

# Nursing care of patients during the dying process: a painful professional and human function

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## Nursing care of patients during the dying process: a painful professional and human function

**Objective.** This work sought to describe the care functions of nurses with patients during the dying process. **Methodology.** This was a qualitative study with ethnographic approach stemming from the analysis of the culture of nurses; it was conducted in the city of Medellín, Colombia. Theoretical saturation was obtained with 23 interviews. **Results.** Nurses feel the duty to care for patients throughout the vital cycle through functions defined as: serving, helping, accompanying, offering support, advocating, educating, and representing, which they identify as indispensable. They also perceive as their own the social responsibility for some issues related to death and due to this they get involved at the personal level, appropriate care and are affected as persons. **Conclusion.** Patient care during dying processes transcends the limits of the nurse's professional functions to become a human obligation.

**Key words:** nursing care; death; stress, psychological; interpersonal relations.

## El cuidado de enfermería al paciente en proceso de fallecer: una dolorosa función profesional y humana

**Objetivo.** Describir las funciones de cuidado de las enfermeras con el paciente en proceso de fallecer. **Metodología.** Estudio cualitativo con enfoque etnográfico partiendo del análisis de la cultura de las enfermeras, realizado en la ciudad de Medellín, Colombia. Se obtuvo saturación teórica con 23 entrevistas y 100 horas de observación. **Resultados.** Las enfermeras sienten el deber de cuidar del paciente a lo largo del ciclo vital mediante funciones que definen como: servir, ayudar, acompañar, brindar soporte, abogar, educar y realizar el rol de vicario, las cuales identifican como indispensables. También, sienten como propia la responsabilidad social por algunos asuntos relacionados con la muerte y por esto se involucran personalmente del cuidado cuyo resultado es su afectación como personas. **Conclusión.** El cuidado

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del paciente en proceso de morir trasciende los límites de las funciones profesionales de la enfermera para convertirse en una obligación humana

**Palabras clave:** atención de enfermería; muerte; estrés psicológico; relaciones interpersonales.

### **O cuidado de enfermagem ao paciente em processo de falecer: uma dolorosa função profissional e humana**

**Objetivo.** Descrever as funções de cuidado das enfermeiras com o paciente em processo de falecer. **Metodologia.** Estudo qualitativo com enfoque etnográfico partindo da análise da cultura das enfermeiras, foi realizado na cidade de Medellín, Colômbia. Obteve-se saturação teórica com 23 entrevistas e 100 horas de observação. **Resultados.** As enfermeiras sentem o dever de cuidar do paciente ao longo do ciclo vital mediante funções que definem como: servir, ajudar, acompanhar, brindar suporte, advogar, educar e consolar, que identificam como indispensáveis. Também sentem como própria a responsabilidade social por alguns assuntos relacionados com a morte e por isto se envolvem a nível pessoal, se responsabilizam do cuidado e resultam afetadas como pessoas. **Conclusão.** O cuidado do paciente em processo de morrer transcende os limites das funções profissionais da enfermeira para converter-se numa obrigação humana.

**Palavras chave:** cuidados de enfermagem; morte; estresse psicológico; relações interpessoais.

## Introduction

The duty of nurses of caring for people, considered by Henderson as the nurse's debt with the patient,<sup>1</sup> is additionally proposed in the Nursing Code of Ethics as "the nurse's primordial professional responsibility".<sup>2</sup> The duty of caring is the seal of the discipline, which goes beyond the medical diagnosis and due to this "nursing is in charge of caring for people – especially when they have no possibility of healing".<sup>3</sup> Nurses are committed to caring for lives,<sup>4</sup> they also care for and worry for the quality of life of patients in a transition processes like death.<sup>5,6</sup> In spite of being part of their professional functions, "death is something problematic in the nursing practice";<sup>7</sup> besides, it "has implications on the private and working lives of nurses".<sup>8</sup> Due to this, this article proposes that although the deaths of patients is a reality nurses experience in the hospital;<sup>9</sup> it is not a trivial phenomenon that leads them to become accustomed; rather, it is object of meanings that must be known to improve care. The aim was to describe the care functions of nurses with patients in the dying process.

## Methodology

This research was conducted via particularistic ethnography techniques<sup>10</sup> and was carried out in Medellín (Colombia) between December 2012 and February 2014. Criteria to select the participants included being a nursing professional and having cared for a patient in the dying process at least once during their working life. The study had 23 participants between 25 and 50 years of age; 19 women and four men, eight with graduate studies in nursing in areas of care of adults and children in critical state and two in oncology and palliative care, graduated from different universities in the country and working in different hospitals in the city.

The information was gathered through semi-structured interviews to capture "the point of view" of nurses regarding patient care during the dying process. One session per participant was held; the data were collected until reaching theoretical saturation. Questions depended on the development of the interview. A field diary was kept, where notations were made on the development of the interviews, the verbal and non-

verbal language of the nurse during the session, and analytic and methodological notes were taken on themes justifying further exploration. For information analysis, a general Reading was made and then codes were selected that were cut and grouped to make up categories and subcategories; this was done in parallel to the collection of the data.<sup>11</sup> To guarantee credibility of the study, the preliminary results were presented and discussed with the participants; and with the intention of seeking alternative explanations for the data, these results were presented to an additional 20 nurses who have cared for patients during the dying process and to academic peers during two international events. To ensure auditability and transferability, the methodological route was detailed; data were examined as a whole, the results describe the typical in the responses of participants.

During the research, ethical aspects were protected, as well as the dispositions required in Resolution 8430 (1993) from the Colombian Ministry of Health for low-risk investigations; participant confidentiality was protected by analyzing data globally and when a particular testimony needed citing it was done in impersonal manner, using names of characters from universal literature as pseudonyms, which occasionally was chosen by the nurse. Informed signed consent was secured prior to the interviews. This research was endorsed by the Ethics Committee of the Faculty of Nursing at Universidad de Antioquia with record N<sup>o</sup>\_CEI-FE 2012-3.

## Results

Two categories were found; the first describes death as an issue of importance for the discipline and, thus, the functions of nurses and their social responsibility are contemplated. The second describes how the patient's death is related to the nurse as a person; here, two sub-categories were found: appropriating of care and death touches the nurse as a person.

### Death is a Nursing issue: the duty of caring until the end

The participants consider that when the therapeutic measures for healing fail, we must look for the best possible conditions for the patient; thus, care falls largely on the nurse: *I think the moment of death is clearly assumed by nursing, speaking of healthcare personnel. Obviously, the family is there, but that is for nursing; a physician will not go and place a pillow so you can feel comfortable, right* (Dulcinea, 4). Under these circumstance, they offer care in search of comfort, cleanliness, pain relief, and a comfortable environment; this was referred to in the following interview fragment: *You are the one there, asking the doctor to order an analgesic; let's give the patient something for pain, make sure he is comfortable, with the family; a physician is not the one who will let the relatives enter, you are the one there throughout the moment, during that whole process of transition to death...* (Dulcinea, 4).

The participants consider that to care for patients and their relatives, they must carry out functions like serving, caring, helping, accompanying, offering support, advocating, educating, and performing the vicarious function. Service appears as a vocation, given that not everyone could be dedicated to the direct service of others in condition of vulnerability; it is a personal conviction to willingly perform some required tasks, according what this participant says: *I sense service as equivalent to the vocation because you don't have vocation for everything and not everyone has vocation for the same* (Sherezade, 9). Helping patients with their necessities supposes person-to-person interaction to know the needs and perform interventions that help fulfill the goal of care, which is for the patient to have humanized process of death, as evidenced in this testimony: *the reason for being in nursing is that of helping patients and families, being with them the whole shift and spending less time at the nursing station* (Sherezade, 5). The participating nurses feel they worry about fully meeting the patient's needs, some of which are shown by the following: *aspire the patient if necessary* (Sherezade, 7),

*avoid choking* (Ana Karenina, 6), and *the patient needs support* (Pocahontas, 3).

Helping patients and relatives refers to being and feeling useful to another, an aspect that nurses in this study think is their key and unique function *because they know they make the difference in the life of a person and help them* (Sherezade, 6). Another meaning of the concept of *helping* is that of facilitating the solution to patients' needs, giving them the possibility of conserving their autonomy and giving the relatives the opportunity to participate in the care, *helping is being with the relatives, [...], you help them and teach them; you are there, but they are the ones caring for the patient* (Sherezade, 8). Accompanying, even if it hurts, is an important function; the participating nurses feel the duty to provide companionship to patients and their relatives during the death process. This is a pillar of care, coming to force as the moment of death approaches, when care focuses on accompaniment and it is one of the care functions that persists until after death *the care we offer implies keeping them company during that process of mourning* (Ana Karenina, 5). They must also be a support for the patients and their relatives. The concept of supporting has two meanings. In the first, the nurses identify that they are a type of rock to keep patients and their relatives from crumbling during their situation of vulnerability and suffering, as expressed by this participant, *you are the rod that supports the immediate pain of patients* (Pocahontas, 1). In another, supporting is sustaining oneself without faltering; it is putting up with your own pain to keep from increasing the affliction of the relatives, *until that day I conceived that we shouldn't cry in front of the relatives because it would precisely increase that pain; you should be the strong part of the issue* (Celestine, 10). This is where the cultural nature of care decisions made by nurses gain importance, given that this way of understanding the concept implies enduring in solitude their personal involvement because they understand being professional as being objective and strong.

Likewise, nurses feel protective of patients and of their rights, in a function of advocacy *we are*

*the angels for the patients and advocates for them and their relatives* (Sherezade, 4). Another function is that of educating the patient's relatives, its importance is centered on their learning how to care for the patient at home, management of symptoms, prevention of aggravating circumstances like ulcers due to pressure, added infections, or pain, as well as when to seek help with the hospital, *I told them how to care for the patient at home, how to perform curing procedures, and everything about home care, where to find creams and anti-decubitus mattresses* (Sherezade, 4). The last of these functions is the vicarious function, which refers to replacing relatives in actions they cannot perform due to their moment of grief. This includes making calls to other relatives or those pertinent to the funeral arrangements, as noted in the following fragment: *at times you have to call the funeral services, look in the phone book,(...), and do that* (Julietta,7). Another reason for doing this is that the relatives need time to be with the corpse: *it is horrible with the pain of the moment, and look, go call and I don't know what, no [...], just give me the information and we will take care of that, for the family to have space with the corpse* (Dulcinea, 3). In addition to the functions, the participants mention that nurses have a social responsibility concerning death, given that they should educate the population in general on aspects related to it, to speak freely, even of their preferences for the last days of their lives; what they would want after dying, as well as their position on organ donation or the limitation of the therapeutic effort, as shown in this testimony: *you have to be very sensitive about life being very short, but with dignity* (Fausto,2). This function seeks to facilitate the decisions of relatives at a given moment.

### **Death has to do with nurses, it is a personal issue**

Death is also tied to the nurse as human being and means appropriating of the care and making the care something personal. The participating nurses mention how the appropriate of the care and on occasion of the person, given that they consider

that patients are under their responsibility and their death behooves them; this is why they try not to cause harm or let no one else cause harm. In the words of the participant: *your patient dies* (Joel, 4) with *emphasis on the voice* (field diary), showing that he perceives the patient as his property, which shows the other face and it is a way of not recognizing the patient in his or her condition of an autonomous being. Three forms of appropriation emerged: making the care something personal for the patient, making the care something personal for the nurse, and committing to care. Appropriating when it is taken as something personal for the patient means performing personalized care for the patient and his/her relatives, so that it includes their considerations, preferences, and religious and cultural beliefs; this position is a way of showing interest for patients and their process: *whatever happens is important to you and you look for the patient not to be subjected to heroic measures and if he or she is going to die it is important that they be okay, for example if they request a priest* (Aureliano, 3).

Nurses may also make decisions of care, stemming from their perspective and from what they would not want for themselves or for their families; thus, they make of care something personal for themselves, attributing the prerogative of making unilateral decisions: *if you think, I'll care for you as I would want my mother to be cared for* (Scarlett, 3). This form of appropriating of care may be taken by patients and their relatives as adequate and they are thankful because nurses place themselves in their position and are sensitive in light of their situation and pain. However, nurses do not always manage to fulfill the expectations and needs of patients and their relatives. Appropriating of care also means making the commitment for the patient to have a humanized process of death. Thus, nurses may go beyond compliance of protocols and the function commissioned by the institution, and show that their motivation is not merely wage related: *but it hurts me, that is why I get stressed; look at my cell phone and you will see my missed calls, I have left about 10 messages there* (Joel, 4). Commitment may also lead to extending the schedules, as shown by the

fragment: *oh yes, I told him that even if I have to stay here during plate restriction [Scheduled restriction for vehicular circulation in the city, depending on the license plate number] and stay longer, I won't leave him* (Juliet, 7).

Likewise, the deaths of patients touches nurses at the personal level in a way that can transcend the limits of their professional functions: *that death also touches you, it is important to let death touch you as a person* (Celestine, 18). Nurses can be affected by the patient's own death and because they are affected by the reality of a person who dies; a human being with a story, with a family and projects: *well, because I am moved personally, I think nurses are touched greatly, all patients move us a lot* (Dulcinea, 4). Three variations are contemplated: consider the patient as a similar, adopt the patient affectively, or be moved. Nurses believe that to care for patients it is necessary to consider them as similar, with whom they share – among other things – the condition of mortality, *nursing care depends a lot on you being a person, on accompanying them, on showing that we are not made of stone; rather, that we are human like them* (Sherezade, 10). Thus, nurses do not establish distance among them, the patients, and their relatives in the care relationship; they become accessible, sensitive, with a capacity to understand the situation of another, without the cultural idea that they must hide their feelings because they are professionals. The following fragment highlights the importance of converting care into a person-to-person encounter without establishing a professional distance: *I think that is what a nurse should do, remove that veil of degrees and things and just be a person who accompanies; cut distances, it is no longer nurse, patient, family, now we are people* (Mafalda, 3).

Sometimes, nurses relate with patients in ways that they end up establishing affective ties with them, carrying out a process of affective adoption: *because she was almost adopted by us; that is, she was a baby that became part of the healthcare staff* (Celestine, 6). This phenomenon occurs with patients of all ages.



It was also found that the nurses in the study consider it important to be moved by the suffering of patients and their relatives, given that they consider that, thus, the care can be better: *I have a personal motto that the day I stop feeling pain for the people and not offer that companionship, I stop being a nurse, that will be my last day* (Ana Karenina, 8).

### **The vulnerability of nurses**

Nurses feel vulnerable because they are in frequent contact with death and must support the pain of others: *enduring pain, we must support because we live amid much pain and suffering* (Celestine, 17), a situation that, according to the participants, has not been recognized or intervened: *but nobody intervenes in us* (Celestine, 17). In turn, lack of recognition may keep them from communicating it. Furthermore, nurses sense a lack of legal protection to back their decisions at a given moment: *from the legal standpoint, we are not covered because they only talk about the medical part, so we are being exposed* (Faust, 2).

## **D**iscussion

This study among nurses found that for them caring for a person during the death process – in great measure – is a nursing responsibility, thus, caring for the moribund affects their professional lives, but they also indicated feeling affected in their personal lives, an aspect that coincides with findings by Castanedo *et al.*,<sup>12</sup> who found that the deaths of patients affects nurses in both aspects.

### **Death is a nursing issue: the duty of caring till the end**

It was found that the participating nurses consider they have the duty of caring for patients and their relatives, within care that does not end, for the purpose of patient receiving comfort, company, and relief of annoying symptoms; likewise, Hodo and Buller<sup>13</sup> think that nursing care is crucial in creating a peaceful experience at the end of life.

In this sense, they have a role and functions to comply in patient care. In this regard, Codorniu *et al.* found that the nurses in their study deal with “care as an application of a technical and specialized treatment, and care through being concerned with the person and their necessities as global or comprehensive approach”.<sup>14</sup>

One of these care functions at the end of life is *service*, which coincides with Paredes, who also mentions it as an important part of the professional identity.<sup>9</sup> The service function emerged as the way of meeting patient needs and those of their relatives with care pertinent to the situation they are experiencing, which contrasts with theoretical categories like basic or invisible care that have been described by authors like De la Rosa and Zamora.<sup>15</sup> Care implies being direct and aimed at necessities of all types, including emotional, which participants in this study call *psychological support* offered by nurses, an aspect that coincides with Almenares.<sup>16</sup> However, saying direct nursing care could be a tautology, given that care is understood as the patient-nurse interaction.<sup>17</sup> Nurses also describe *helping* as one of their functions, which means being and feeling useful; this meaning stems from the conviction that their actions as nurses make the difference against a state of vulnerability of patients, similarly, Waldow found that care is a way of helping people with suffering.<sup>18</sup> The fourth nursing function is *accompaniment*, which appears as an indispensable function of nurses in care, making patients feel they are important,<sup>16</sup> likewise, Bello *et al.*<sup>19</sup> found that nurses in their study consider accompaniment therapeutic at the end of life. The fifth function of nursing is *support* to patients and relatives, which coincides with the findings among nurses by Bello *et al.*<sup>19</sup> and with Morse<sup>20</sup> upon saying that they must offer comfort in the suffering of patients and their relatives. Additionally, this study found that nurses must “bear up”, which according to the same author is a way of suffering to do what must be done. The function of *advocacy* comes about because nurses feel they are there to protect patients; likewise, Hodo and Buller found that the advocacy of nurses contributes to better communication

among the healthcare staff, the terminal patient, and the relatives.<sup>13</sup> These nursing functions are congruent with the definition of palliative care by the World Health Organization,<sup>21</sup> seeking relief for symptoms, offering comprehensive care, improving the patient's quality of life, and helping the relatives.

### **Death has to do with the nurse; it is a personal issue**

The second category of death has to do with nurses because they feel affectation in their personal lives. In this respect, Watson<sup>22</sup> holds that "care transcends the level of the nurse's professional control"; this is contrary to the view of a culture of objective professionals who should not get involved at the personal level. This study found that nurses take the death of the person as something personal and, to this measure, they appropriate of the care, thus, showing empathy toward patients and their relatives and make care decisions by placing themselves in their shoes, which could have good results or, on the contrary, homogenize those who die, given that they do not listen or understand their necessities and preferences. Bello *et al.*<sup>19</sup> found this type of empathy and compassion toward the patient in dying process. In this regard, Skilbeck and Payne<sup>23</sup> describe that the ideal is a position that gets to know the patients and meets their preferences and necessities. Nurses appropriate of care by showing commitment, the same way King and Thomas found that nurses in their study see themselves as strongly committed to patients having an end as comfortable, peaceful, and dignified as possible.<sup>24</sup> It was also found that the participating nurses manifest that the deaths of their patients affect them; this happens because they consider the patient as similar to them and in that respect they think of death as an inescapable reality.<sup>25</sup> They also adopt the patient as a relative, a phenomenon that was also found by Moss *et al.*<sup>8</sup>

But taking patient care as something personal may make nurses more vulnerable due to the possible implications on mental health, leading to "stress due to compassion".<sup>26</sup> Bello *et al.*<sup>19</sup> found that 50% of the professionals in their study

feel emotional burden upon caring for patients in terminal phase. However, it would be interesting to explore if the sense of vulnerability increases in the mental health of nurses by the fact that they withhold showing their feelings, by being in this cultural amalgam of the duty and the need to withstand and be a support. To diminish this vulnerability, psychological support is important.

In conclusion, death transcends the limits of professional functions to become a human obligation. In this sense, caring for a patient in the process of dying and for their relatives means a professional and human obligation. Additionally, nursing as a discipline cares during the whole vital cycle, until the end of life and even after, with specific functions that seek to improve the patient's quality of life and to help their relatives; but balance is also needed with care taken as a personal issue where involvement goes beyond the professional, a situation that is not always evidenced by the scientific culture where they are immersed, where they understand that as professionals they should not get too involved as people. Further research is recommended in this respect to strengthen the concept of nursing that shows commitment and compassion without suffering or wavering. It must be kept in mind that nurses can have personal implications with the death of their patients, even if they do not express it, for the purpose of facilitating support and educational groups where they can manifest their emotions and strengthen coping mechanisms that help them to find a balance between their personal and professional perspectives.

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