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SHORT COMMUNICATION

Illness and death: how we cope with the end of life of a family member as health professionals

Enfermedad y muerte: cómo afrontamos el final de vida de un familiar siendo profesionales de la salud

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ABSTRACT

As healthcare professionals, we face the daily challenge of providing quality care to our patients with different pathologies at different stages, often even at the end of life. However, what happens when one of our family members is the one who is going through the end of life? Are we able to get involved as primary caregivers? If we do, how does it affect us emotionally? Has our profession given us the necessary tools to handle such a situation? We ask these questions based on the premise that, although we are dedicated to caring for others, we are only sometimes prepared to do so with people we are united by love or affection. About the subject of study of this work, we highlight the personal experiences of this team and colleagues, who could/we were able to contribute different life experiences in the personal sphere without leaving aside our professionalism when making decisions, finding a bibliography that relates in a scientific and empirical professional way that serves us as a theoretical framework, but that does not propose its application in the specificity that we propose, that is, our professional being related to the personal experience lived. As a common denominator, most of the colleagues consulted, and ourselves believe that experience in the practical field helps us to provide comfort and security to both the patient and the family environment, not only in the end-of-life process but also in the context of some pathology in the acute phase.

Keywords: Illness; Death; Familiar; Final De Vida; Healthcare Professionals.

RESUMEN

Como profesionales sanitarios, nos enfrentamos diariamente al reto de prestar una atención de calidad a nuestros pacientes con diferentes patologías en distintas etapas, a menudo incluso al final de la vida. Sin embargo, ¿qué ocurre cuando uno de nuestros familiares es el que está atravesando el final de la vida? ¿Podemos implicarnos como cuidadores principales? Si lo hacemos, ¿cómo nos afecta emocionalmente? ¿Nuestra profesión nos ha dotado de las herramientas necesarias para manejar una situación así? Nos planteamos estas preguntas partiendo de la premisa de que, aunque nos dediquemos a cuidar a los demás, sólo a veces estamos preparados para hacerlo con personas a las que nos une el amor o el afecto. Sobre el objeto de estudio de este trabajo, destacamos las vivencias personales de este equipo y compañeros, que pudimos/pudimos aportar diferentes experiencias vitales en el ámbito personal sin dejar de lado nuestra profesionalidad a la hora de tomar decisiones, encontrando una bibliografía que relaciona de forma científica y empírica profesional que nos sirve de marco teórico, pero que no propone su aplicación en la especificidad que proponemos, es decir, nuestro ser profesional relacionado con la experiencia personal vivida. Como denominador común, la mayoría de los colegas consultados, y nosotros mismos creemos que la experiencia en el ámbito práctico nos ayuda a proporcionar confort y seguridad tanto al paciente como al entorno familiar, no sólo en el proceso final de la vida sino también en el contexto de alguna patología en fase aguda.

Palabras clave: Enfermedad; Muerte; Familiar; Final De Vida; Profesionales Sanitarios.

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INTRODUCTION

As healthcare professionals, we face the daily challenge of providing quality care to our patients with different pathologies at different stages, often even at the end of life.

However, what happens when one of our family members is the one who is going through the end of life? Are we able to get involved as primary caregivers? If we do, how does it affect us emotionally? Has our profession given us the necessary tools to handle such a situation?[1]

We ask these questions based on the premise that, although we are dedicated to caring for others, we are only sometimes prepared to do so with people we are united by love or affection.[2]

Through this essay, we consider the emotional resources our profession gives us to face the end-of-life care of a family member or person with whom we have an affective bond.[3]

At the end of this work, we hope to be able to reflect on these circumstances of which we are all a part but which we face differently, being able to give an account of the experiences lived by the members of this work and some colleagues who went through a similar situation.[4]

DEVELOPMENT

Dying, or the end of life is a concrete act from which no living being is exempt. As health professionals, we see family members close to our patients in the hospital setting, sometimes just accompanying them, other times providing the care that the patient needs, collaborating with the health team.[5]

However, how do we act when a loved one needs care? Are we capable of caring for them? Do we act as health professionals or family members? How do we face the end of the life of someone so close to us?

Let us start by giving a notion of what palliative care is. According to the definition of the World Health Organization, it is a care model that improves the quality of life of people who are going through an incurable disease or situations in which life is at risk, alleviating suffering and physical, emotional and spiritual pain, both of the patient and his or her environment, trying to reduce the negative impact of the disease and the treatments that the patient faces to cope with it or to minimize the discomfort, pain or suffering that this moment implies.[6]

As nurses, countless times, we have had patients needing palliative care. Sometimes, the patient was alone, as during the COVID-19 pandemic, and in those moments, we often had to give the patient a hand so that he/she would not feel alone or afraid beyond the pertinent care according to each one's situation.[7]

Other times, the patient was accompanied by family members, and they were in charge of their care, collaborating with the health team, as well as those who only accompanied the patient because they said they did not know how to proceed with the patient's needs, but they were willing to collaborate.[8]

In order to carry out this project, we have searched for a bibliography (cited in the corresponding section). However, we have also consulted colleagues who have been the primary caregivers of relatives.

One of the questions to be answered is the emotional impact, not only to cope with the mourning for the loss of the loved one but also the constant stress to which the family caregiver is subjected when assuming this role. It is not only providing care for the illness but also fulfilling the wishes of the patient-family member or even deciding not to do so if necessary, for example, when the patient decides to stay at home to spend his last moments, but it is necessary to admit him to an institution for better care. Long hours close to the patient lead to physical, mental and emotional fatigue, which we need help to avoid.[9]

Some colleagues reported not having experienced being the primary caregiver of a family member, and most wished they would never have to go through that situation again.[10]

Below, we refer to the interviews with colleagues and among ourselves, which cannot be added as a file in the bibliography due to technical issues (impossibility of attaching audio files to a .doc sheet):

On the other hand, Licenciada Betiana Llanos, a nurse on duty and of long trajectory and preparation, who could not care for her grandparents at the end of their lives because they were far away, expressed herself by saying that she would not know whether to agree to the care of someone close and in case of doing so, patient care should take precedence over emotions.[11]

Eliana Larramendi is trained as a social psychologist and nurse practitioner in adult general hospitalization. She reports caring for her in-laws, her former brother-in-law and a woman she knew with terminal cancer. In her experience, she tells us that her professional training gave her the tools to talk to the doctors and report the symptoms or adverse effects of the patient's family member or even help with a bath or suggest it if the patient agrees.[12] The conditions are right to do so, prioritizing the comfort at the end of life of the patient-family member. Lorena Orbe is a nurse practitioner and a social psychologist.

Lorena Orbe is an ICU nurse. She was a caregiver for her parents and told of two different experiences. In her mother's case, she only had the necessary experience for the practices performed during her professional training.[13] Her mother, after minor surgery, was hospitalized in intensive care. At that time, she did not know how to suggest care or minor interventions related to the patient's comfort, which, in her words, are the result of experience. This reason also led her not to have the tools to manage emotions in that situation. On the other hand, when she was with her father, she was calmer and took the situation with more temper since she had more experience and knowledge about the situation her father was going through. Moreover, she maintains that she would be emotionally and professionally empowered if she had to go through that situation again.[14]

Iván Mendoza, a nurse practitioner in emergency medicine and adult ICU, tells us about his experience caring for his father, who had terminal colon cancer. He refers to his professional training, which helped him to cope with the situation and even says that while taking care of the stoma, he would talk to the father, explaining what they were doing to give him peace of mind.[15] Regarding

the situation itself, he says that having had patients in palliative care led him to work together with family members, which helped him to talk to his family about how to handle the situation and what to expect, but, even so, all this experience did not help him to cope with the moment of caring for his father. She reports a strong bond with the father and that all her training and experience could not be applied to caring for her loved one.

Rosalia Cruz, an adult general hospital nurse, refers to her father's illness when she was still a student.[5,16] She maintains that not only the technical part is important but also the practical experience in patient management. Rosalía says that this knowledge would have given her the tools to manage better in the hospital setting and at home. After this situation, she had a patient with whom she managed to bond after months of care and provided all the necessary care. She states that with this patient, named Luis, she feels that she was able to vindicate the shortcomings she had with her father at the end of his life.[17]

We, who are thinking about this project, are no strangers to the care of relatives or acquaintances, and we have different experiences that we would also like to capture.

Ivana Tolaba, a nurse in the Imaging area, has not had to go through an end-of-life situation with family or friends where she was the primary caregiver since she became a professional. However, she has been consulted by relatives at a distance. A 35-year-old cousin who lived in Brazil suffered from COVID-19, and they asked if he could return to Argentina since the borders were closed. He did not have a primary disease, but his health worsened, and he was hospitalized in intensive care until he died. Family support was critical.[18]

Juan Carlos Manos worked as a nurse in the ICU and PICU. In his case, he was not his father's primary caregiver since a family group supported the situation. He relates that in his family experience, he only gave his opinion since decisions were made jointly. He maintains that his training and experience gave him the tools to be able to guide his family in making decisions, giving priority to the patient's comfort and not invading with measures that would only serve to prolong an unfailing process, thus adding measures that would not only generate discomfort and pain but would also be a merely technical end without taking into account the patient's humanity at the time of the end-of-life process.[19]

Antonella Linares, an adult General Hospitalization and Intensive Care Unit nurse, had two different experiences with her parents. Her mother became ill with COVID-19 at the beginning of the pandemic. At the beginning of the illness, while she was at home, she treated her mother the same way she would treat a patient, explaining procedures and administering medications and other care. This was not the case at the hospital level since, in the first instance of the pandemic, patients were isolated without the possibility of family visits.[20] Two years later, his father was diagnosed with late terminal testicular cancer. He reports having had the experience and the necessary tools to cope with the situation, prioritizing comfort and reducing as much as possible the suffering of the patient-family by deciding not to perform invasive measures in the face of the irreversible condition or the administration of sedation in the face of the agony of the family member despite the patient's lucidity and performing the relevant care in the hospital environment, as well as collaborating with the nursing staff by performing some bathing, mobilizing the patient-family member and being attentive to the signs of the end of life.[21]

CONCLUSION

About the subject of study of this work, we highlight the personal experiences of this team and colleagues, who could/we were able to contribute different life experiences in the personal sphere without leaving aside our professionalism when making decisions, finding a bibliography that relates in a scientific and empirical professional way that serves us as a theoretical framework, but that does not propose its application in the specificity that we propose, that is, our professional being related to the personal experience lived.

As a common denominator, most of the colleagues consulted, and ourselves believe that experience in the practical field helps us to provide comfort and security to both the patient and the family environment, not only in the end-of-life process but also in the context of some pathology in the acute phase.

Although each person has his or her tools to face stressful situations in life, we all agree that the training we have is essential for the comfort, safety and peace of mind of the patient, who must also be emotionally prepared to cope with the last stages of his or her life together. Their intimate/family environment.

As health professionals in the field of nursing, concerning moments of palliative care assistance, we suffer continuous exposure to traumatic situations. However, it is also worth mentioning the feeling of satisfying emotions that compensate for moments of anguish. Possessing resources such as training in self-care and emotional regulation, as well as having social support, is vital to include in our training, taking into account the holistic orientation of health sciences education, in order to provide quality care and avoid the appearance of compassion fatigue, with emotional and physical responses.

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