

Communicating of poor prognosis to child patients

Marjory Dionizio Toma¹, Walter Lisboa Oliveira², Catalina Naomi Kaneta³

Abstract

Child death is a difficult issue to deal with, even for healthcare professionals. This paper discusses the attitude of health professionals on the child patient with a poor prognosis and its communication. A narrative bibliographic review with national and international articles besides book chapters on the themes of death, children patients with terminal illnesses, breaking bad news and poor prognosis was made. It was observed that a more emphatic communication, considering and validating the emotions of the patient, tends to bring better results. It was noticed that many professionals feel stressed and have difficulties dealing with this kind of communication, which can be overcome by professional training and early contact with such discussions.

Keywords: Death. Terminally ill. Prognosis. Child.

Resumo

Comunicação de prognóstico reservado ao paciente infantil

A morte de uma criança é um assunto difícil de ser abordado, mesmo para equipes de saúde. Este trabalho discute sobre a postura do profissional da saúde diante da necessidade de comunicação sobre um paciente infantil com prognóstico reservado. Para tanto, foi realizada revisão narrativa de artigos nacionais e internacionais, além de capítulos de livro sobre os temas morte, pacientes infantis com doenças terminais, comunicação de más notícias e prognóstico reservado. Observou-se que uma postura mais enfática, atentando e validando as emoções do paciente, costuma trazer melhores resultados. Encontraram-se também estresse e dificuldade de muitos profissionais em lidar com esse tipo de comunicação, o que pode ser contornado com capacitação e contato mais precoce com tais discussões.

Palavras-chave: Morte. Doente terminal. Prognóstico. Criança.

Resumen

La comunicación del pronóstico reservado al paciente infantil

La muerte de un niño es un tema difícil de abordar, incluso para los profesionales de la salud. En este trabajo se discute la actitud del profesional de la salud ante la necesidad de comunicar al paciente infantil con pronóstico reservado. Para este fin, se llevó a cabo una revisión narrativa con artículos nacionales e internacionales, además de capítulos de libros sobre el tema de la muerte, pacientes infantiles con enfermedades terminales, comunicación de malas noticias y pronóstico reservado. Se observó que una posición más enfática, teniendo en cuenta y validando las emociones del paciente tiende a traer mejores resultados. También se encontró el estrés y la dificultad de muchos profesionales en el manejo de este tipo de comunicación, lo que se puede superar con la formación y el contacto temprano con tales discusiones.

Palabras-clave: Muerte. Enfermo terminal. Pronóstico. Niño.

1. Graduada marjory.dt@gmail.com – Faculdades Metropolitanas Unidas, São Paulo/SP, Brasil **2. Doutorando** walterlisboa@rocketmail.com – Universidade de São Paulo, São Paulo/SP, Brasil **3. Mestre** catalina.kaneta@gmail.com – Universidade de São Paulo, São Paulo/SP, Brasil.

Correspondência

Marjory Dionizio Toma – Rua Barão de Loreto, 34, Ipiranga CEP 04265-030. São Paulo/SP, Brasil.

Declararam não haver conflito de interesse.

The contact with death often difficult for patients and even to the health team, arousing their anguish, helplessness, guilt and denial, which can often interfere with the professional / patient relationship. Such difficulties increase when the patient is a child, which intensifies dilemmas and questions among these professionals. On the one hand, the team has the urge to save the child from suffering, to be a painful and difficult process. On the other, there are professionals who advocate open dialogue, citing the need for the children and their families organize themselves psychologically, elaborate rites, performing last wishes and desires, and the right to know the truth.

According to religion, culture or family tradition, each person believes, gives meaning or create a different representation for death. Are them charged embodiment, qualities and shapes. Death can be seen as loss, breakage, disintegration, degeneration, or also as allure, seduction, delivery, rest and relief. Can be defined as the state in which the signs of life, as consciousness, breathing, heart activity and reflexes, cease, but all these vital functions can be replaced by machines, prolonging life indefinitely. Thus, the dying process is completed when there is destruction of organs and cells as brain and eyes ¹.

Despite being a common phenomenon, our unconscious can not create the end of the image of our lives, that is, for him, can only be killed, but never die of natural causes or old age. Therefore, death is represented as something bad, fearful that leads us to reward or punishment ². Freud says that, in fact, *it is impossible to imagine our own death and, whenever we try to do it, we can see that we are still present as spectators [...] no one believes in his own death, or saying the same thing in another way, in the unconscious every one of us is convinced of his own immortality* ³.

Human beings throughout history, seeking immortality, challenging and trying to overcome death. Trying to escape the terminally situation, although they know that one hour will pass through it. Still, life goes on, trying to postpone this meeting, avoiding think, speak or ask questions about the death while one is not forced to face it. But before the inexorable, would not be wiser to face and think about death? It would be much simpler, and less fearful if we could admit the possibility of his own death? ⁴

What is sought is not only eternal life, but eternal youth, the pleasures, strength, beauty; not eternal old age, with losses, ugliness and pain. The

detachment about death that prevails increasingly in society is strengthened by the cult of the body. With the commitment to achieve the ideal body, the aesthetic dimensions and health, the human being leaves no room for that death will enter in your daily life, as this consciousness brings a sense of fragility and shows human vulnerability .

So even being aware of their finitude, many people act as if death did not exist, establishing plans for the distant future in an attempt to ignore that are deadly. Such cultural and psychological devices protect us from the fear of death and are used as defense mechanisms of denial, repression and displacement ¹. Although should not live thinking only in death, human beings need to face her, even to cherish life .

This work discusses the health professional attitude towards child seriously ill patients with a poor prognosis, and the communication of this state to them. After reflection, indicate subsidies to health professionals to deal with these issues in their daily lives with the child patient with terminal illness.

Material and method

We conducted a literature review to support narrative stage of practice in health psychology in a pediatric unit, they were selected from exploratory search, 16 national and international articles, and book chapters and other documents of interest, dealing with the problem raised. From the categories identified after reviewing the material, were discussed important aspects of the approach to the child, such as age, psychological and behavioral conditions, both the child and the family, taking into account their perceptions, idealizations and maturity level of cognition, among others.

Results

The results are arranged in topics in which will be presented to death and their representations, meanings, fears and beliefs in order to afford to weave reflections and closing remarks.

Attitudes towards death

Death is always present, some rituals are part of it, and in some cases there is a belief immortality, regardless of awareness that death is real and natural. Each group, according to the season, culture

and the place has rituals to avoid death that end up serving protection, as a language, amulets and talismans. Signs and symbols are transmitted by various materials, and sacred behaviors also serve to immunity from death, as prayer and fasting ¹.

The representations of the human subject to create death vary over time. Aries considers that, in the Middle Ages, for example, death was “tamed” as it was seen as a natural part of the evolutionary process of all beings. The moment was expected in the bed, as public ceremony, where relatives and friends gathered in the sick room, disaffected came to ask forgiveness or be forgiven and ecclesiastical blessings were granted. The rituals were performed with expressions of grief, sadness and pain. The greatest fear of the patient was dying suddenly, without receiving homage from his loved ones ⁵.

Currently, however, is not common this relationship with death. With the advancement of medicine, most people die in the hospital, it is the place where you expect to receive the most appropriate care. This family away from the bad aspects and the disgust of the disease. Relatives are also further away, so do not bother the sick and not hinder the work of doctors. It, is what Aries ⁵ called inverted death. It is the shameful death, hidden, what happens, but goes unnoticed, as if nothing had happened. It is no longer considered as the natural end of life, but as failure, which reveals impotence, and thus is shameful show it. For this, are also used drugs that hide the disease, suffering, and produce death in silence.

Fear of death

Despite various cultural views, death in many people generates fear, apprehension and dread. Fear, with its various aspects and dimensions, is the word most psychologically well placed when it comes to death. In addition to the fear of the own finitude, there are fears the unworthy death, hidden, and prolonged suffering, pain, alienation and abandonment. The current society excludes the death as a form of protection, and the human being was deprived of his dying process size the degree of invasion of privacy ¹.

For some people, death is seen not only as the end, but also as a loss of consciousness or control. Fear is associated with loneliness, separation, judgment by the attitudes when in life, there is the fear of the strange, the unknown, and fears related to people who are, objectives and plans unrealized. According to the personality and personal history,

each fears an aspect to think about death itself, and is currently appearing a lot of insecurity and uncertainty. Regarding the fear, Carvalho ⁶ lists:

- fear of dying: fear of suffering and personal indignity;
- fear of what comes after death: fear of judgment, divine punishment and rejection;
- fear of extinction: unknown threat, fear of finitude, of ceasing to exist, to be forgotten;
- fear of dependence: fear of losing autonomy, control, depend on other people to do something that was alone;
- afraid of what will happen to the family: fear of suffering that the family will face, think about how they will survive without the loved one;
- fear of not accomplish personal goals: fear of dying early, not to complete something that was planned or desired;
- fear of pain: fear not stand the pain, to be something very bad and painful, and not be careful, do not be accepted for pain relief.

Although not are born with fear, its manifestation begins in infancy. Early on, the child comes in contact with gradual death, through family experiences and, later, of his social circle. Before it was not believed that children were afraid of death, not understand it and not know it. However, the fear may arise at the time deny children’s parents vital impulses, and thus children who are suffering a greater negative experiences anxiety towards death ⁷.

The human being has the two fears: of life and death. Not to suffer, some people choose to not feel afraid to let go, of being, of life. To live is to risk, and it is natural to go through situations that not all times will please, that will not always be expected or desired. Why fear death and the enormity of life, the human being ends up creating a protection and leaves to live it. This fear can be deadly if powerful and restrictive, and so the person ceases to live thinking about not die ¹.

Terminal patient

The term “terminal patient” is widely used in the literature to refer to people who had changed from the extension of their disease, with symptoms and varying levels of intensity. Conveys the idea, both for people in general and for health professionals, that nothing more can be done to overcome the disease, so that the patient can die at any moment. The patient realizes that his life coming to an

end usually live extreme concern and anxiety about impending death and often tries to demonstrate to others that is "strong" and can accept death without fear, treating the situation calmly and tranquility, even to save family members who are also worried and distressed ⁷.

It is almost impossible to distinguish when a patient ends the therapeutic procedure and starts palliative, especially when it comes to children. But the goals of short, medium or long-term treatment should be established between the patient, professional and family, so it is not as impressive transition from aggressive procedures for palliative care ⁹.

The terminally ill patient goes through many losses, considered as symbolic death, being part of the grieving process, which involves feelings of sadness, fear, anger and resignation. In addition, it becomes strange to himself, losing autonomy, their points of reference, and this makes the recognition of signs of other people become essential. With the approach of death, there is the risk of symbolically kill the patient before he dies, taking his will, his desires and the need to talk about what you want and feel and eliminating its integrity as a human being. He needs to talk of pain, not only physical but also emotional: one that only he has property and right to express ¹⁰.

However, because death is still taboo, the subject is avoided between patient, family and professionals. It is believed that talk about the subject can increase pain and suffering, depressing the patient. So often, the family, even with aspects of grief, pretends to be all right with the patient, and this, although it has many symptoms and suspicious of your state, try to avoid worry the family. This situation is very common, but exacerbates the suffering for both parties. This may also occur for only one side, as when the patient does not know about your state because you are withheld information by family option. The situation is reproduced also in reverse, when the patient knows, but tries to save the family, to avoid suffering and farewells ².

Many patients in advanced stages of the disease, even without them said anything, know that they will die and talk about death for messages, signals and gestures. Therefore, mutual listening is always important, communication with the patient, so that their wishes and desires are met when possible, which reduces the anxiety, suffering, and brings tranquility to the patient.

Children facing death

Such care terminal patients are even more delicate when it comes to children, because depending on cultural and age factors, each will have unique understanding of death. Thus, it is for the health professional when confronted with this situation, also pay attention to the child's cognitive maturity.

Relate the concept of death with the following cognitive structures: children 1-3 years do not have the capacity to draw up a formal concept of death; between 3 and 5 years, have no notion of death as final and can associate only to sleep or separation, and the perception of death as something temporary, gradual and reversible; between 5 and 9 years may see death as a personality, as someone who comes for the dead person and is already perceived as irreversible, but not universal ¹¹.

Especially from 8 years, the child is able to develop a sense of his own death, which revolves around physical loss. Death is the final separation of the body. And children between 9 and 10 years understand death as closure activities occurring in the body, leaving the vital behaviors, considered universal and natural phenomenon. The understanding of health and disease, its onset and healing, matures with age and the experiences that the child spends ¹¹.

According to Torres ¹¹, there are three levels of death concept related to periods of cognitive development presented by Piaget:

- (a) pre-operational period: not distinguish animate and inanimate beings, do not deny death, but not see it as something definitive and irreversible;
- (b) period of concrete operations: can distinguish between animate and inanimate beings, but do not give logical answers of death causality; perceive it as irreversible;
- (c) period of formal operations: recognize death as universal, give logical explanations of causality and define it as part of life.

Despite the seemingly naive, children have great capacity for observation and perception of everything that happens around him and his inner world. May have anxiety attacks, which are presented hidden in the form of symptoms, or expressed in words. However, children demonstrate fear of death, especially nonverbally, often with games, drawings or mime, expressing his most painful fantasies. These forms of communication also respond

to different possibilities of maturation and development and should be taken into account, as indicated Freud, quoted by Aberastury¹².

Faced with children of varying ages, including newborn, which make up a complex reality that is added to the specifics of palliative care, which set out different care and treatment, whether at home, hospital or hospice. Some children, usually in complex chronic conditions, die in hospitals; other, with genetic, congenital, neuromuscular and metabolic diseases, more often die in their homes. In all these situations, the child terminally ill may experience grief in advance, due to his increasing isolation, loss of function, withdrawal from social life and living at school and with friends⁷.

Ultimately, the problem of child about death is the ultimate separation from the body, as it has direct and close contact with your body, realizing thus the deterioration that the disease causes them. Besides the fear of death, fear suffering and the treatment they face or are already facing. These fears are exacerbated by the fact of having to go through constant separations of families, especially in hospitals, away from home, the known, welcome to the place and people can give you all the time¹².

Thus, we see the harsh reality imposed on the child to get in palliative care. In this reality, life and death set is very difficult because, in their perception, death is no movement, no expression, no longer exists, interruption of vital functions. But, as mentioned, for some children, death can also be something reversible, which can be "fixed" or broken, a fact that can be seen in contact with pediatric patients. Still, in these cases, contact with death is accompanied by pain and grief, at which time the child processes your losses, cry, despair and then just conforming, as well as in adults².

Besides the peculiar understanding of each age group, there are several other factors related to children's reaction to the death, such as stress, physical pain due to illness, separation anxiety due to hospitalization, aspects of personality, experience and quality of their parental relationships¹². Other factors to consider are varied explanations about death to a child in the most diverse cultures and families, as there is wide variety of beliefs. Some of them talk about reincarnation and divine intentions, and others focus irreversibility of ideas of death and the process of natural causes. Regardless of how the process of death is taught, the important thing

would be to talk about death with the child because it facilitates their understanding from an early age, leaving it ready when you have to approach it¹³.

The health professional and the poor prognosis in children

The human being does not tend to face death simply, only when forced to face it, so all we should make it a habit to think and reflect on death and dying, for when we are faced being more prepared and not feel the extreme fear that this situation may cause us. This serves both to reflect on your own death, and upon the death of the other. However, often these reflections do not occur throughout life, or vocational training and the theme of death itself arises only when this is reality because of a serious accident or illness. This is also occurs when the patient is informed of a terminal illness that ends the raising awareness of their possible deaths of more scary.

The communication of difficult prognosis is also a clinical decision that requires professional reflection, deliberation and reflection¹⁴. Studies show¹⁵ intense experience of stress by doctors before and after this time, extending in some cases for more than three days. When the diagnosis in question is cancer research¹⁵ points difficulties of clinical oncologists and surgeons in communicating the diagnosis because they feel a lack of ability on the symbolic weight and fantasies related to this disease.

Still referring to this clinical picture, this family of more frequent way it is observed that in other diseases, often establishing protective relationship with the patient, trying to spare him the suffering caused by the treatment and the evolution of the disease¹⁴. This also occurs because it is not only the risk of death that scares the family, but the suffering resulting from treatment, as side symptoms, consequences, secondary diseases and late effects¹⁶.

In these circumstances, the patient's life with terminal illness can last for months, and ethical conflicts arise about the proper use of truth in communication: whether it would be a positive action to the patient, or the most prudent would be a paternalistic attitude that would interfere with patient autonomy and to protect him, since there is the fear that the knowledge of the psychologically difficult to predict desorganize and interfering with the proper conduct of the case^{14,17}. In fact, there is an emotional impact

of the communication of bad news, but in the same way that there can be negative (such as confusion, suffering and resentment), if done properly, with skill and sensitivity, can provide better driving treatment^{18,19}. In this scenario, a recurring question is how and when discussing a child with the difficulties of treatment and terminal illness of their disease²⁰.

Given this social interdict, which seeks to stave off death and suffering, hide them and avoid talking about, the health professional must be prepared to address the issue when inevitable or even necessary to discuss treatment. Therefore, beyond the particularities of each child, need to think in the factors involved in each decision and its implications. However, given the difficulties highlighted previously, most professionals prefer to communicate only to parents, offering the child only part of the information. So the family is often the decision maker to tell or not, making an agreement for the patient to die without knowing who will die, even if the body is emitting death signals²¹.

Some authors¹⁷ point to the loss of a child as the most dramatic event that a human being can experience. This type of situation ends up interfering in family dynamics, passing through moments of hope, fear, guilt, despair, denial and anger²², which in turn affects the professional relationship with the patient, either by an absence or excess interest¹⁴. provided parents, many prefer to hide the truth behind a supposedly cheerful countenance, believing be benefiting the child, but most of the time this sees reality and seeks pretend too, trying to save the family. This makes it more difficult to communicate and prevents a greater clarification regarding the disease, affecting family and patient²³.

In many cases, it is observed that, in clinical practice, before the concealment of death for adults, the small child can react with self-destructive actions such as rejecting food, sleep disorders, accidents, falls, injuries, signs and symptoms that progressively lead to physical and psychological deterioration, which may go unnoticed.

There are also cases where children are removed by family members as a way to protect them from the weight of death. But when the child realizes that there is something wrong, it can be suspicious of adults who avoid your questions and suspicions, seeking ways to please them, distract them, making their wills or even buying them gifts. However, the child's observation capacity is very large, and she manages to capture what happens to be around. Thus, the lie or omission of facts in these cases is the worst way to try to protect her.

In addition to this growing distrust also runs up the risk of the child discover the truth, which will result in irreversible lamentations, wrapped in fear, mystery and trauma². Thus, the Trust is break she had in adults. Often, children are asking questions, in fact, clarification or confirmation of something they already know, and the omission of the truth may cause the child the feeling of being deceived, or who consider it too naive, and this is harmful because it causes deep sense of loneliness¹².

On the one hand there are cases of avoidance of the truth protection, on the other there are cases in which¹⁴ family members move away from the patient, leaving him in direct contact with the doctor in charge. Thus, when dealing with patients in these conditions and their families, especially when the patient is a child, it is for the professional to be prepared to communicate properly and motivate families to participate actively in treatment whenever possible.

From an ethical point of view and moral Aberastury¹² believes that the truth must always prevail, however difficult they are the news and the person who should be informed. There are two rules to be respected before the revelation of the prognosis: the truth should not be presented in a cruel and astonishing way; and the lie must be banned at this point because, although it is often charitable and reassuring, it decreases the professional authority and undermines the confidence placed in him. In this sense, Pinto²⁴ warns that lying attacks the child's thinking ability and leaves harmful brands in its development, although counted under the assumption that deny the pain you can cancel it and thus cause positive effect of short-term.

This is, again according to the same author²⁴, because adults fear, more than children, the confrontation with death, since design them your children's party who fears death and rejects the knowledge of the truth. Thus, the loss of control of fear takes care of everyone, including the child, which can react regressing to earlier and early stages of development, marked by dependence and need for family protection.

Despite this reality, one must understand that talking about death can relieve and help the child develop their losses. For the professional inform some news, you must understand how children of a certain age understand the health-disease process and know what is the best way to provide them with information²⁵.

According to Kübler-Ross², the most important in medical communication is to convey to the patient

and the family always the truth and security that will not abandon them, stating that it is a battle that will face together - physicians, patients and family - giving no importance for the final result. This communication is essential because patients and families come to feel more confidence in the doctor and help you face more calmly this time. It is also important to talk about death with the patient in an open and clear way, through a debate, allowing the total negation patient or talk about fears and concerns that are facing. It is the patient's choice into the matter or not, but it is important that the professional is open to it. About family, Constantine and Hirschheimer⁹ show the need for the health team to pay attention to physical, affective and emotional comfort of the patient and his family. Espinosa et al¹⁷ state that parents or guardians must have good interaction with the doctor and, where possible, include children in decision-making and to see that steps are taken towards a worthy experience of illness.

As regard to the sincerity of the health professional about the prognosis, Piva and colleagues²⁰ also recommend careful dialogue, adding that treatment should be centered child welfare and the involvement of the family, while the team driving an open dialogue. One should take into account an individual child, respecting his moment of development, your chances of intellectual apprehension, their demands, their "time" and your wishes²¹. Each child has a reaction that varies according to their level of understanding and maturity: the older, larger, complex and realistic is his understanding¹².

Pinto²⁴ adds that the demand for these children is for attention and affection, need opportunities to talk about their fears, anxieties and fantasies about death. In this sense, Barbosa, Lecussan and Oliveira⁸ suggest that is recommended and indispensable participation terminals children in some therapy, either individual or collective.

In this regard, the American Academy of Pediatrics²⁶ recommends a always direct, clear and realistic with parents, involving, where possible, the child in the discussions. This, in turn, should be encouraged to talk about their feelings of fear, sadness, loneliness and guilt. In Brazil, the debate on the duty to report or not the prognosis can be extended, taking into consideration that the Statute of Children and Adolescents (ECA) reinforces the right to freedom, dignity, preservation of identity and autonomy, ensuring for their dignity, personal space and physical, mental and moral. Your article 18 says: *It is the duty of all to watch the dignity of the child and adolescent, preserving them safe from*

*any inhuman, violent, terrifying, harassing or embarrassing*²⁷.

Also in Brazil, the Resolution 41/1995 of the National Council for the Rights of Children and Adolescents (Conanda) deals with the rights of children and adolescents hospitalized, prepared and submitted by the Brazilian Society of Pediatrics, reinforcing the protection of rights life, health, to be accompanied by parents or guardians during hospitalization, as well as to have a dignified death. We highlight the Article 8 which refers to the *right to have adequate knowledge of their illness, therapeutic care and diagnoses to be used, prognosis, respecting their cognitive phase, and receive psychological support, when necessary*²⁸.

However, before the recommendations to be open dialogue and stress experienced in contact with death, communication can be a major challenge for health professionals^{15,17,18}. Studies point to the existence of concern to physicians be empathetic while indicate difficulty in dealing with communication difficult prognostic²⁹.

Therefore, several authors make recommendations^{14,15,18-20,30} to assist in the communication strategy of difficult news to patients and families. We pay special attention to the Spikes¹⁸ protocol, which stands out for its emphatic use of empathy and the care with understanding and feelings of patients³¹. It is defined by its authors¹⁸ as approach to strategy, not script to be followed categorically that highlights the most important features of the bad news and suggests methods to deal with the situation. The letters appointing the protocol relate to each strategy:

S - setting (context / environment): prioritize place to ensure privacy, such as room or bed with curtains; communicate the patient in a situation where it is properly sanitized and dress, addressing the attentive and calm manner;

P - perception (perception): see if patients adequately understand the symptoms and, if necessary, provide further explanation before you report the news;

I - invitation (invitation): inviting the patient to dialogue, respecting their right to know or not know the disease and prognosis;

K - knowledge (knowledge): before passing the prognosis, prepare the patient for what he shall hear, talking quietly, transmitting information gradually, avoiding breaking the news of sudden way, allowing time for it to prepare psychologically;

E - empathy (empathy): listen to him and try to identify and embrace emotions, validating their feelings;

S - strategy and summary (strategy and summary): check what was understood, summarize the information and give you opportunity for questions and clarifications, before talking about the possible treatment strategies.

Although there are proposals such as Spikes¹⁸ protocol, they are not always known or used, as shown in the literature^{14,19,22}, often for little contact or concern with the possible reductionist systematic procedures. It is also reported lack of investment in skills enhancement for communication in undergraduate medical curricula¹³. According to studies by Perosa and Ranzani²⁵, 48% of the physicians discussed the matter at graduation, and only 30% reported having received specific training. Knowledge of appropriate communication strategies can be acquired through appropriate training, so it is recommended to invest in it in undergraduate and continuing education programs^{14,22}. The methods of learning, studies¹⁹ suggest the use of drama as it allows training in a protected environment, error-prone and learning from our difficulties and failures. In addition, studies with Spikes protocol, which can be used as a reference in drama, are in favor of an approach to professional early, enabling him properly for reporting bad news³².

In addition to these care in the formation of health professional, it should be noted the importance of dialogue with other areas of knowledge and other members of the multidisciplinary team who have specialized training in emotional and subjective aspects, especially psychiatrists and psychologists, favoring the overall care the children and their families^{13,16}, indispensable resource for taking joint decisions and resolving ethical conflicts.

Final considerations

Says the adage that death is the only certainties. Still, it is subject often avoided and almost ubiquitous in serious illness and hospitalization, especially with difficult to predict. Even for teams accustomed to dealing with this reality, communication is a challenge, since the subjectivity before death varies according to religion, culture, society, family tradition or personal experience. These difficulties in establishing an appropriate dialogue often marked before children. Thus, this research aimed

to discuss the attitude to communication to children critically ill patients on difficult and terminally predictions.

The fear of death brings with it many other fears. It is feared suffer, lose dignity, control and autonomy, having to depend on other people as well, according to religious beliefs, the fear of postmortem events as divine judgments and punishments. For children, there are other variables to the subjective experience of terminal illness, such as life history, how these issues are addressed previously by parents and cognitive abilities to understand the phenomenon of death.

Each child has a specific universe, with the health professional to prevent certain types of standard procedures for certain medical diagnoses. On the one hand, there is the interest in protecting the child patient, mentioning only promises of healing and omitting important information about the treatment of their difficulties, or even the risk of death. On the other, there are professionals who bolster the idea of a free speech, free of obstacles, arguing with the child openly about the disease and its prognosis. Such a stance that values truth, is strongly encouraged, provided that take due care. It is recommended to listen first, seeking to know the children and their families, taking into account the child's understanding about their clinical, emotional maturity, cognitive maturity and cultural factors. Many may, in some way, already be in contact with his death, within their limitations, without having voiced it, and may even be in the grieving process, with intense emotional and psychological distress.

Despite careful to have empathy and proper etiquette when communicating bad news, many professionals report difficulties and stress present in these situations. This, as observed in studies, can best be overcome by recent research recommendations, strategizing, like Spikes¹⁵ protocol, and implementation of training for specific skills in undergraduate and continuing education courses.

Health professionals already formed, it is recommended to seek training if they feel is unfit to handle this type of event. They can also count on the support of psychiatrists and psychologists, who could assist in the overall understanding of the patient and the development of strategies to realize the communication.

Understanding children's experience and his family before the disease helps them cope better and to intervene in this reality, bringing more quality of life and preserving the dignity of child patient.

Referências

- Kovács MJ. Morte de desenvolvimento humano. 2ª ed. São Paulo: Casa do Psicólogo; 1992.
- Kübler-Ross E. Sobre a morte e o morrer. São Paulo: Martins Fontes; 1969.
- Freud S. Reflexões para os tempos de guerra e morte. In: Obras completas de Sigmund Freud. Rio de Janeiro: Imago; 1915. v. XIV. p. 327.
- Freud S. Op. cit.
- Ariès P. A história da morte no Ocidente. Rio de Janeiro: Francisco Alves; 1977.
- Carvalho MMMJ. Dor: um estudo multidisciplinar. São Paulo: Summus; 1999.
- Kovács MJ. Bioética nas questões da vida e da morte. Psicologia USP. 2003;14(2):115-67.
- Barbosa SMM, Lecussan P, Oliveira FFT. Particularidades em cuidado paliativo: pediatria. In: Oliveira RA, coordenação institucional. Cuidado paliativo. São Paulo: Conselho Regional de Medicina do Estado de São Paulo; 2008. p. 128-38.
- Constantino CF, Hirschheimer MR. Dilemas éticos no tratamento do paciente pediátrico terminal. Bioética. 2005;13(2):85-96.
- Stedeford A. Encarando a morte: uma abordagem ao relacionamento com o paciente terminal. Porto Alegre: Artes Médicas; 1986.
- Torres WC. A criança diante da morte. São Paulo: Casa do Psicólogo; 1999.
- Aberastury A. A percepção da morte na criança e outros escritos. Porto Alegre: Artes Médicas; 1984.
- Zavaschi M, Bassols A, Sanches P, Palma R. A reação da criança e do adolescente à doença e à morte. Aspectos éticos. Rev. bioét. (Impr.). 2009;1(2):165-72.
- Geovanini F, Braz M. Conflitos éticos na comunicação de más notícias em oncologia. Rev. bioét. (Impr.) 2013;21(3):455-62.
- Ptacek JT, Ptacek JJ, Ellison NM. "I'm sorry to tell you...": physicians' reports of breaking bad news. J Behav Med. 2001 abr;24(2):205-17.
- Almeida MD, Santos, APA. Câncer infantil: o médico diante de notícias difíceis – uma contribuição da psicanálise. Mudanças – Psicologia da Saúde. 2013;21(1):49-54.
- Espinosa AG, Mancilla OH, Cruz AC, Garcia ED, Lucas CR. Decisiones médicas al final de la vida de los niños. Acta Pediatr Mex. 2006;27(5):307-16.
- Buckman RA. Breaking bad news: the Spikes strategy. Psychosoc Oncol. 2005;2(2):138-42.
- Bonamigo EL, Destefani AS. A dramatização como estratégia de ensino da comunicação de más notícias ao paciente durante a graduação médica. Rev. bioét. (Impr.). 2010;18(3):725-42.
- Piva JP, Celiny P, Garcia R, Lago PM. Dilemas e dificuldades envolvendo decisões de final de vida e oferta de cuidados paliativos em pediatria. Rev Bras Ter Intens. 2011;23(1):78-86.
- Bowlby J. Perda. São Paulo: Martins Fontes; 1985. vol. 3.
- Sanches MVP, Nascimento LC, Lima RAG. Crianças e adolescentes com câncer em cuidados paliativos: experiência de familiares. Rev bras enferm. 2014 fev;1:28-35.
- Silva MJP. Falando de comunicação. In: Oliveira RA, coordenação institucional. Op. cit. p. 33-45.
- Pinto LF. As crianças do vale da morte: reflexões sobre a criança terminal. J Pediatr. 1996;72(5):287-94.
- Perosa GB, Ranzani PM. Capacitação do médico para comunicar más notícias à criança. Rev Bras Educ Med. 2008;32(4):468-73.
- American Academy of Pediatrics, Committee on Bioethics and Committee on Hospital Care. Palliative care for children. Pediatrics. 2000;106(2 Pt 1):351-7.
- Brasil. Lei nº 8.069, de 13 de julho de 1990. Dispõe sobre o Estatuto da Criança e do Adolescente e dá outras providências. Diário Oficial da União. Brasília, v. 128, nº 135, p. 13.563-77, 16 jul 1990. Seção 1.
- Brasil. Conselho Nacional dos Direitos da Criança e do Adolescente. Resolução nº 41/1995, de 13 de outubro de 1995. Diário Oficial da União. Brasília, v. 133, nº 199, p. 19.319-20, 17 out 1995. Seção 1.
- Farber NJ, Urban SY, Collier VU, Weiner J, Polite RG, Davis EB *et al.* The good news about giving bad news to patients. J Gen Intern Med. 2002;17(12):914-22.
- Burlá C, Py L. Particularidades da comunicação ao fim da vida de pacientes idosos. Bioética. 2005;13(2):97-106.
- Pereira ATG, Fortes IFL, Mendes JMG. Comunicação de más notícias: revisão sistemática da literatura. Rev enferm UFPE. 2013;7(1):227-35.
- Lino CA, Augusto KL, Oliveira RAS, Feitosa LB, Caprara A. Uso do protocolo Spikes no ensino de habilidades em transmissão de más notícias. Rev Bras Educ Med. 2011;35(1):52-7.

Participação dos autores

Marjory Dionizio Toma – Aluna da FMU que realizou trabalho de conclusão de curso sob orientação dos professores Walter e Catalina, que supervisionaram e participaram da redação e revisão final do artigo.

Recebido: 2. 8.2014

Revisado: 5. 9.2014

Aprovado: 11.11.2014