Unfinished business: report of a meeting and a rite of passage

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Abstract

Palliative care has arisen in medicine in order to optimize the medical care offered to patients, aiming at the relief of symptoms and holistic care for the individual rather than the disease. Because it is a relatively new specialty, professionals in this field often face situations that cannot be explained simply by technoscientific knowledge. Based on an experience report, this article aims to reflect on the circumstances involved in the pre-death period.

Keywords: Bioethics. Palliative care. Hospice care. Spirituality.

Resumo

Assuntos inacabados: relato de encontro e rito de passagem

Os cuidados paliativos surgiram na medicina com o intuito de otimizar a assistência médica oferecida ao paciente, visando o alívio dos sintomas e a atenção integral ao indivíduo em si, e não à doença. Por ser especialidade relativamente nova, muitas vezes o profissional dessa área depara-se com situações que não podem ser explicadas simplesmente pelo conhecimento tecnocientífico. A partir de um relato de experiência, este artigo objetiva refletir sobre as circunstâncias envolvidas no período pré-morte.

Palavras-chave: Bioética. Cuidados paliativos. Cuidados paliativos na terminalidade da vida. Espiritualidade.

Resumen

Asuntos pendientes: relato de encuentro y rito de pasaje

Los cuidados paliativos surgieron en la medicina con el propósito de optimizar la asistencia médica ofrecida al paciente, tendiendo al alivio de los síntomas y a la atención integral al individuo en sí y no a la enfermedad. Por ser una especialidad relativamente nueva, muchas veces, el profesional de esta área se enfrenta a situaciones que no pueden ser explicadas simplemente por el conocimiento tecnocientífico. A partir del relato de una experiencia, este artículo tiene como objetivo reflexionar acerca de las circunstancias involucradas en el período pre-muerte.

Palabras clave: Bioética. Cuidados paliativos. Cuidados paliativos al final de la vida. Espiritualidad.

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In addition to offering comprehensive care to the patient and enabling him or her to die a dignified death according to its precepts, the palliative care ward exposes the health team to certain times and conditions involving dilemmas. The São José dos Pinhais Hospital and Maternity (Hospital e Maternidade São José dos Pinhais, HMSJP), located in São José dos Pinhais, in the metropolitan region of Curitiba, Paraná, Brazil, recently implemented its palliative care service, under the guidance of a bioethics master's doctor, and has already gifted its team with some of those moments. "Gifted" because they are situations that make explicit the fact that medicine cannot yet explain the nature of emotions and their impact on human life and death.

Thus, from the pre-death report of a case that occurred at the HMSJP medical clinic in 2018, the purpose of this article is to exemplify one of these situations, reflecting on the circumstances that possibly make it possible. In order to preserve the anonymity of those involved, the authors deliberately chose to hide their identity. The reflection was based on books and texts that address death and bioethics.

Clinical case

Death is inexorable, often failing any medical effort to try to postpone it. However, subjective observation of some cases suggests that certain patients wait for certain events to allow themselves to die. The case in question occurred at HMSJP, in the same city where the 83-year-old patient had lived with her daughter for two years, since she became progressive and totally dependent on activities of daily living due to vascular dementia syndrome.

The hospitalization occurred in April 2018, when the patient was taken by her daughter to the hospital because of mental confusion. Clinical and complementary exams showed bronchoaspiratory pneumonia. The care-giving daughter was consulted about the patient's values and informed of the clinical condition and, after reflecting on the patient's total and progressive functional loss, by shared decision, we opted for comfort measures for a dignified and painless death, among the loved ones.

The patient remained confused and, within her babbling, the only understandable word was the name of the granddaughter to whom she was most attached. As only one of the three daughters lived in the city, the family members requested her transfer to her hometown, Palmas, Paraná, Brazil, where the other relatives and the granddaughter she had called lived. While the bureaucratic processes were underway for transfer, the patient's condition worsened with organ dysfunction secondary to ongoing pulmonary sepsis, presenting hemodynamic instability and ventilatory and renal dysfunction requiring morphine to control dyspnea. Since this progression of the condition made it impossible for the patient to transfer and her family members had no means of transport to travel to the hospital, it was decided that the care-giving daughter would go pick them up.

From that moment, the multi-professional team became the only source of affection and social and spiritual support that the patient had in that environment. Progressively, despite palliative measures, her breathing became agonized, requiring palliative sedation for comfort; clinically, the team estimated these to be the last minutes or hours of the patient's life. However, the situation, which until then had been rapidly worsening, stabilized without any dysthanasic measures, remaining unchanged for two days. At 4 pm on April 27, the granddaughter for whom the patient was crying so much at the beginning of the hospitalization arrived at her grandmother's room; At 4:10 pm the patient's condition evolved to a comfortable cardiorespiratory arrest, in the presence of her family members and the multidisciplinary team.

Discussion

This argument is purely philosophical and speculative since there are no qualitative or quantitative data in the medical literature that provide a causal relationship between the arrival or presence of family members or the resolution of personal issues and the evolution to death. However, people working in hospitals, where death outcomes are recurrent, know that situations like this occur, although they are poorly reported. The most skeptical, on the other hand, may view these cases as mere coincidence or the work of chance. Still, the few records on the subject make this article unique in the medical literature, despite reporting only one case.

The concept of total pain proposed by Cicely Saunders [1] in the 1960s at St. Joseph Hospice in England may help to analyze the issue. A patient whose physical symptoms are controlled (without dyspnea, receiving timely analgesia, bronchial hygiene measures, etc.) may remain with uncontrolled social, physical, emotional, or spiritual symptoms, possibly being the reason for the patient not to "let go".

In this conception, health and absence of pain are disconnected and the individual is comprehended in its entirety, in all aspects, including spiritual ones. It is also worth noting that sometimes spirituality is the way to cope with illness and alleviate suffering [2]. Leonardo Boff points to the fact that *spirituality has been discovered as a profound dimension of the human being, as the necessary moment for the full unfolding of our individualization and as a space of peace amid social and existential conflicts and desolations* [3].

The confrontation with serious illness reminds the human being of the brevity of life and the urgency of really important projects. Usually, in this final stage, the individual, when ranking values, realizes that the affectivity, family ties, and human relationships are what is really essential. Saunders [4] mentioned that patients seek people who strive to understand them, and in this sense, the feelings and attitudes of the multidisciplinary team deserve to be understood and worked in order to contribute to the relief of emotional and social suffering. Elisabeth Kübler-Ross [5], in "On Death and Dying," highlights how the assistant team tends to deny the terminality of their patients and to avoid it. This generates, in the professionals, reactions of indifference or even hostility that affect the patient's care and therefore need to be worked out [5]. Even in this context of non-physical pain, the same author shows that often the family reflects the stages of grief that the patient is experiencing, and once again, it is the role of the assisting team to prepare family members to accept the separation process more smoothly.

Clinical practice shows that not everything in medicine is predictable or explainable. Sudden improvements or incomprehensibly postponed deaths are sometimes accompanied by the need for encounters with medicinal powers, that is, those that can heal. So it is also important to remember that each individual is part of a web of relationships and affections that is sometimes the support of many. When one element of this connection dies, aspects of the lives of others, interconnected in this web, die as well. Understanding this living and connected structure of bonds and affections, we also understand the importance of re-signification events and reunions for both the departing and the remaining [5].

Final considerations

We cannot, after all, understand issues that deal with something still immeasurable, but recognizing the existence of unexplained clinical improvement in order to allow encounters is already the first step for medical and multidisciplinary teams that care for end-of-life patients. This is an event that cannot be technically explained yet, but whose occurrence is found in the practice of palliative care. Reports like this are still the exception in the literature, perhaps because current medicine focuses too much on protocols and scales, perhaps because of the complexity of trying to explain them. In a way, by reporting a single case, the article is at fault for "scientific weight"; However, it is necessary to emphasize the difficult task of writing about something so subjective.

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Participation of the authors
Adriana Rodrigues da Silva Utida supervised the work and complemented the version to be published. Alexandre da Silva Faco Junior prepared the introduction and the discussion. Geraldo Karam Joaquim Mousfi wrote the case report.

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