



LEARNING ABOUT THE DEATH: EXPERIENCE REPORT IN THE POST-GRADUATE DEGREE

APREENDENDO SOBRE A MORTE: RELATO DE EXPERIÊNCIA NA PÓS-GRADUAÇÃO APRENDIENDO SOBRE LA MUERTE: RELATO DE EXPERIENCIA EN EL POSGRADO

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ABSTRACT

Objective: to describe an experience lived by a post-graduate degree student in the discipline “Thanatology and Palliative Care”. **Method:** this is an experience report conducted during the course of a post-graduate discipline in the 1st semester of 2012, in a public university in the city of Salvador-BA/Brazil. **Results:** we have designed five analytical categories: 1. The dichotomy knowledge x religion; 2. The power and the ego of the nursing professional before the death; 3. The body and the death; 4. The care in the end-of-life process; 5. The authentic death. **Conclusion:** the creation of spaces for discussion in the academic scope and in healthcare services about the process of death and dying should enhance and transform the care methods, by enabling reflections and redefinition in this process by nursing professionals, allowing them to develop further skills and coping and care strategies to individuals who experience the end-of-life process. **Descriptors:** Thanatology; Palliative Care; Death; Nursing.

RESUMO

Objetivo: descrever a experiência vivenciada por uma discente de pós-graduação na disciplina “Tanatologia e cuidados paliativos”. **Método:** trata-se de relato de experiência realizado durante o curso de uma disciplina de pós-graduação no 1º semestre de 2012, em uma universidade pública na cidade de Salvador-BA. **Resultados:** foram construídas cinco categorias de análise: 1. A dicotomia conhecimento x religião; 2. O poder e o ego do enfermeiro de frente com a morte; 3. O corpo e a morte; 4. O cuidado no processo de terminalidade; 5. A morte autêntica. **Conclusão:** a criação de espaços de discussão no meio acadêmico e nos serviços de saúde sobre o processo de morte e morrer devem fortalecer e transformar os métodos de cuidado, possibilitando reflexões e ressignificações nesse processo pelos profissionais de enfermagem, tornando-os capazes de desenvolver novas habilidades e estratégias de enfrentamento e cuidado aos sujeitos que vivenciam o processo de terminalidade. **Descritores:** Tanatologia; Cuidados Paliativos; Morte; Enfermagem.

RESUMEN

Objetivo: describir la experiencia vivida por una alumna de posgrado en la materia Cuidados Paliativos y Tanatología. **Método:** se trata de un relato de experiencia realizado durante el curso de una materia de posgrado en el primer semestre de 2012, en una universidad pública de la ciudad de Salvador, BA. **Resultados:** fueron construidas cinco categorías de análisis: 1) La dicotomía conocimiento - religión; 2) El poder y el ego de enfermeros frente a la muerte; 3) El cuerpo y la muerte; 4) El cuidado en el proceso de terminalidad; y 5) La muerte auténtica. **Conclusión:** la creación de espacios para discusión en el ámbito académico y en los servicios de salud sobre el proceso de muerte y morir deben fortalecer y transformar los métodos de cuidado, posibilitando reflexiones y resignificaciones en este proceso por parte de los profesionales de enfermería, haciéndolos capaces de desarrollar nuevas habilidades y estrategias de enfrentamiento y cuidado a los sujetos que viven el proceso de terminalidad. **Descriptores:** Tanatología; Cuidados paliativos; Muerte; Enfermería.

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INTRODUCTION

The definition of death as an act of dying; the end of plant or animal life; deadline, end, destruction, ruin, great pain, deep sorrow [...] ¹ seriously demonstrates the negative conceptualization of this word.

The death is a kind of phenomenon faced and experienced in varying degrees by each society ², and it is culturally built and understood since childhood. The phenomenon of death and its process of experience are socially built from its social significance and confirmation. The death occurs, often, in individuals who believe they are sick or in death process, even without any "physical disorder" perceptible by the biomedical area, only for having committed transgressions or "sins" socio-culturally rejected. ³

The death, according to one of the authors of this report, has always been a taboo within its family environment. As a child, she had never experienced the death of a friend or an older loved one. Such happening only existed in movies, television, novels, and it was something totally fictitious and faraway.

As its religious basis is spiritualist, with belief in reincarnation and afterlife, suffering because of the death had no meaning, since the life never ends. Nonetheless, all ready-made answers to the few held questions on this issue were dashed with the loss of a loved family member, and it was at this point that the concerns arose up.

For three years, she had a psychological therapy through the psychoanalytic method, but the death was little worked and discussed at the meetings. After that loss, the death started to become an important axis in the consultations, which was perceived by herself and her therapist; both concluded that the need to rethink the death and give a meaning to it was an urgent matter. At that same point, it emerges the opportunity to study a particular discipline as a special student of the post-graduate course, at the Nursing School from the *Universidade Federal da Bahia*, which was entitled "Thanatology and Palliative Care", a discipline which was never released during her graduation in the Nursing Course from the same university.

Rethinking the death should always be a constant practice on the part of the nursing professional, since he/she plays a key role in caring for the client who dies, because, this is the worker who spend most time with the subject through the provided care. ⁴ Being constantly facing the death shows that most professionals are not yet prepared to face the

death of another one and, consequently, confront their own finitude.

When performing a historical retrospective about the representations of death in the most varied cultures, it is observed that each period is marked by peculiarities. At the first Middle Ages period, the death was seen as a natural process of life, and the dying fact permeated the everyday of society. As for the second Middle Ages period, we have realized some transformations; the death won a burden and started to be seen as a penance. ⁵

In the contemporary society, the death is marked by individualism and selfishness. The medicalization becomes a practice strongly articulated to the new personal desires. The practice and the medical discourse started to provide new meanings and senses in the health-disease-death processes. ⁶

The chill death and hidden in the hospital environment became a concern by some researchers, which address the difficulties of healthcare professionals to deal with the process of death and dying, due to their training having always been contrary to the confrontation and naturalization of such process. ⁷ These professionals do not feel qualified and when the end-of-life becomes inevitable, they tend to wriggle and defend themselves with the available tools. These reactions bring about discomfort, both for professionals, for the family and for the client under their care, preventing the formation of the bond, which is the primary linkage to the experience of finitude. Only through reflection on the death, society, and specifically the healthcare professionals, can transform their care practices from the attribution of meaning to their deaths and their lives.

The real reason for our fear towards the death stands on the fact of not knowing who we really are. Dying is facing itself, with its own and single presence, with loneliness and the unknown. Thus, facing ourselves is a completely hopelessness experience. ⁸

Within the perspective of the coping actions and skills on the part of healthcare professionals, we emphasize at this point the role of the nursing professionals. Many of them report that, when caring for individuals who are dying, they feel powerless and guilty, whether by the alleviation of the being who passed away and was in distress or by the provided care, which was not the best that could be done ⁹, confirming their anxiety and inability to cope with the death.

The death became a phenomenon treated with indifference on the part of nurses, by

being observed in some speeches that, often, the coldness and detachment are required attitudes of self-defense to withstand stressful and exhausting labor conditions, because the vast majority is not prepared to deal with the death.¹⁰

From an exploratory and documentary study on the scientific productions about the death in the academic context, it was possible to verify that the universities still do not appear able to adopt a critical and reflective stance on the discipline of Thanatology, and some papers have shown that students have “pre-concepts” regarding the process of death and dying, which would need to be overcome through a more deep and critical work on this theme. The teachers themselves feel insecure and unable to stimulate the expression of their pupils about the death, as they also have difficulties to cope with it and, in their academic training, the death has hardly been mentioned.¹⁰

This experience report constitutes itself, therefore, in an attempt to expand the gaze, from nurses, on the confrontation of the death as healthcare professionals and, especially, as subjects that inevitably will die and must rethink their place in the world and in their own lives.

- Reporting the experience of a special post-graduate degree student during the execution of an elective discipline that addressed issues of the process of death and dying.

This is an experience report of a post-graduate degree student, from a public university in the city of Salvador-BA/Brazil, who has studied a discipline entitled “Thanatology and Palliative Care”, held in the 1st semester of 2012.

A journal was produced, from the notes immediately made after each taught class, about feelings, concerns and conclusions felt and obtained at every meeting. There were a total of 13 meetings (weekly classes of two hours), starting on March 16th and end on June 29th, 2012.

For getting a greater understanding and deepening of the theme, it was necessary that previous readings were held so that the questioning about the process of death and dying could get closer to the field of scientific knowledge.

From the reading of the notes written in the journal, it was possible to subdivide the main addressed issues into five categories: 1. **The dichotomy knowledge x religion**; 2. **The power and the ego of the nursing professional before the death**; 3. **The body**

and the death; 4. **The care in the end-of-life process**; 5. **The authentic death**.

RESULTS AND DISCUSSION

For making a better temporal explanation of the findings, reflections and transformations of the student, the themes that emerged from her respective notes were organized into categories and based in the qualitative analysis of speech.

• The dichotomy knowledge x religion

It is impossible to assign meanings to the death without a prior understanding of its history, culture, beliefs and values, because “Culturally, the ways in which societies experience these two phenomena (health and disease) structure and symbolize the manners in which it faces its fear of death and exorcise its ghosts [...]”.^{10:198}

Thus, it is possible to see the ambivalence of feelings emerged when faced with the death, and the beliefs that belong to the imaginary of this student in the stretch below:

Understand that the fear of death is an awe inherent to the human being, which generates discomfort and suffering, made me feel more human, but also guilty, because, now I fear it. I never had agreed to fear the death; death in my religion does not exist, since in the spiritualist viewpoint, the life never ends, we just change from the material to the spiritual state...then, why to fear it only now? Am I losing my faith? I never conceived the death since my childhood, it does not exist! (Journal-3^o meeting-30/03)

At this time, it emerges the opposition of the knowledge that was being acquired in the discipline in relation to the culturally formed knowledge, which is interpreted as absolute truth. It has started to raise a need to obtain the truth, which only could exist with the destruction of one and the acquisition of another, and not with its complementarity. The religion became a mechanism of denial that hindered her discovery and her differentiated perception about the death.

Our predominantly Christian culture is imbued with concepts, definitions and multiple reasons for the illness and the death, which are the release and revelation of the transcendent Christ, and denying religion and their explanations may mean an act of courage of the patient before the death, by taking its loneliness. Owning a religion or even only believing in a creed can be a necessity present in the human being, when it goes through the “unknown” or even unexplained situations.

The human frailty before the life and death adversities is addressed in a book, as well as its need for attachment to a divine belief, when it experiences an accident that makes him quadriplegic and totally dependent: Anyone who is in a deep suffering, dying or whatnot, becomes mystical. At these times, we appeal to all. It doesn't mean that I have converted myself to the Catholicism, but I believed in popular bullshits [...].^{12:48}

• The power and the ego of the nursing professional before the death

By rethinking the nursing practice in the care for the client who dies, it was possible to problematize the nurse's shares in a more deep way. Talking and thinking about the death is not part of everyday life of healthcare professionals, neither of the general population. In healthcare institutions, environments where the death is constant, the professionals feel unable to address the end-of-life with the necessary humanization and/or naturalness, closing up themselves and avoiding suffering. At their training, the death is synonymous with failure, loss and technical disability, and its overcoming, an achievement able to inflate the egos and promote feelings of adequacy and competency.¹³

When reflecting during the class about the medicalization of the death, its hospitalization and concerns of healthcare professionals in winning it, I realized how much suffering I have experienced with regard to the matters of death when I was an undergraduate student. In losing a patient who was under my care, a feeling of powerless and stagnation took hold of me. Does the pain and insecurity that I experienced were a manifestation of my ego as a healthcare professional? Would it be best for that client or the best for me? Maybe I just wanted to have the power to overcome it, and was not only about having compassion upon that being who passed away, as I thought. (Journal-4^o meeting-13/04)

From this speech, it is possible to realize that the feelings produced by the loss of a patient can be much deeper and complex than they are apparently. The anguishes experienced by professionals do not arise only because of compassion or concern for the being who dies, but they are also linked to the frustrations and the loss of power from the professional before a much stronger phenomenon, the death: "[...] I have realized that we, nurses, most importantly, we are human beings, who feel fragile, unsafe and unprepared to perform a differentiated care for the subject in the end-of-life process, which affect the nursing care, regarding the

being, its history and its context". (*Journal-9^o meeting-10/05*)

A study conducted with healthcare professionals from an Intensive Care Unit (ICU) has observed how painful it was for the healthcare professionals to define and to verbalize their fears and anguishes before the death, and how, through non-verbal language, they showed the discomfort of being questioned about it and its meanings.¹⁴

The sense of failure pervades most professionals who, usually, see themselves as co-responsible for the death of another person and are faced with ambivalent and uncomfortable feelings, which encourage them to move away from the person who dies and him /her family, by adopting a posture of defense and avoidance. The existence of the desire for improvement and healing pervades the imaginary of professionals, so, death becomes synonymous with loss and professional failure.¹⁵

Several factors can trigger defense mechanisms in the nursing professionals who are constantly faced with the death of another person. Experiencing such process can cause numerous sufferings to the professional, such as memories of previous losses, as well as a sense of failure, powerless and, even, the lack of autonomy in decisions to care for the client. These defense mechanisms are created and grounded by the ego, which seeks the denial of any sense of distress and anxiety, and is closely related to the degree and the depth of defenses originating from its influence. As the ego becomes more immature, these mechanisms will be more primitive.¹⁶

• The body and the death

In the sixth meeting held by the discipline, the definition of the *own body* discussed, from the phenomenology of Merleau-Ponty. Understanding the body from the phenomenological perspective was extremely innovative for the students, who were not used to dealing with this study methodology, by demonstrating how their knowledge process was rooted to the positivist medical model.

Initially, it was difficult to understand the relationship between the study of the own body with Thanatology and palliative care, but after, from the relations of the own body and the body of another person with the practice, it was possible to build a deeper understanding about the theme.

The meaning of the body for some nursing professionals, usually, only is based on its care, through nursing techniques and

procedures, or, then, in handling the corpse; in fact, we have argued about the body to die at a meeting of the discipline at stake:

Understanding the body as a 'one self' which is ready for dying gave me vertigo. To see myself as a possible corpse left me inert and stunned. By taking care of another one who dies, we face with our own death and finitude, and perhaps such fact often brings the disgust of the body that agonizes in front of us [...] (Journal-6º meeting-27/04)

The nurse has a peculiarity inherent in its professional practice, which is the care for the dead body, i.e., the body preparation. This activity is permeated with symbologies and anguishes capable to make this action quite poignant and uncomfortable. A Research has found that this practice was aimed at performing an action as quickly as possible, by professionals, in order to achieve the purpose, which demonstrates the difficulty to cope, on the part of the nursing staff, and reflect on this action, through the maintenance of senses of denial and escape before the death.¹⁵

An article highlights the complexity of rethinking the body from the internal perspective, through the phenomenology of viscerality.

Looking at the body from within proved to be strange, something new, and even beautiful, organized and structured for some colleagues, as well as for me. Looking at your own or look at the other through the viscerality of the positivist model reinforces the idea of internal breakdown, where the parties appear to be randomly constituted. However, from the phenomenological gaze, and perhaps built by the new healthcare perspective, the visceral becomes beautiful and harmonious, where the parts are properly and perfectly fitted. Thinking and reflect on the body from within, from the phenomenological gaze, prevents the reduction of the human being to a simple carcass of a corpse, a way that customers are often treated by professionals, and allows us to visualize the body as fundamental, single and essential for the human existence. (Journal-8º meeting-11/05)

● The care in the end-of-life process

The teaching of palliative care in Brazil, as well as the literature on the theme is still limited in comparison to other countries in relation to nursing and medicine courses; here, there are few schools that present this thematic in the curriculum guidelines.¹⁸ There must be a recasting of the hospital paradigm, which views the hospital as a place of healing, by transforming and solidifying the idea of hospital humanization, where the hospital is

space of respect to the right and dignity of the human being, with the possibility of dying quietly.¹⁹

The process of care needs to be constantly grounded on values involving respect, concern, dedication, solidarity and responsibility among the involved agents. With the demonstration of these feelings, a relationship of trust and mutual respect is established, in which the subject starts to be treated as a single being and individual that he/she is.²⁰

Nevertheless, handling and care for the individual who dies is not an easy task for many nurses.

[...] On the one hand, I felt frustrated by never having deeply thought on what I could offer the subject dies. I felt I was powerless and unable to modify the death process of the other person, as few therapeutic techniques could be carried out; but, today I realized how powerful we are as professionals, and able to not only change the life of one subject who is dying, as well as modify our own lives through the experience of caring for someone who dies and, therefore, adopt a more therapeutic stance than previously imagined. (Journal-9º meeting-18/05)

With the study conducted at the specific sector of ICU, it was observed that the individual who experiences the death-dying process is treated and regarded as like any other client, with no differences and particularities in the admission time, by the patient service unit's nurses. On the other hand, there are great respect and attention in the care of these individuals by nurses, which demonstrates that they are, frequently, sensitized by the suffering of the subject who dies, but have not yet become able to develop coping and psycho-spiritual support strategies, focusing, commonly, only on care from the use of devices, techniques and hard technologies.⁴

Another way to create opportunities to hold an increasingly human and individual care is to advocate and adopt an ethical stance in the care for the client who dies. It is very common that the healthcare professional, personally, favors some bioethical principle in the light of another one, normally when advocating the beneficence and maintaining a stubborn attitude, in order to promote what he/she considers right and best for the other human being, as can be seen in the following speech:

Understanding that there is no hierarchy among the bioethical principles made me feel confused and unsure before future decisions, however, also made me feel free

and confident to give more freedom to the other person who is in the point of death, giving it a voice, and finally knowing how it truly is. (Journal-5º meeting-20/04)

From the study conducted on the concept of the health team about autonomy in the context of palliative care, it was possible to verify that such principle has differentiated connotations for professionals of such a service. For some, autonomy stems from a political and legal concept of absence of external interferences in the actions of the other one, by removing any liability of professionals who start to adopt a stance of complete neutrality in the face of the individual decisions about their care. For others, professionals and family are mainsprings that enhance and empower the autonomous exercise of the individual in the end-of-life process, by being co-responsible for their choices and behaviors.²¹

In a study focused on the nurses' knowledge on the palliative care therapy, it was possible to verify that its principles are not yet attached to the discourse of professionals who directly deal with this care way. The ignorance in relation to the signs and symptoms of the final stages of the end-of-life process and the lack of knowledge of the principles and concepts that underlie this field are among the major found errors.²²

● **The authentic death**

In this category, the objective is to explain the rediscovery of the death process by the post-graduate degree student. Through her trajectory across the discipline, some changes that deserve special attention and care were observed and felt. The choice of the title of this category took place due to reading the analysis made by certain philosopher regarding the human existence, where the death enables us to do a critical gaze on the human life, an authentic gaze and living through him life experiences.²³

The Heidegger's search for establishing a metaphysical understanding aiming at overcoming the modern Western thought model, by being that the metaphysics should be addressed of an authentic way, able to go beyond the self in view of identifying the being.²⁴ In Heidegger's design, to understand what is happening and the people senses, it is necessary that the person is in the world and is launched on it, in order to share experiences, since nobody is *ex-sists* if it is not in interaction, or if it is not present or living with, *being-with*, something or someone, and this is an inherent characteristic to the being.²⁵

The human being, while authentic a creature starts to assign meanings to himself, from the acceptance and understanding of its more authentic conception: the death. Accepting the death is an authentic decision, from the observation of its irreducibility. The death is the more authentic consequence of each one, which makes all living beings are creatures for dying.²⁶ A study conducted with elderly people was able to understand that the death exists, but “[...] usually is not recognized as a more appropriate possibility of its presence, by occurring the escape and concealment of this condition, because, in our daily lives, the presence is targeted to the worldly occupations, in order to not reflect on the only certainty in life”.^{26:158} Such finding reflects the limits of the human nature in recognizing the death process as an actual possibility and assign it a faraway meaning, in which the present time should be occupied by its total absence. It is in this spirit that the inauthentic being builds its experience before the phenomenon of death and dying.

The whole being, full, existing in its entirety should cover all your living, not being considered as infinite, but with the awareness of the existence of an end. However, the death must be understood as a possibility and not as an end in itself.²⁶

Thus:

(...) my experience to the initiation of the discipline took place in the way advocated by Heidegger, an inauthentic way of life, where I hid myself from the anguish and pain, living in a superficial way, without truly face the death; death was something far and inert for me, which did not provoke me any kind of feeling, since it was not aware, attentive, neither experienced. So, I remained oblivious, believing that the death could not shock me, until the moment I entered this course and found that, in my heart, such event possessed a power capable to provoke reactions hitherto never experienced. (Journal-10º meeting-01/06))

CONCLUSION

Among the professionals who reflect about the death-dying process, the healthcare ones are still unsure and faraway from this theme, being that the same is largely approached by the human sciences, where since ancient times philosophers have addressed the complexity and singularity of the death “of” and “for” the human being. Nonetheless, it is in healthcare field in which the countless and tireless manifestations of this phenomenon remain, through its daily experience.

The quantity of works that replicate the human quest for healing, for technical and

hard therapy in view of performing the healthcare assistance is pretty high, being that to face the death, by individuals who care, is a barrier to the humanized care that demands contemporary needs. Hence, this study aimed to explain the actual need of a nurse while student of the discipline "Thanatology and Palliative Care", in search of recognizing and redefinition of the death in a particular way, which might serve as an example to promote changes that may also be experienced by other professionals in their care practices, so that, truly, be able to deal and act "with" and "for" the death of another subject and, especially, of themselves.

Experiencing and promote discussions on this curricular component has allowed the conduction of deep reflections by students. This discipline has expanded the number of available vacancies to students, because of its high demand, which showed the interest and need of nursing professionals toward this theme.

Some studies on the process of death and dying show that such disciplines are able to empower healthcare professionals, by stimulating their capacity for reflection and meaning, in order to develop skills in line with the needs of individuals in the end-of-life process, as well as for themselves and their lives.

Prior to any action to care of the individual who dies, or to the weakened individual and in process of suffering, it becomes necessary that professional, caregiver, family member, friend, rethinks and stays aware concerning the meanings attributed to this phenomenon, so that it get committed to a really true care and relationship. Only from the self-awareness and reflections on the death, we, beings of the world, we will be able to fully live.

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