconstruction of the units of analysis. The last step of the analysis was the description and interpretation of the meanings.<sup>13</sup>

## RESULTS AND DISCUSSION

Six nurses, six nursing technicians and 11 nursing assistants were interviewed. The nurses, whose ages ranged from 28 to 54 years, had completed their nursing education between six and 24 years prior to the study, and their working time in the CU varied between two and a half years to ten years. Among the mid-level professionals, 12 were female, and had experience in caring for terminally ill patients, shown by their time working on this unit. Their ages ranged from 32 to 64 years, they ranged from five to 30 years after their formal education, and the time working on that unit was between two and 19 years; they were able to show their perception about this type of caring in the hospital environment.

In the process of data analysis, two categories emerged, namely: Caring for the terminally ill patient by workers in hospitals; and Staff members' point of view on care of the family of terminally ill patients in hospitals".

### The care of a terminally ill patient by nursing staff

The care of a terminally ill patient, according to the interviewed staff, involves several aspects, including the need for greater availability of time and attention by professionals, which can be compromised by both the fragile training for this kind of care, as well as the environment of the organizational unit, hindering the care provided and favoring the suffering of staff.

Those patients, because of their physical condition, require a greater commitment of time both for the care, as well as the availability for listening, talking t with them and devoting attention to their families: [...] *people who like to do this job... take the patient out of bed... turn them over to wash them... bathing them... some people don't take it seriously [that work] needs dedication... time to care [...]* (N4). [...] *looks like they're in pain... you start talking, it seems that pain is gone [...]* (N10). [...] *even if I'm overwhelmed... I stop to listen to them [...]* (N6). [...] *Sometimes, we talk with the family members too, because they also suffer [...]* (N15)

Dialogue shows up as a fundamental tool in the care of terminally ill patients, benefiting them, as well as their families and staff, who will be able to identify their most urgent needs and questions,

\* In Brazil, nursing is divided into three categories: nurse, nursing technicians and nursing auxiliaries, being the highest level is a nurse, followed by technicians and auxiliaries. Translator's note.

managing to ease the difficulties experienced by these patients. Therefore, the exercising of this tool, which is so essential in health care, approximates and enables the knowing of the other in his/her singularity, with his/her limitations and potentialities, favors a more effective and humanizing care planning for both these patients and their families,<sup>1</sup> especially because of the difficulty of addressing the situation of the finiteness of life.<sup>4</sup>

Thus, a relevant commitment and a detachment of the staff in the exercise and action of knowledge are necessary,<sup>14</sup> both physically and emotionally, as, beyond the physical pain, these patients experience existential conflicts and needs that medicine or technological devices cannot provide. So, they need to feel cared for, supported, comforted, valued and understood throughout their process of finitude.<sup>8</sup>

However, the nursing staff members recognize that the dialogue established with patients commonly occurs at a level of amenities and even superficiality, as seen in the following statements: [...] *never go into the question of their disease... always trivial conversation, cheerful, pleasant* [...] (N3). [...] *talking with the patient... always transmitting good energy to the patient... never say... never even tell to the family member or even to imply to the patient that he is bad... ever... ever* (N23).

Thus, the staff, maybe due to insecurity, fearing to approach the disease situation being experienced, which can cause the patient anguish, can make it difficult to ease the pain and suffering, as well as that of their families. In view of this, when the staff members have the opportunity to maintain a dialogue with the patient and their families, they must take advantage of this moment to learn what they understand about the disease and how much more they would like to know, since it is an ethical duty of the professional to maintain a true and sincere dialogue with the patient and his family.<sup>15</sup>

So, in certain situations in which the concealment or distortion of the diagnosis of the terminally ill occurs, both on the part of the caregiver, as well as the health team, the staff are not necessarily contemplating the needs of these patients in the process. Often, the physical being is being cared, but the emotional and the spiritual components are not included in this process.<sup>15</sup>

The staff members recognize that caring for terminally ill patients is compromised by the high workload, including the result of long periods of hospitalization of these patients. *Sometimes, we take care of over 12 patients... it's impossible to give special attention I* [...] (N5). [...] *you do the basics and that is it* (N17).

This fact requires the development of dynamism and organization in the performance of various actions in the daily work of the nursing staff, which can be aggravated by the lack of human resources, commonly faced by the nursing staff. So, with this increased workload, some harm may occur to the health of these professionals, as well as the quality of the care provided.<sup>16</sup>

With regard to the scheduling of the nursing professionals, such as the care provided to terminally ill patients and their families which is complex, the human resources deficit is costly, emotionally and physically, for this professionals.<sup>17</sup>

Some respondents also stated the absence of a place that ensures better privacy for these patients and their families, compared to the other patients of the same unit, exposing them in a very difficult moment of life: [...] *We try not to isolate them, but put some screens [...] to let them kind of isolated [...] patients who come for treatment and they are next to patients who are about to die [...] it's bad* [...] (N15).

The other patients with the potential for healing and their families, in turn, can experience the physical sensation of death, and may be shocked by having to witness such situations. However, standards are not established about accommodating patients with the potential for healing close to a terminal patient, just as there are not defined standards for the diagnosis of terminal illness, which raises fears in the healthcare professional to recognize such diagnosis.<sup>18</sup>

As PC units do not exist, it is important to reinforce the importance of using some principles of care in order to guide the actions of nursing staff, in the care of terminally ill patients. In this sense, the relief of pain and discomfort, the respect for autonomy and patients' / families' choices; the non-anticipation of death; and avoiding abandonment or patient isolation by families and health professionals in the hospital environment are important.<sup>2,19</sup>

According to some nursing professionals, care of the terminally ill patient is committed by the lack of consensus on the decision as to whether or not to invest in their healing, causing suffering to patients themselves, their families, and professionals who are watching their suffering. *He goes [physician] and intubates him [...] extending the suffering, as you know that [that patient] there is no return... I will not lie to you... I already got home and cried* [...] (N9). [...] *a [physician] says he will not resuscitate, then, another one arrives and does* [...] (N20).

Again, the dialogue among healthcare team staff with patients and their families, is shown to be a relevant and essential tool in order to avoid conflicts and

misunderstandings between clinical strategies, and especially the therapeutic futility causing unnecessary suffering to the people involved in this process.<sup>20</sup>

Thus, the diagnosis of a terminally ill patient, in practice, involves much more than a critical evaluation, neutral and without prejudice, but rather is complex and without logical reasoning.<sup>18</sup> In this sense, the determination that a patient's diagnosis is terminal should be shared with the entire team and also with the family of the patient and, preferably, with the patient himself, when possible, avoiding the professional suffering because of an isolated decision or even the transmission of a negative picture of abandonment of these patients.<sup>18</sup>

### Staff's view on the care of family of terminally ill patients in the hospital environment

According to the terminally ill patient care, in the hospital environment, nursing staff stated the difficulties of care for family members, highlighting their need for care as well.

According to the nursing staff, some family members are helpful, collaborative, and participate in the care of their loved ones. However, other family members demonstrate difficulty in taking care of these patients. *We have a good job here at the hospital and the daughters have great work at home... so, you can teach them... when I am caring I teach the family member [...]* (N8). *A great need is that the family members participate more because it is a very difficult time for them [patients]... they feel very alone and forsaken [...]* (N9). *[...] I feel that most of them [patients] are very needy ... for the family [abandonment]* (N10).

The presence of the family member with the terminally ill patient seems fundamental; however, many families demonstrate the need to be prepared for the care of their loved one. Being with a terminally ill patient can lead a family member to face his/her own mortality, causing him/her to feel fragile and to back away, triggering emotions of sadness and anguish. Thus, he/she feels unable to help the patient, afraid that his/her attitudes, gestures or words cause greater suffering.<sup>21</sup>

There are situations in which, with the proximity of death, family caregivers feel very fatigued, have difficulty sleeping, with little time to take care of themselves and, most of the time, feeling responsible to be with their relative at that time. Then, discussing the death process is necessary in order to strengthen family ties and give meaning to life and death. The professionals can therefore facilitate the experience of this process, helping to create better conditions

for the families, guaranteeing them their right to support at home.<sup>21</sup>

Therefore, it is necessary that the nursing staff and other health professionals are better prepared to deal with the dying process, to understand this anguish of the family, and to be able to prepare the family member who will be close to that patient in his direct care, either in the institution or at home. Thus, family caregivers can be prepared by means of the assessment of their needs, and the planning of interventions according to their satisfaction, such as informing, encouraging, discussing the decision-making, minimizing or managing the dilemmas in addition to promoting an exchange of affection and care, guiding so that the communication about death happens as something that is just part of life.<sup>4</sup>

The nursing staff must supervise the care provided for these families and contribute to its improvement and its humanization, as well as contributing to enhance the security of the family to perform in their daily lives.<sup>22</sup>

According to the statement of these professionals, in addition to the need for the preparation of family members to provide appropriate care for terminal patients, they also need to be cared for and considered, because they do not always accept or understand this process of mortality: *[...] some family members don't even touch [the patient] [...]* *It seems that they are afraid of [...]* *can you imagine at home [...]* *the trend is to reverse* (N10). *[...] because sometimes some family members do not accept the condition of their loved one* (N9).

Terminally ill patients and their families experience stages of grief, including shock, denial, ambivalence, anger, bargaining, depression, acceptance and adaptation. Such steps may consist of a process of adaptation and preparation of the family members on this impending loss, experiencing anticipatory grief, in addition to the necessity of developing strategies to deal with different feelings experienced by their loved ones in this phase of their lives.<sup>22-23</sup>

The family caregiver also suffers in physical, social, psychological and financial aspects, when caring for his/her loved one with a terminal illness, because of fatigue and stressful overburdening in relation to this daily and uninterrupted activity care, also requiring, to receive care. Thus, for the effectiveness in addressing the needs of these patients, family members should be considered to be a part of this care, with an appropriate support network throughout the process of care.<sup>24-25</sup>

## CONCLUSION

According to this study, the majority of nursing staff demonstrated difficulties in working with terminally ill patients, still strongly mobilized by feelings of sadness, grief and helplessness by the imminent death process of the patients, even though some have expressed satisfaction for being able to perform proper care for patients.

An open dialogue with patients and families is important and necessary, in order to respect their will, avoiding major sufferings. Consistent education is necessary, especially from the problematization of the difficulties experienced in the work environment, such as those relating to the terminally ill, which is recommended to be delivered through continuing education, humanizing and qualifying the nursing care, as well as ensuring dignity and comfort for patients and their families.

From this perspective, the commitment with the subject is important, both in the education of the professionals as the institutional management, training the staff, and qualifying the care for patients and their families. Attention to the family of the patient in the process of death must be improved, by means of manifestations of care, support and comfort in strengthening the care of relatives of those who are severely ill. Nursing actions need to be planned in order to give to the family a less painful experience.

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