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Pediatric palliative care, end-of-life and spirituality: Are we ready?

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Abstract

The pediatrician's daily challenge in dealing with children who develop life-threatening or life-limiting illnesses and their families requires that we extend the perception of care to the whole human being with its physical, psychological, social, and spiritual dimensions. In this context, the look at spirituality becomes essential in the care of children, adolescents, relatives and, ourselves, health professionals. Are we ready?.

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INTRODUCTION

While performing their duties, healthcare workers deal with individuals in various stages of their lives. These stages are quite clear in pediatrics: we care for them as they are born; as they take their first steps; as they start going to school; as their voices change amidst a rush of emotions and changes caused by hormones. We care for children in all stages of development and welcome their parents in their fear, joy, and uncertainty.

However, some moments are happier than others. When a child falls ill, we are faced with the fear and insecurity of their parents or guardians. When the possibilities of a cure are slim or when the child does not respond to the prescribed therapy and the end of life seems imminent, fear triggers an avalanche of distress that affects everyone involved in the care of the child (family and healthcare workers), particularly when the offer of palliative care is made.

According to the definition published by the World Health Organization in 1990, "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."¹

The WHO definition of palliative care for children says that "Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. Health care providers must evaluate and alleviate a child's physical, psychological, social, and spiritual distress."¹

Technological development has allowed children with complex chronic conditions to survive for longer. They often present with signs and symptoms associated with the isolated or combined involvement of the cardiovascular, respiratory, neuromuscular, endocrine, immune, and rheumatologic systems, and thus require specialized care and admission at a tertiary care facility.² These patients are entitled to having specialized pediatric palliative care the moment they are diagnosed with disease, regardless of whether or not they are receiving treatment directed at the disease in question. Palliative care can be provided in hospitals and even in children's homes with their families.¹

Palliative care encompasses spirituality, which may be broadly defined as a search for meaning and purpose in life, transcendence, the holy, and connectedness with the self, family, others, and nature.^{3,4} It manifests as an individual search mediated by religious groups with common beliefs such as faith in God, naturalism, humanism, family, or art.⁵ Therefore, spiritual care may be understood as attention to spirituality, presence, empowerment, and bringing peace to decrease distress, which implies creative, narrative, and ritual work.⁶

The end of life for pediatric patients brings up a number of relevant issues in bioethics, since the event is seen as a tragedy by the families and healthcare workers treating

children whose life cycles - being born, growing, giving birth to offspring, aging - are precociously interrupted. With these ideas in mind, we attempted to understand, by reviewing literature on the matter, how healthcare workers see disease, finitude of a child's life, and spirituality. And more specifically, how pediatricians face death and the feelings it evokes, and the strategies they use to cope with and overcome this stage of care.

TALKING ABOUT DEATH

*"We shall all meet it, sometimes as spectators, sometimes as leading actors."*⁷ Ana Cláudia Arantes

Although death is a natural, biological, inevitable event (it is the only thing we are certain of after we are born), we tend to ignore and repel it for not being able to fully comprehend it. In contemporary society death is cloaked in mystery, uncertainty, and fear of the unknown. These attributes have driven different cultures to find answers in myth, philosophy, art, and religion to remedy the anxieties inherent to death.^{7,8}

Death is still taboo in our societies. But it has not always been so. In ancient times, death was celebrated and understood as something valuable and special. The dead were cared for, mummified, appreciated and celebrated without fear or perceptions of failure. Modern age and the development of technology and science in the 20th century - and in the 1970s in particular - gradually imposed a scientific perspective on death over a humanistic approach. Death also ceased to be a family event. People no longer die at home with their families, but alone in hospitals.^{7,8} In medical training, the finitude of human life and death are now seen as failure, a perception that often interferes with the physician-patient-family relationship.

At times we forget that it is our job as health care providers to heal whenever possible and care for our patients always. To do so, healthcare workers must be well enough - spiritually, too - to provide the best care possible to patients and their families.

HEALTHCARE WORKERS, DEATH, AND SUFFERING

"Death has the power to put things in their places. Away from its glance, we are imprisoned by the eyes of others and fall into the trap of their desires." (Rubem Alves)

Death is something physicians in general hope not to encounter any time soon, and pediatricians much less. In ancient times, infectious disease outbreaks decimated entire populations, with children being particularly vulnerable. Advances in medicine have led to the development of vaccines, powerful antibiotic agents, better tests, and more effective treatment protocols, which have ultimately changed the scene and pediatric care in particular.

Although more frequent in intensive and neonatal care units, the death of children is also a reality in general hospitals and inpatient oncology units. According to data published by the José de Alencar National Cancer Institute (INCA) and the Brazilian Society of Pediatric Oncology, cancer ranks second in the list of causes of death of children and young adults.¹⁰

Feelings of apprehension, fear, restlessness, and failure tend to emerge when we are faced with patients with no hope for cure. Medical training taught us very little about how to deal with death and the finitude of life. The way physicians deal with death affects the teams they work with, patients and their families. In Western culture, the death of children triggers one of the most painful forms of grief.¹¹

We can never forget the fact that we are human beings filled with yearning, fear, and anguish. We will never find a solution for or drive death away by not talking about it. Understanding finitude is what drives the spiritual development of humans and connects us to our essence. We will only be prepared to face the death of our young patients when we are fully aware of our own finitude.¹² Suffering is inevitable when healthcare workers are disconnected from themselves, from the deeper meaning and purpose of their lives and work, and from the spiritual dimension of life.¹³

According to Reich, suffering is anxiety experienced as a threat to one's serenity, ingeniousness, realization of intentions and, more profoundly, as a frustration of the concrete meaning one finds in one's personal experience. It is anxiety caused by injuries or the threat of injuries to oneself and, therefore to the self in the center of suffering. Underlying all such threats is the threat to one's integrity, to the internal state of totality of every dimension in oneself.¹⁴

Spiritual integrity involves moral character integrity, compliance with moral norm, and behavior consistent with a set of principles and commitments. Thus, treatment decisions and dilemmas may undermine the definition of what healthcare workers believe to be justifiable and unjustifiable and befog the meaning of their work. We are vulnerable to rupture and must enhance our comprehension of suffering and finitude.¹³

Other perspectives are possible

When asked about what constitutes a "good death" in pediatric intensive care units, Garros D. concluded that the application of the basic principles of palliative care and family-centered care promotes dignifying deaths, even in high-technology environments. This is possible when families play an active role in a decision-making process characterized by mutual honesty, privacy, proper management of the child's symptoms, and openness to accept the rituals the family deems relevant. Therefore, observing the human elements and the spiritual dimension is a fundamental step in comforting children and their families during the course of the disease, whether or not it ends in death.¹⁵

CHALLENGES AND SPIRITUAL CARE: ARE WE READY?

Life-threatening and life-limiting diseases, particularly in pediatrics, are fraught with dilemma and ambiguous feelings of hope, guilt, and fear; quantity and quality of life, love for the child, and releasing them from suffering. When palliative care is offered to pediatric patients, we are invaded by feelings of sadness and failure for not being able to deal with this stage of the evolution of life.

When one of our patients dies, our minds are inundated by a wave of thoughts. Many health professionals choose to show empathy and seek explanations for the death of patients as a way to cope with it by attaching meaning and purpose to the event. We connect to our spirituality, to our essence.

Some of the papers published by healthcare workers (pediatricians, nurse technicians, and nurses) working with pediatric patients offer insight into the feelings and actions taken in situations of end-of-life care.

A study carried out at a university hospital in the State of Rio Grande do Norte probed into the feelings experienced by pediatricians when their patients died. The study also looked into how well they had been trained to deal with the death of pediatric patients. The authors found that the interviewed physicians had trouble accepting finitude, doubt as to whether there was something else they could have done for their patients, and difficulty accepting the imminent loss of patients to untreatable diseases on account of the lack of formal training they received on the matter at medical school.¹⁶

Another study enrolled 30 nurses working at the pediatric ICU of a large hospital in the city of Curitiba. The authors found that 30% of the nurses worked at the general pediatric ICU, 30% at the pediatric cardiac ICU, 20% at the neonatal ICU, and 20% at the surgical ICU. The participants answered questions related to the process of dying and death, expected and unexpected death, feelings experienced during the process, and how they coped with these situations (Chart 1).¹⁷ The study showed that the nurses felt unprepared to deal with death and dying children, an assignment they described as extremely painful. Several feelings emerge in the face of death, with powerlessness ranking as the most frequent among physicians and nurses.

A study carried out in February and March of 2013 enrolled nurses and nurse technicians working at a neonatal and pediatric ICU of a hospital in northwestern Rio Grande do Sul. Seven of the 11 healthcare workers initially enrolled answered questions on three topics: 1) the process of dying and the death of pediatric patients; 2) caring for the families as their children are provided end-of-life care; and 3) the need for professional training and knowledge on the subject.¹⁸

The following feelings and actions were cited when subjects were asked about Topic 1: the need to comfort patients and families and soothe their pain; the amount of energy one has to muster from within; the need to be "cold"

Chart 1. The process of dying at a pediatric intensive care unit - Question categories and answers

Categories	Answers	
How do you feel when your patients are dying/die?	Common	Difficulty interacting with patients and families. Empathy towards families as patients are dying/die.
	Nurses	Powerlessness before death/acceptance
	Technicians	Powerlessness before death/no acceptance
How do you feel when you are faced with expected and unexpected deaths?	Common	Acceptance
How can the care provided by a nurse be helpful in this process?	Common	Provide nursing care and comfort the families
	Nurses	Understand the limits of therapy
	Technicians	Do not understand the limits of therapy
What feelings do you experience as your patients are dying/die?	Common	Sadness and anxiety
Do you have or need support after the death of a patient to cope with the loss?	Common	Difficulty expressing feelings
Do you understand the cause of death?	Nurses	Understand the complications and progression of the disease
	Technicians	Do not understand the complications or the progression of the disease
Does it affect your work?	Common	It affects the climate at work
Does it affect the care you provide to other patients?	Common	No, or not anymore
		It affects the working environment
		It makes us reflect on the job we do
	Technicians	Feel unmotivated at work

Source: Souza PSN & Conceição AOF, 2018.¹⁷

at times in order to deal with the situation; feelings of defeat and frustration, given that they were trained to fight death and keep patients alive.¹⁸

With regard to caring for the families (Topic 2), participants mentioned empathy and compassion emerged from the ties and relationships developed with patient families during hospitalization; allow parents to spend as much time as possible with their children and comfort them by letting them hold their children on their laps while they are alive and even after they have died.¹⁸

Topic 3 - need for professional training - evinced a perception of lack of formal training at school to allow participants to reflect about death and dying and understand the process of dying as part of the cycle of human existence, regardless of the age at which it begins.¹⁸

These studies indicate that the discussions held at the institutions where we work and the curricula used as reference in the training of healthcare workers - physicians, nutritionists, nurses, physiotherapists, and others - must be reviewed along with the contents of medical residencies and fellowships. Multidisciplinary teams open to discussing these topics and the feelings and actions of healthcare workers might be more at ease to deal with their concerns and fears and provide better emotional support to face and understand death. In this process, they become better at handling spiritual, physical, and emotional issues and more prepared to work with the families of patients.¹⁸

Spiritual care translates into the human need for hope, love, safety, protection, and trust, and the desire to connect with the holy. Hope and love bring the ability to dream, assign meaning to one's unique life story, and appreciate the legacy derived from touching the lives of many.¹⁹

Spiritual care may be fostered by any member of the multidisciplinary team through actions such as assigning meaning to the values and/or religion of patients and families, building trust through communication, creating a legacy, resignifying relationships, conciliation, rituals, sharing fears, connecting with the holy, materializing wishes and hopes, and dealing with ambivalence.¹⁹

As healthcare workers, we must preserve our integrity and wellbeing by learning to deal with emotional responses, grief, and suffering. Cultivating a harmonious connection between body, mind, and spirit is the basis for caring for ourselves and others. Contemplative practices (meditation), adjusting one's lifestyle, mind-body practices, spiritual connections, appreciating gratitude, generosity, optimism and compassion, identifying things that give meaning to life, being close to nature, among other things, help establish a sense of purpose and meaning.¹³

Therefore, the requirements to implementing spiritual care include the development of skills such as self-reflection, give visibility to spirituality and spiritual care, and invite spiritual counselors to join the existing organizational structures.⁶

Regardless of specialty, as pediatricians and health care providers working with children and adolescents, we

must observe our purpose in offering care to patients in any stage of their lives, no matter how different care might be for patients at the start or at the end of their lives.

FINAL CONSIDERATIONS

Although we try hard to keep death at bay in our jobs, it will eventually meet us. It is at the end of the existence of our patients or of our own that significant reflections are made and attitudes change.

The meaning of life cannot be lost in its final stages.^{20,21} We must learn to use palliative care and to treat our patients as physical and spiritual beings, to thus care for their diseased bodies and soothe the pain of their souls and spirits, which may not be as ill as their material bodies. The essence of palliative care is spiritual, since it transcends human suffering and death by assigning meaning to it.²²

Spirituality is a profound, intimate human aspiration, a yearning for a vision of life and reality that integrates, connects with, transcends, and assigns meaning to existence, coupled with the development of qualities and values that promote love and peace.²³

The dimension of spirituality - a factor of wellbeing, health, and hope - should accompany our practice. Therefore, public and private health care institutions should offer spiritual care to healthcare workers, patients, and families.

We have chosen, as pediatricians, to help children and adolescents requiring differentiated treatment and care for them and their families. And provide care to them until the end of their stories with us.

Let us be physicians not only of the body, but also of the spirit, so we may "add life to our remaining days instead of adding days to our remaining lives."²⁴ Rita Levi Montalcini

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