

Communication of bad news in palliative care within pediatric oncology

Keyssiane Maria de Alencar Lima¹, Anice Holanda Nunes Maia², Isabel Regiane Cardoso do Nascimento³

Abstract

The study aims to understand the process of communicating bad news experienced by families of patients in hospice care from the pediatric oncology reference center in Fortaleza, Ceará, Brazil. This is a qualitative descriptive study using structured interviews with families of children and adolescents in palliative care and guided by thematic and categorical content analysis. It was observed that, in the view of family members, communication brings ambivalent reactions, involving the need to know and the suffering caused by the prospect of the child's death. Humanizing factors, such as an empathic stance, welcoming attitude and affection related to the others' suffering experience, resonate in the good relationship between professionals and family members. It is concluded that the communication in palliative care is an imperative in everyday pediatric oncology and causes suffering that requires mental health care. Thus, professional practice needs constant improvement in order to qualify the services of palliative care.

Keywords: Health communication. Truth disclosure. Medical oncology. Child.

Resumo

Comunicação de más notícias em cuidados paliativos na oncopediatria

Este estudo objetiva compreender o processo de comunicação de más notícias vivenciado por familiares de pacientes em cuidados paliativos exclusivos do centro de referência oncopediátrico de Fortaleza, Ceará, Brasil. Trata-se de estudo qualitativo-descritivo baseado em entrevistas estruturadas com familiares de crianças e adolescentes em cuidados paliativos e norteado pela análise de conteúdo temático e categorial. Observou-se que na visão dos familiares a comunicação provoca reações ambivalentes, envolvendo a necessidade de saber e o sofrimento causado pela possibilidade de morte do filho. Fatores humanizantes, como postura empática, acolhimento e afetos positivos relacionados à vivência de sofrimento do outro, repercutem na boa relação entre profissional e familiar. Conclui-se que a comunicação em cuidados paliativos é imprescindível no cotidiano da oncologia pediátrica e provoca sofrimentos que demandam assistência em saúde mental. Assim, a prática profissional necessita de constante aprimoramento de modo a qualificar os serviços.

Palavras-chave: Comunicação em saúde. Revelação da verdade. Oncologia. Criança.

Resumen

Comunicación de malas noticias en cuidados paliativos en la oncopediatria

Este estudio tiene como objetivo comprender el proceso de comunicación de malas noticias vivenciado por familiares de pacientes en cuidados paliativos exclusivos del centro de referencia oncopediátrico de Fortaleza, Ceará, Brasil. Se trata de un estudio cualitativo descriptivo, basado en entrevistas estructuradas con familiares de niños y adolescentes en cuidados paliativos y orientado por el análisis de contenido temático y categorial. Se observó que, en la visión de los familiares, la comunicación provoca relaciones ambivalentes, involucrando la necesidad de saber y el sufrimiento causado por la posibilidad de la muerte del hijo. Factores humanizantes, como una postura empática, la acogida y afectos positivos frente a la vivencia de sufrimiento del otro, repercuten en la buena relación entre profesional y familiar. Se concluye que la comunicación en cuidados paliativos es imprescindible en el cotidiano de la oncología pediátrica y provoca sufrimientos que requieren asistencia de salud mental. Así, la práctica profesional reclama un constante perfeccionamiento en orden a cualificar los servicios.

Palabras clave: Comunicación en salud. Revelación de la verdad. Oncología médica. Niño.

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1. **Especialista** keyssipsi@gmail.com – Centro Universitário Católica de Quixadá (Unicatólica Quixadá) 2. **Especialista** aniceholanda@hotmail.com – Unicatólica Quixadá, Fortaleza/CE 3. **Mestre** isabelregiane90@gmail.com – Faculdade Ari de Sá, Fortaleza/CE, Brasil.

Correspondência

Keyssiane Maria de Alencar Lima – Rua Benjamin Constant, 275, Alto São Francisco CEP 63908-235. Quixadá/CE, Brasil.

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In 1990, the World Health Organization (WHO)¹ completely redefined the concept of palliative care, but in 2002, it emphasized the need for prevention and alleviation of suffering as a way to improve the quality of life of patients and families facing issues associated with life-threatening diseases. This perspective includes early identification of the disease, in addition to the correct evaluation and treatment of pain and other physical, psychosocial, and spiritual distresses^{1,2}.

The therapeutic advances in the prevention, diagnosis, and treatment of childhood cancer have contributed to the increasing survival and cure rates of approximately 70% of patients diagnosed early. Despite the progress, cancer is already the second leading cause of deaths among children and adolescents under the age of 19³.

Cancer aggressiveness and other life-threatening chronic diseases requires active monitoring of the patient and family members since diagnosis. In this context, when the impossibility of cure becomes evident, it is estimated that 30% of cases will result in death. Therefore, palliative care, as an approach to improve the quality of life through integral and continuous care actions, aims to promote life and demonstrate that death is a natural process that should not be extended with futile therapeutic treatments^{1,4}.

The word “communicate” comes from the Latin “*comunicare*”, meaning “to make something common”⁵. Communicative situations in health care encompass decision-making and the health and quality of life of those involved in the process, which also require understanding between the parties and are not limited to the exchange of information, considering that the message is always linked to a feeling. Thus, all communication consists of two parts: the content one wishes to convey, and the feeling of the one who communicates. From that perspective, communication is a tool that can either strengthen the relationship among patient, team, and family members by bringing the parties involved together, or make their interaction more difficult^{6,7}.

The transmission of bad news carries ambivalence that affects both the patient and health professionals. Therefore, it requires assertive management in a process that uses healthy and adaptive coping resources, enabling the exchange of information among professionals, patients and families. In oncology, difficult news are frequent because the major changes caused by the decline of the patient’s clinical condition. It is a complex process that requires prior consideration of the

limitations of who is responsible for delivering the news and those of who is receiving them. Health professionals must value and improve their empathic capacity, as well as being willingness to listen^{8,9}.

This study aimed to understand how family members accompanying children and adolescents treated at the pediatric oncology reference center of the state of Ceará deal with the communication process of bad news.

Method

This is a descriptive, analytical, qualitative study conducted at the Centro Pediátrico do Câncer (CPC) (Pediatric Cancer Center) a unit that is reference for the treatment of childhood cancer, linked to a children’s hospital located in the state of Ceará. In 2009, the CPC implemented a palliative care service made up of a multiprofessional team specialized in childhood care. The information provided by the Center indicates that 3,435 children were treated under palliative care between January 2015 and June 2016, either as hospitalized patients or according to an outpatient regimen.

The data used for this study was collected between December 2016 and March 2017, in compliance with the requirements established by the research ethics committee. The study counted with the participation of three mothers and two accompanying parents of children and adolescents treated under exclusive palliative care, duly informed by the assistant physician. The age of the five participants ranged between 30 and 53. One of them was illiterate, two did not complete elementary school (grade 1 to grade 5), two completed elementary school (grade 1 to 9). Four interviewees were catholic and one was gospel-centered; only one was single and the other four, married. The number of children ranged from 3 to 9. Two of the parents were maids, one was a salesman, one a fisherman, and the fifth one was not working. The follow-up treatment time of their children ranged between 1 and 4 years.

Procedures

The CPC’s psychology service was used to identify accompanying family members and compose the sample, as this sector archives daily censuses and monthly reports regarding patients treated under palliative care. With the help of the psychologist responsible for the palliative care program, it was possible to check the inclusion

criteria, as well as family members of children and adolescents treated under palliative care, of both genders, of any kinship, who played the role of being the permanent companion, either individually or joined by someone else, who were accompanying CPC patients and informed by the assistant physicians that their children or close relative were being treated under exclusive palliative care.

Exclusion criteria included companions who presented any sort of cognitive deficit, who were emotionally weak, or involved with complications, so that it was not advisable to approach them; those about whom there were doubts if they knew their relatives were being treated under exclusive palliative care, or those who did not agree to participate in the study. Companions of dying patients were also excluded for the study.

Once the participants were selected, the free, prior informed consent was signed. An instrument was used to collect sociodemographic data and a script including structured questions was prepared to guide the interviews. The researcher visited the research location on Friday mornings and afternoons, Saturday mornings, and Monday mornings and afternoons. Participants were interviewed for about 40 minutes each, preferentially in the CPC's psychology room, or in other specific areas due to the work schedule of the caregivers responsible for

patients treated under palliative care. Permission was requested to audio record the interviews, and the files were permanently deleted after use.

Data analysis

The material was then transcribed, analyzed, and decoded by the categorical-thematic content analysis method¹⁰. The recording units (UR) were extracted from each interview and grouped into categories named after data processing, referring to the meaning of the speech. In total, 140 sentences were spoken by the family members regarding the theme addressed.

Results and discussion

The communication of bad news at the pediatric palliative care unit

Based on the communication among accompanying relatives, physicians, and other professionals, the following categories emerged: the first communication in regard to exclusive palliative care; sequential communication with team professionals; and feelings related to daily communication about exclusive palliative care. The excerpts that exemplify each category are shown in Table 1.

Table 1. Thematic-categorical analysis: significant excerpts based on category

Categories	Significant excerpts
The first communication in exclusive palliative care	
A room, family members, and professionals	<i>"It was just the doctor and I at the time of communication. Other professional came by later"</i> (F2)
Recall and unveiling of "everything"	<i>"They remembered everything about him and told me"</i> (F3) <i>"They talked about the situation; told me everything as soon as I walked in here"</i> (F2)
Sequential communication with team professionals	
Turn to the doctor for news	<i>"I ask the doctor"</i> (F3) <i>"I ask Dr. B"</i> (F5)
Seek other professionals to obtain news	<i>"I ask each one"</i> (F1) <i>"I ask Dr. B and the nurses"</i> (F5)
The positioning of physicians	<i>"It is hard for them, but that's their job"</i> (F5) <i>"It is normal for doctors"</i> (F3) <i>"But they have to do their job and let parents know; they have to tell parents so they can take action"</i> (F5)
Daily communication	<i>"They provide us with information a step of a time; they are careful with us. Others are very direct"</i> (F4)
Physicians who can communicate and sympathize	<i>"Dr. P is the best doctor; he works well. I would give him ten out of ten. He treats everyone well; he's a very good man"</i> (F4) <i>"Dr. B and the nurses tell us everything"</i> (F5)

continues...

Table 1. Continuation

Categories	Significant excerpts
The positioning of parents	<i>"But for me it is more difficult; I am the mother"</i> (F3) <i>"But for me it is very difficult"</i> (F2)
Awareness of what is going to happen	<i>"They tell us about his situation. They tell us about everything. It's great though I already know about his condition and what is going to happen"</i> (F3) <i>"But I am aware he is going to leave us. Because one out of 100 can overcome this disease; and his is adult-like, very difficult, something that is really evil, the worst there is; even surgery will not help him"</i> (F5)
Becoming aware of the situation	<i>"You keep hearing that your child can't get any better and the worst is going to happen"</i> (F3) <i>"It's hard to know he's not getting better"</i> (F1)
Suffering due to the reaffirmation of bad news	<i>"Until one day I asked them to stop saying that all the time. (...) So, I asked them to stop telling me; when I want to know, I will ask"</i> (F2)
Feelings towards everyday communication about exclusive palliative care	
Despair	<i>"I was desperate, it's not easy to hear that your child is going to die"</i> (F1)
Losing hope	<i>"Because when I first came here, they gave me a lot of hope; I went through a lot"</i> (F2)
Trust in God	<i>"I trust God"</i> (F4) <i>"Because God is wonderful and if it is His will, my son will get up from that bed"</i> (F4)
Non-acceptance	<i>"To this day, I haven't accepted it yet"</i> (F3)

The communication of bad news, within the scope of the service surveyed, does not follow a specific protocol, and there is no standard or operational procedure established. Although the impossibility of adopting a uniform, restricted procedure is emphasized due to the uniqueness of each conversation, the literature highlights the need to acquire specific knowledge and skills required to perform such activity. The protocols are considered guiding tools, and the importance of planning the interview considering the particularities of the moment is highly emphasized.

Lack of proper education or training generates non-empathic, brief, and iatrogenic communication. Thus, the relevance of changing formative practices throughout undergraduate programs and the need to create spaces to discuss the quality of the dialogue established between the sender and the receiver becomes more important than anything else. Studies also point out that elements such as sincerity, bond and empathetic contact are crucial during communication^{11,12}.

The analysis of experiences in palliative care conducted at the institutions mentioned in this research revealed that dealing with childhood terminality is still a complex process for health professionals and family members to deal with, in view of the tragic connotation linked to the death of children. This occurrence is exacerbated by the idea of survival built by the care team due to the recovery capacity of pediatric patients. When the possibility of death becomes evident, the

communication of bad news becomes more difficult between health professionals and family members, who are already affected by the outcome that has been just announced¹³.

The first communication in exclusive palliative care

The sentences given as examples in Table 1 indicate that the timing of communication is structured and decisive. Parents are taken to a reserved place and, in some cases, other family members and more than one health professional may get involved. Respondents reported that prior to being given the bad news, the whole case is recapitulated and then the news are delivered. Remembrance leads to the gradual revelation of the blunt news, announcing the possibility of finitude. The analysis of this process reveals the great amount of pain family members have to endure.

Disclosing the fact that the therapeutic treatment has failed fulfills an ethical right to information and a bioethical respect towards autonomy. It interferes with satisfaction and adherence to treatment and involves active subjects in the illness process, strengthening their ability to make choices, according to the principles of beneficence and non-maleficence, establishing the direct dialogue with the precepts of palliative care⁹.

The first communication revealed that the ambivalence of difficult news within the exclusive

pediatric palliative care requires assertiveness during the transmission of information to configure the humanizing aspect of health care. The possibility of death among children and adolescents reverses the logic of social life and makes it difficult to accept the idea of finitude.

A study conducted with 11 nurses from a neonatal and pediatric intensive care unit of a general hospital located in northwestern Rio Grande do Sul revealed how important it is for health professionals to understand what parents are going through so that they can establish clearer and more effective communication to prevent parents from continuing to believe their children will survive in face of the impossibility of cure. The way each family interprets and experiences death is unique and is directly related to their beliefs, context, and history¹⁴.

Sequential communication with team professionals

This category demonstrated the centrality of the physician when companions seek clarification, as they consider the task of informing something naturally incumbent upon physicians. However, other professionals are also named as good communicators based on the way they sympathize and inform. Parents acknowledge the ambivalence of the communicative process as they need to know (and some wish) what is going on, even though they realize how difficult and painful this daily communication may be. In the face of pain, many family members avoid learning any information and prefer to obtain it only when asked so.

Giving bad news involves listening to one's feelings in an attempt to realize the power and emotions that can be triggered by what is being transmitted. It requires empathy towards the one who is suffering, being available to listen, and analyzing how much the patient or family member is able to know. It is a difficult and delicate skill that requires learning⁶.

The interviewees in this study showed that it is important for professionals to know and take into consideration their concerns, the context in which they live at the moment of communication, and their need for empathy in the face of the emotional repercussions that bad news may cause. In addition to the content of the news, often unavoidable because of the ethical context, the way, timing, place, and speaker's demeanor were also considered by the participants. As Afonso and Mitre claim, *the set of actions –, conscious or not, [make up for] the totality of the communication.* (...) Information,

when given directly or harshly, [generates] suffering and [characterizes] an act of dehumanization¹⁵.

Feelings towards everyday communication about exclusive palliative care

The third category revealed the prevalence of “despair” and the “loss of hope”, which demonstrates that receiving the news is more difficult, although these feelings are usually not expressed. To cope with such difficult times and suffering, many family members seek spiritual support.

The possibility of death, announced by exclusive palliative care, leads some family members to a stage of denial, as shown in the analysis of the statements, which highlights that the most difficult part is to accept the situation and learn to deal with complications, feelings of impotence in the face of a suffering child or adolescent, and the imminence of death. They acknowledge the importance of professionals who sympathize, listen, and provide emotional support.

The patient's family goes through three phases in an attempt to organize this situation. The first phase is a stage of crisis, which starts before diagnosis, and concerns the family's interpretations of signs and symptoms. The chronic phase arises when the disease materializes by confirming the diagnosis and generates unknown conditions. The final phase corresponds to the entry into palliative care, when death becomes inevitable and the difficulty of dealing with changes and grief increases¹⁶.

Facing terminality within the context of palliative care requires the understanding of death not as a disease but as a dimension of existence for which there is no cure. Thus, caregivers need to be aware of themselves and their personal needs to learn how to cope with death and the process of dying¹⁷.

A study conducted with ten parents properly informed about the diagnosis of cystic fibrosis of their children aged between 2 and 12 years old analyzed the meaning of the communication of bad news according to family members. For all participants, the communication launched the war against the disease and the various instances of life that it would change; suffering became constant, the uncertainty of the future and the threat of death became part of their everyday lives. Parents also revealed that the relationship between the content of the news and the way it was transmitted made it even worse, as they could perceive through the demeanor of the professional delivering the news the extent of his/

her involvement, interest, concern, and commitment towards their children and family members¹⁴.

Although death is a natural process, it is not easy to provide care to someone who is terminally ill, especially a child, because experiencing such process requires early dealings with the loss of a loved one. Children are by nature their parents' successors, and their death is shrouded in deep despair. Delivering bad news also makes caregivers feel uneasy, as they inevitably start reflecting about their own finitude.

This amalgam of painful emotions makes it very difficult to face and share this moment, making this terminal follow-up one of the biggest challenge caregivers can face¹⁸. It is a process permeated by fear and insecurity. However, listening and providing support to people who want to be heard is a therapeutic factor in itself. There is no specific technique or correct way to help these patients, because dying is as unique as living.

Due to the uniqueness of the process, the team responsible for communicating the bad news must be technically prepared, which is highly emphasized by the literature available. Dramatization, role play, mock patients, standardized patients, and workshops are useful strategies for teaching undergraduate medical students so they can develop and improve their communicative skills. Studies indicate that skillful and non-iatrogenic communication can be taught to medical students, for example, through didactic classes, group discussions, individual or group practice with simulated patients, and didactic sessions during clinical care, highlighting that role play is the best technique for this purpose^{19,20}.

Many of the interviewees pointed out that death is a veiled subject that triggers strong emotions, possibly justified by the denial caused by the potential loss of their children. Not talking about it helps to disguise the concretization of the inevitable. Silence in face of the imminence of death can still be seen as a defense mechanism against growing fear and powerlessness.

Family members demonstrated that their understanding of communication exposes a tenuous relationship between content and form. Assertive communication can ease uncertainties and fears,

being an important factor for accepting disease and active participation in palliative care. Factors considered humanizing, such as an empathetic attitude towards the one who is experiencing pain and suffering, definitely dictates not only the kind of relationship health professionals, patients, and family members will establish among themselves, but also the quality of life of all involved and good death.

Final considerations

The communication of bad news is a daily imperative action within the pediatric oncology scenario, although the practice has not been formalized by protocols yet. Difficult news are delivered based on experience and observation, sustained by medical ethics and team empathy, still complying with the principles advocated in the literature. The current situation signals the opportunity to improve the team in relation to the complex object incumbent upon their professional practice.

Information sharing in palliative care involves ethical issues that determine its obligatoriness, but also generates psychological repercussions that may affect the family members of those who are terminally ill. This study revealed that communication about closed prognoses becomes even more difficult because it reiterates, on a daily basis, the suffering resulting from the subject's complex confrontation with death.

Due to the ambivalence of bad news, professional communication in palliative care reveals itself as a generator of suffering for the family members of children and adolescents who evolve without therapeutic success. This finding draws attention to the need for permanent mental health care for family members and strategies for the technical and ethical preparation of the professional team.

The study including accompanying relatives exposed the experiences of an important component of the team/patient/family triad, which further proves that future investigations are required to approach such experiences from the point of view of professionals and patients as well.

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Participation of the Authors

Keyssiane Maria de Alencar Lima prepared the research project, collected and analyzed data, and wrote the manuscript. Anice Holanda Nunes Maia guided the project and the final writing of the text. Isabel Regiane Cardoso do Nascimento guided the final work and revised the manuscript.

Keyssiane Maria de Alencar Lima

 0000-0002-0774-8922

Anice Holanda Nunes Maia

 0000-0002-3308-5413

Isabel Regiane Cardoso do Nascimento

 0000-0002-5665-0577



Annex

1. Observation script

Date: ___/___/___

Shift: _____

Location: _____

Research participants: _____

Aspects observed:

2. Interview script with accompanying family members

Participant #: _____

2.1. Sociodemographic data:

Gender: _____

Age: _____

Relationship with the patient: _____

Education level: _____

Occupation: _____

Religion: _____

Marital status: _____

Number of children: _____

How long have you been following the treatment provided to your child/relative?

2.2. Interview script

2.2.1. Which Pediatric Cancer Center professionals do you usually communicate with about your child/relative and what do you think about this communication?

2.2.2. Could you describe how you were made aware about palliative care for your child/relative?

2.2.3. What do you think the communication was like for the professionals involved and for you?

2.2.4. In your opinion, how should physicians inform you about the clinical condition of your child/relative on a daily basis?

2.2.5. How do you feel when physicians and other health professionals talk to you about the clinical condition of your child/relative?

3. Interview script with physicians

Participant #: _____

3.1. Sociodemographic data:

Gender: _____

Age: _____

Graduated in: _____

Years of specialization in pediatric oncology: _____

Specific training in palliative care: () yes () no

3.2. Interview script:

3.2.1. Are health professionals well trained to communicate with the family/legal guardians of patients who must undergo exclusive palliative care?

3.2.2. How is this communication structured as far as when (day, time) it is delivered and to which family members?

3.2.3. Do other professionals, in addition to health professionals, participate in this communication? How and what are their objectives?

3.2.4. How often, where, and to whom is the information about the evolution of the palliative care patient transmitted?

3.2.5. Is there any kind of daily medical bulletin for hospitalized palliative care patients?

3.2.6. Are there, according to medical ethics, specific guidelines for communicating bad news?
