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## RESEARCH

## Bioethical reflection on caring for a child facing death

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### Abstract

Ethical problems involved in death are exacerbated or more complex in the case of terminally ill children. Using the deliberative method, this article reflects on the value of human dignity based on the case of a girl at the end of life. We address issues related to therapeutic efforts, respect for the parents and children's autonomy, nurse role as an advocate for the patient's well-being and the self-care of health professionals. Death is a difficult process for the health team. Providing care at this stage implies respecting dignity, promoting autonomy and good dying. For this, new proposals are essential to contribute to the well-being of people at the end of their lives, particularly when health institutions do not meet their needs.

**Keywords:** Death. Bioethics. Pediatric nursing. Terminally ill.

### Resumo

#### Reflexão bioética no cuidado da criança em estado terminal

Os problemas éticos diante da morte são mais graves ou complexos quando envolvem crianças. Este artigo reflete sobre o valor da dignidade humana a partir de revisão do caso de uma menina em fim de vida, analisando-o pelo método deliberativo. Consideram-se ainda questões relacionadas com a adequação do esforço terapêutico, o respeito à autonomia de pais e filhos, o papel dos profissionais de enfermagem como defensores do paciente e o autocuidado desses profissionais perante situações de morte. A terminalidade é processo difícil para a equipe de saúde, e o cuidado nessa fase implica respeitar a dignidade, promover a autonomia e a boa morte. Para isso, são essenciais novas propostas que contribuam para o bem-estar das pessoas no fim de suas vidas, principalmente quando as instituições de saúde falham em atender a suas necessidades.

**Palavras-chave:** Morte. Bioética. Enfermagem pediátrica. Doente terminal.

### Resumen

#### Reflexión bioética al cuidar un niño que enfrenta la muerte

Los problemas éticos ante la muerte se agudizan o complejizan con los niños. El presente artículo reflexiona sobre el valor de la dignidad humana a partir de la revisión del caso de una niña que enfrenta la muerte, analizándolo desde el método deliberativo. Se revisan problemáticas en torno a la adecuación del esfuerzo terapéutico, el respeto por la autonomía de padres y niños, el rol de la enfermera como defensora del paciente y el autocuidado de los profesionales de la salud ante la muerte. La condición terminal es un proceso difícil de manejar para el equipo de salud, y el cuidado en esta etapa implica respetar la dignidad, fomentar la autonomía y favorecer el buen morir. Para ello, se hace imprescindible responder con nuevas propuestas que contribuyan al bienestar de las personas al final de sus vidas, particularmente cuando las instituciones sanitarias no logran dar respuesta a sus necesidades.

**Palabras clave:** Muerte. Bioética. Enfermería pediátrica. Enfermo terminal.

Ethical decisions at the end of life are frequent problems health professionals face. In their social role of containment and assistance, they often feel overcome by pain and even the fear that death can cause.

Caring for a child facing death transcends their grieving family. The training of health care professionals should be sufficient to support a good death, facilitating tranquility and the absence of pain, and at the same time contain the family's grief.

As such, the nursing staff caring for these patients require training in the technical and human aspects that will enable them to support the family and to provide palliative care for a good death. It also requires a strong bioethical formation allowing them to collaborate in deliberations regarding decision-making at the end of patients' life, influenced by promoting autonomy, which is understood as the capacity for self-direction based on rational reflection, and recognizing the health team's fragility, which often considers death a failure and refuses to stop the medical treatment.

Caring for terminally ill patients requires commitment and decision from those who assist them in a reality marked by temporality, since there is no time. Decisions must be made, and measures taken to promote a good dying. It requires high-level professional and human demands, since it involves caring for terminally ill patients, sharing fear, compassion, and pain with them and their family.

This article aims to discuss the value of human dignity based on a case review of a terminally ill girl, the result of an experience of one of the authors, using bioethics as a theoretical reference to review: adequacy of therapeutic efforts, respect for the autonomy of parents and children, nurse's role as the patient's advocate and self-care of health professionals when facing their patients' death.

### Account of a pediatric nurse

*"Gloria is a 12-year-old girl from a rural village near the city who is undergoing treatment for acute leukemia. Her prognosis is not good, she is in the terminal stage. The specialist committee's recommendation delivered two days ago is to suspend chemotherapy, continue palliative care and return home with the family. Her physician, however, insisted on continuing chemotherapy and hospitalizing her in isolation. Despite objections from the patient, her parents, and*

*nurses, insisting on returning home, the doctor ignored their request. Gloria was very weak, crying inconsolably and requesting to go home with her family; she wanted to be with her little brother who she had not seen for months. The clinical nurse, seeing the family's despair and empathizing with the situation, decided to request an evaluation and discharge from the doctor on duty. The pediatrician on duty said he was not qualified to discharge the child, but advised the family to speak directly with the Hospital Director, who upon hearing the request and reviewing the clinical file, agreed to the discharge, and the child returned home with her family that same Friday. Gloria died on Saturday at home, surrounded by her family. Gloria's mother called to inform and thank the nurse for helping the girl to share her last moments. She was especially grateful because Gloria fulfilled her last wish to see her little brother again and finally left peacefully" (Matilde, pediatric intensive care unit nurse).*

The analysis of this case takes as its starting point the dignity of the human being, which implies respect for people's autonomy and fundamental rights. Here, the children's right to be heard is materialized to respect their dignity when facing the end of life<sup>1,2</sup>.

The theoretical and methodological reference used was the ethics of deliberation proposed by Diego Gracia<sup>3,4</sup>, adapted to the context of poverty and social exclusion in Chile by Juan Pablo Beca and Carmen Astete<sup>5</sup>. Essentially, they emphasize the need to recognize others in their social, family, and personal context to establish health procedures that better addresses the needs and care possibilities that respects the will of the terminally ill patient.

Dialogue appears as a potential condition for reaching a consensus on patient care and all those involved. For this, the family and health team must participate in the decision-making process when assisting the terminally ill. Moreover, interdisciplinarity and self-care are promoted among health professionals affected by the other's pain.

Similarly, in a context of inequality and social discrimination, the dialogical work of nursing in patient care stands out, acting as the defender of the patient's rights. In particular, we highlight the work done by nursing to empower the patient's will against both the unequal opportunities in the Chilean public health system and the asymmetry of

wills between the patient (or the family) and health professionals, especially the doctor.

Given this, this article considers the deliberative process a rational analysis that promotes a reflexive advance of a collaborative type, confronting different views in search of prudent solutions, which can be posed as an alternative for decision making<sup>6</sup>.

We consider that Gloria's case allows reflecting on the following aspects of care at the time of death: the adequacy of therapeutic efforts, respect for the autonomy of parents and children, role of the nurse as the patient's advocate, and the self-care of health professionals when facing the patient's death.

### Adequacy of therapeutic efforts

Training health professionals for centuries has been focused on saving lives and applying every possible technique to keep the patient alive. The 20th century with its incredible technological and therapeutic advances brought forth the problem of adequacy: how long is it right to artificially prolong a life? Hence, in the second half of the 20th century, concepts such as excessive therapy, disproportional treatment and dysthanasia emerged. They point to the health team's inability to know when to stop medical efforts to save a life, an inability that subjects patients and families to great physical, emotional, and even economic suffering.

One of the contributions of the Ethics Committees was to develop the idea of limitation or adequacy of therapeutic efforts, reestablishing a balance between the benefits of a technique or medical treatment and the costs (physical, emotional and economic) involving patients and family.

Currently, the adequacy of therapeutic efforts lies in applying therapeutic measures proportional to the patient's context, clinical situation, and wishes. When the adequacy of therapy results in suspending the curative treatment because the patient is at the end of life, the treatment should continue, helping them in a good death by providing pain management measures such as sedation and support for the best possible quality of physical, psychological and spiritual life for the patient and their family<sup>7</sup>.

This adequacy has as its ultimate goal a dignified death, avoiding prolonging the agony, but also not precipitating death by external actions. The central tool for its correct application is the dialogue between patient, family, and health team. Knowing

wishes and fears is vital to help weigh the benefits produced by a treatment according to the burdens it poses on the patient, being able to evaluate its usefulness for each person.

The reviewed case highlights the difficulty that the health team, the family, and Gloria faced to establish a dialogue. In this case, communication problems arise due to the doctor's obstinacy in imposing his clinical authority over the rest of the health team and ignoring the wishes of the sick girl and her family.

The expert is the one who should adjust the treatment, here the doctor, as he holds the knowledge to do it. The doctor makes the diagnosis, the prognosis and proposes the appropriate treatment for the evolution of the disease in each patient. However, this is not the only consideration in decision-making.

Therefore, we should consider different factors in each case: 1) the diagnosis and possible treatments; 2) the patient and his family's will; 3) the context or reality of the family and clinical environment; and 4) the goals to be achieved in each case<sup>2</sup>. The four areas are mutually demanding, and deciding from only one of them is technically and morally inadequate from a professional standpoint. A broad understanding, considering all aspects of the case, is essential for a good analysis of the situation.

However, these aspects are not sufficient for establishing an adequate dialogue between the parties involved – even more essential is display a receptive attitude. This consists in all participants considering each other as valid intermediaries, that everyone has the right to express their will and others should accept it as authentic, genuine, and worthy of respect.

Being an expert in medicine knowing the technical aspects of a treatment is a fundamental contribution to decision-making, but it does not disqualify others involved in the situation. To decide, each of the participants must contribute with their knowledge and experience so the decision may be considered in its correct measure, promoting a better decision-making process.

This requirement falls primarily on the physician – as the one responsible for the treatment decision –, who has greater clinical authority and decision power, as well as greater responsibility to ensure that all those involved express their knowledge and will.

First, we must recognize that the situation is complex, and the responsibility placed on health professionals, particularly the physician, is daunting, as the death of a child is difficult to accept. However, professionals who cure, care for or accompany patients with high chances of developing a terminal illness require specific professional training that allows them to deal with the challenges in the dying process, putting the well-being of the sick person and their family first.

As in Gloria's case, health teams often do not reach a consensus on what is the best for a patient; thus, the professional must listen to the patient and their family. In general, doctors are unprepared for the death of their patients – they are psychologically unprepared to assist the dying person<sup>8</sup>. On the other hand, health teams lack sufficient training in bioethics, which delays decision-making about the end of life<sup>9</sup>.

These shortcomings are not a secondary issue in the health professionals' training; on the contrary, it is what differentiates a good professional from a bad one. Scientific knowledge, technical experience and even a clinical eye are insufficient to constitute a good professional – personal ethical competences are also required, such as the ability to dialogue with peers, although with different capacities, functions, and responsibilities.

### Respect for the autonomy of parents and children

Decisions should not be centralized only in physicians, but should be accessible to the healthcare team, the family, and the advice of clinical ethics committees. But cases where the patient and their family's opinion are ignored in the decision to adapt or reject treatment still exist.

In Gloria's case, for her physician, the desire to cure the disease was superior to the last wish of the girl and her family. Technical evaluation often exceeds the human one, and the maleficence of the fact is completely disregarded. By ignoring the sick girl's desire to return home and spend her last moments in the company of loved ones, the doctor condemned her to die alone. On the other hand, Gloria's parents are resigned and feel the need to dignify their daughter's death, respecting her last wishes of companionship and love.

In this case, the health team should review and agree on the measures that will adapt the therapeutic effort. It requires maintaining honest

and respectful communication with all participants. Health professionals must be committed and willing to listen repeatedly to the patient and their family<sup>10</sup>, as dialogue establishes the path for deliberation, decision-making and the correct exercise of autonomy.

Patient autonomy as a clear expression of respect for personal dignity is increasingly recognized in health centers. In private clinics, this occurs when treating the patient as a client who has the right to buy a clinical service or, as is happening in the public system, when law imposes the user's rights. In Chile, the law on patient's rights and duties aims to empower people to demand quality care, a dignified and respectful treatment<sup>11</sup>.

But this requires a respectful attitude based on the equal dignity of all human beings. A better life is achieved by mutual respect and in recognizing the value of each person's individuality. When applied to the care of the terminally ill, autonomy is understood as respect for the patients' ability to make decisions for their well-being. This decision must stem from sufficient and appropriate information given by the health team. Thus, autonomy becomes relevant for the patient to consent or refuse treatment.

When dealing with a terminal patient, we must remember that the person's history is ending; thus, we should ensure a life as comfortable as possible. Who better than the patients themselves to know what makes them happy at the end of their life, who they want to be with, how they want to face their last time, what they expect from what is left and after it, what they think of the impenetrable mystery of death? These questions are relevant at this time, with the evolution of the disease depending on the cure taking second place.

### The role of nurses as the patient's advocate

Patient protection is an important element of nursing care. Some authors report that the closeness established between this professional and the patient, through the continuity of care, determines listening and respecting the patients' autonomy, acting as their advocate<sup>12</sup>. It is not surprising, then, that the nurse is the one who advocates for Gloria and her family, since she understands that the girl is living her last moments and wants to spend them with her family. Most public hospitals lack appropriate conditions for the family to stay with the patient, and in this case, Gloria's last wish was to be with her little brother at home.

Under a paternalistic paradigm in health, the nurses' role was dictated by biomedical work and focused on the demands of health institutions. From 1960s to 1970s, when this paradigm ended, nursing professionals oriented professional care to users from the empowerment of their autonomy, defending and protecting patients from aggression or injustices of the health structures, empowering people of their bodies and accompanying them in the decision-making process<sup>13</sup>.

In the 1980s, this advocacy became recognized as essential to professional ethics given the closeness and time that this professional spends with the patient<sup>14</sup>. In the reviewed case, the nurse respects and understands Gloria's family values regarding the end of life, which led her to act as an intermediary prioritizing the patient's values against the team and the institution.

Nurses must recognize the needs of the patient and their family, helping to respect them as much as possible. Part of being a nursing professional is to manage and advocate for the good death of the patients in their care, which implies creating a dignified and respectful environment in the death process faced by the patient and their closest group. If home discharge is impossible, the hospital must provide basic comfort (absence of pain), privacy, companionship and spiritual assistance for the dying.

### Self-care of health professionals facing the patient's death

Institutions must adapt to receive the terminally ill and their family, and train health professionals who work in units that frequently assist end-of-life patients. Nursing professionals, who provide palliative care and accompany good dying, need continuous training to collaborate on the patient's and their family's mourning and to take care of themselves.

As such, health professionals must receive training in self-care, as they are equally vulnerable to the death experienced. Levinas<sup>15</sup> states that experience the death of the other affects us because we have the need to maintain proximity with our peers – the self feels responsible for the other. Accompanying, respecting, and protecting the patient at the end of life is motivated by the common condition of being human<sup>16</sup>.

Self-care is a responsibility of the system in general: on one hand, health institutions must

manage the health team; on the other, caregivers must seek their own self-care<sup>17</sup>. However, the reality in health systems reveals that training in self-care is disregarded in health institutions<sup>18</sup>, highlighting its absence in the professional training<sup>19,20</sup>.

One aspect of self-care is grief management in health professionals. In nursing, this is a widely reviewed topic, with authors agreeing on the lack of adequate preparation for these professionals, which generates feelings of helplessness and frustration. Nursing courses must address this issue to avoid negative attitudes such as escapism, denial, and coldness in clinical practice<sup>21,22</sup>.

Despite the suffering, nurses assume their professional role, often hiding their feelings regarding grief, which affects their mental health and eventually dehumanizes care in health institutions<sup>23</sup>.

Other studies show that some factors facilitate living the grieving process, such as expressing feelings and emotions, establishing positive ties with the family and the patient, caring responsibly, supporting each other and, especially, being assisted by experienced professionals<sup>24,25</sup>.

### Final considerations

Caring for people facing death presents multiple challenges and, in many cases, ethical issues for health professionals. Caring for a terminally ill patient involves respecting dignity, promoting autonomy, and supporting a good death. This task is made possible by assuming ethical deliberation as a method of communication and decision-making. To carry it out properly, the process must include all involved, recognizing that everyone is a valid intermediary, and aiming more at the patient's well-being than at life-sustaining treatments.

To achieve adequate professional accompaniment at the end of life, institutions and medical schools must train the health team to develop skills and abilities in ethical deliberation, as well as communication and grief management strategies for patients and their families. Similarly, health workers must receive continuous training in bioethics that allows facing new problems in critical health decision-making.

Our Latin American reality of geographical dispersion and poverty demands new proposals that can contribute to the well-being of people at the end of their lives, particularly when health institutions fail to respond to their needs.

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#### Participation of the authors

Margarita Poblete Troncoso selected the topic, wrote and reviewed the article. Beatriz Parada Romero worked on the chapter "The role of nurses as the patient's advocate." Marcelo Correa Schnake worked on the chapter "Respect for the autonomy of parents and children," as well as on the final version of the article. All authors worked on the bibliographic review.

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