

The concept of transformed body in end-of-life care patients

O conceito de corpo transformado na pessoa em cuidado ao fim da vida

Cidália de Fátima Cabral de Frias¹ , José Carlos dos Reis Lopes¹ 

ABSTRACT

This work is an argumentative essay on the interpretation of the meanings of the bodies of patients in end-of-life care (EoLC) from a triple conceptual perspective: nurse/patient/family. This triad is relevant to the production of meanings when one deals with the body of the Other that requires physical, psychosocial and spiritual care. The concept of “transformed body” emerged from an investigative study, which aimed to understand the interaction process between nurse and person receiving EoLC in a hospital context. The results point to the urgent need for debates and proper training of health professionals in palliative care (PC), with regard to the meanings attributed to the body of a person in care at the end of life. To make known the meanings attributed to the body is, therefore, the objective of this reflection, opening up a new ontological possibility that highlights the development of the nurse as both a person and a professional. It is concluded that the meaning attributed to the body by the nurse is relevant to the production of meanings when dealing with the body of a person in EoLC, which gains relevance and meaning in PC. Finally, we also highlight that, in the work that gave rise to this article, ethical, consent, confidentiality and data security issues were considered and respected.

Keywords: Nursing; End of Life Care; Palliative Care; Family.

RESUMO

Trata-se de uma reflexão, com características de ensaio argumentativo sobre a interpretação dos significados dos corpos de pessoas em cuidado ao fim da vida numa perspectiva conceitual: enfermeira/paciente/família. Esta tríade é relevante na produção de sentidos quando se lida com o corpo do Outro, requerendo um cuidado físico, psicossocial e espiritual. O conceito de “corpo transformado” emergiu de um estudo de investigação, que teve por objetivo compreender o processo de interação entre a equipe de enfermagem e a pessoa em cuidado ao fim de vida num contexto hospitalar. Os resultados apontam para a urgência de debates e formação dos profissionais de saúde na área dos Cuidados Paliativos, no que diz respeito ao significado atribuído ao corpo da pessoa em cuidado ao fim da vida. Dar a conhecer os significados atribuídos ao corpo é, pois, o objetivo desta reflexão, abrindo-se uma nova possibilidade ontológica que coloca em evidência o desenvolvimento da enfermeira como pessoa e como profissional. Concluiu-se que o significado atribuído ao corpo pela enfermeira, é relevante na produção de sentidos quando se lida com o corpo da pessoa em cuidado ao fim da vida, o qual assume pertinência e sentido nos cuidados paliativos. A presente reflexão respeitou os aspectos éticos inerentes a pesquisa científica.

Palavras-chave: Enfermagem; Assistência Terminal; Cuidados Paliativos; Família.

BACKGROUND

The interpretation of the body is directly dependent on its representation and existing disease. Hence, a possibility arises for the body to be taken as a text, subject to reading and interpretation. The more one values a body, the more difficult

it is to accept its constraints, and the greater the domination exercised over its functioning. The degradation process of a physically vulnerable and suffering body is expressed and discussed with embarrassment, although this process is a phenomenon intensely experienced by a person receiving care at the end of her or his life, as well as by a nurse pro-

¹Universidade dos Açores, Escola Superior de Saúde, Ponta Delgada, Portugal.

Corresponding author: Cidália de Fátima Cabral de Frias; **E-mail:** cidalia.fc.frias@uac.pt.

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professional who accompanies them. The present reflection is justified, therefore, because it is known that recourse to PC units is part of the life experience of many people and their families, and the nurse is aware of the fact that a patient's body is not just a receptacle of care, thus internalizing the importance of the interpretation of the meanings of the body of a person on EoLC. It is verified that bodies change vertiginously, and nurses are aware that a person at the end of life is not an "object", but a body-subject and, thus, they do not run the risk of disintegrating the person and treating her or him as an object of her care¹. This article, therefore, consists of an argumentative essay on the interpretation of the meanings of the body of patients in EoLC from a conceptual perspective: nurse/patient/family.

NURSING CARE AND THE TRANSFORMED BODY

The body is part of a person's unity that maintains care for the other as a "transformed body". Such a body, a result of a disease process itself, highlights the significant impacts that diseases have on the person in care at the end of life, as both patient and nurse perceive the body in different ways. This perception has to do with what is captured by making use of different sense organs and the meanings attributed to them. Hence, their concerns as well as their potentialities and strategies are different in the process of care. Perceiving from the different actors leads to considering the different points of view of the person in EoLC and the nurse. It means that the intervenients know that the disease manifests itself in a body, which leads nurses and patients to use their bodies in the construction of care, although in quite opposite ways and perspectives.

The body of a person in EoLC is fragile and progressively surrenders to the nurse who, in turn, acquires physical and emotional strength by interpreting different meanings. The parts of that body do not come together one at a time to form a system, but are mutually involved, building a whole. In this interaction and based on a doctoral study¹ carried out in Portugal by one of the authors of this article, surrendering the transformed body led both nurse and person in EoLC to a level of mutual trust.

Both conceived the movements of their bodies intentionally, in the case of a circular, self-reproductive process based on trust and interaction, thinking that surrender takes place based on trust¹. In this interaction, there is an interpretation of body sensations experienced by the person in EoLC, attributing a certain meaning to them. That is, helping the patient to become an integral part of an interactive process,

which involves the person in EoLC and the nurse, leading to new meanings and new understandings, albeit with different viewpoints. This perspective highlights the impact of experiencing the disease, in general, in a process of interaction between the people involved. They are conceptual and lived realities arising from successive encounters.

In order to understand the experience of the disease, with a look at the body, it is essential that the nurse is aware of how the person understands the situation that is experienced, expressed by herself, and not based on her perception of it. The way in which the person becomes self-aware of her condition of physical and emotional fragility is a result of her own perception of her disease history, with moments of enthusiasm and discouragement, mutilating surgeries, the late diagnosis of the disease, the health services that belatedly responded in carrying out complementary tests for the diagnosis of the disease. Thus, it is worth noting that it is important to know how the person has accepted her dependence and physical and emotional weakness. This is because the nurse and the person in EoLC are accomplices in knowing the experience of an oncological disease, its social representation and the process of degradation of the body.

The understanding on the part of the person in EoLC of the evolution of her situation leads the nurse to find out how the person understands the evolution of the disease, as well as who has helped her in this process, as we know that physical changes will get worse. The nurse performs a (re) appraisal of the person with the double aim of producing an analysis of the situation and, simultaneously, of planning care, aiming to build individualized care for that body. Thus, it seems important that the nurse has knowledge about the meaning that the person in EoLC attributes to her current moment of experiencing the disease, leading the professional to frame the knowledge that she may already have about the person, which allows her to understand the stage she is in and how she perceives her body.

A patient often arrives physically and emotionally fragile at a palliative care unit. It is important, therefore, to emphasize the nurse's sensitivity, her sense of opportunity, in addition to verifying the dynamism necessary for data collection that is intended to be updated and complete, in order to make it possible to satisfy the needs of the person/transformed body. Thus, nurses are expected to demonstrate their intention to analyze the person's situation and, at the same time, envisage what kind of care needs to be built, which is of fundamental importance, as it helps those professionals to structure care encounters with the objective to draw up a plan that is not dissociated from the disease process that everyone, individually and in their own way, experiences.

The nurse intends to understand the situation of the person in EoLC and wants to understand the experience of a disease process narrated in the first person, marked by several stages and with strategies mobilized by the person, of discoveries of the potentialities. In addition, the nurse also intends to understand who the persons were who helped the patient to “support” this process in recent times. This period refers to the idea of how the patient has overcome the side effects of chemotherapy and/or interruption of treatments, as well as forms of leisure found.

In this way, the first assessment of the patients’ needs is intended to find answers for them in their illness process, which requires an understanding of these same responses that made difficult or still difficult the life of patients and their family, and confronting what they found out with knowledge arising from information to which they had access, from physiology, psychology and sociology, and which help clarify how changes in the body are perceived. It is important to highlight that integrating the social, psychological and spiritual aspects in the care of the person in EoLC is also one of the objectives of palliative care².

Thus, the construction of nursing care is marked by other meetings in which the nurse becomes involved with the patient, in such a way that even the look of the sick person is interpreted by the nurse as a request for help. In those meetings, the nurse intends to know the patient’s possible needs and deepen the changes caused by the disease. The answers given by nurses in the already mentioned doctoral study and corroborated by Viana³ have other underlying issues related to the suffering of the nurses themselves when caring for a person in EoLC, either due to the “subjectivity” of the concept or by the “multidimensionality of symptoms” that a patient may present. Those meetings are often scheduled and interrupted with a “see you later” or a “tickling in the feet”, as a strategy to escape the situation that could cause nurses to suffer.

The nurses were unanimous in recognizing that the presence of the family with their loved one was a way of minimizing their own suffering, understanding that the family is the entity that most helped to support the experience of the disease and their suffering in that transformed body¹. In the same study, the results showed that there are cases in which nurses report suffering when they obtain little data about patients: they are those persons who arrive in a state of agony, without the company of a family member. In these cases, the nurse is left only with an interpretation of the data collected from what they perceive about the patient’s body.

Therefore, it becomes evident that the nurse’s main concern is centered on the ways found by patients in EoLC to

understand what interferes with their comfort and well-being. At the same time, they verify what the sick person’s new concerns are, with the intention of analyzing the situation, and also to demonstrate an intention to build care in an individualized way for “the transformed body”.

Those transformed bodies spend many hours in a state of drowsiness, looking at the ceiling with half-open eyes, without moving, or continually tossing and turning, needing the help of the nurses to perform all activities of life. In this sense, we found that it is necessary to care and monitor the body of a “living dead” frequently, in a growing delivery/attunement of bodies¹, that is, of harmony between both the nurse and the person in EoLC. The “tuning of bodies”, in our understanding, means that two “bodies” have already tuned in to each other. The two bodies have already harmonized, which has an explicit “emotional” character. The body is not purely physical/material, the body is in itself sensorial/emotional.

However, the nurses’ suffering can influence their daily practice in the way they take care of the person in EoLC. Taking care of those patients transcends palliative interventions, which involve actions that promote comfort, family monitoring, in addition to complex care situations. It is something that requires awareness, because what exists are unique situations, in the face of which nurses develop nursing care for patients in EoLC and their families.

CONCLUSION

Thus, it is evident that it is not a problem for the nurse to deal with the transformed body, accepting it as something inherent to human nature. Therefore, as long as the nurse can “be with” to interpret the shortcomings and weaknesses of the person in EoLC, a patient can experience his end of life like any other way of life. The presence of the nurse as a means to safeguard the patient’s vulnerability leads us to affirm, based on our experiences and readings, that a nurse’s presence before a sick person helps to understand that the nurse, the family and the society, in the experience of illness, and in the concrete case of a person in EoLC, attribute meanings to this process, from which they organize themselves in order to face, live with and understand the disease and the sick body.

We believe that this reflection reveals a portion of knowledge arising from practice, which is often hidden and is difficult to be unveiled. In this perspective, by describing that practice, it can help reveal, value and enrich such a practice in order to broaden the understanding of nursing care to the “transformed body”. In view of the breadth and importance of this theme and the moments experienced

by patients and nurses, the possibility of a path for a more in-depth reflection on the theme remains open, thus contributing to the construction of a clinical practice efficient and committed to human care at the end of life.

In this way, the present reflection is intended to bring together theory and practice, leading to an encounter of concepts and research on the subject, and giving rise to a new perspective on body care of a person at the end of life.

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