

THE HEALTH CARE WORKERS' ETHICAL APPROACH TO TERMINALLY ILL CHILDREN

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Abstract: The terminally ill children have been perceived as the patients having special needs who require special care. Most of them have been oncologically or neurologically sick children, also those with different types of congenital physical abnormalities and metabolic diseases. In addition to the Paediatric Department, the terminally ill children have also been provided with care by health care professionals and mobile hospice and some children have been located in the Children's Home in the palliative care sector since birth. The priority objective of the health and nursing care is to ensure an adequate ethics not only to a child but also to its parents (relatives) and implement palliative care focused on life quality and eliminate suffering in a terminally ill child.

Keywords: terminally ill children, ethical approach, quality of life.

1. Introduction

Children represent a group of patients who do not avoid difficult diseases progressing to the terminal condition. These include, in particular, cancer, congenital developmental errors or various kinds of metabolic diseases.

The tumour diseases are the second most common cause of death in children (following accidents – author's note). At present, 14 children out of 100,000 get sick per year in Slovakia. In the Slovak Republic, there has been the annual incidence of tumours at 13.0-13.6 per 100,000 children. This means that there are 170-180 new cancer cases in this age group every year. Another 70-80 cases will appear in a group of 15-18-year olds. In USA, approximately 53,000 and 3,000 adolescents die every year as a result of chronic illness (Ralbovská, Knezović, 2009, 2010; Gulášová et al., 2010; Greydannus, Pratt, 2016).

However, it should be added with regard to oncological diseases in children that 75-80% of haematological malignancies, especially leukaemia, can now be completely cured.

A child patient has not only been age-specific but also by its psychomotor development, which developing terminal disease significantly determines. Not only the terminally ill children, but also their family members require a specific approach by the healthcare professionals in the context of the Human Rights Protection and dignity of the deadly and dying, adopted by the Parliamentary Assembly of the Council of Europe on June 25, 1999.

This topic belongs between the most difficult topics in pediatry. The main reason were authors' rich experience with the treatment of ill and terminally ill children. The author is a University teacher, who and she teaches subject of clinical exercises and shares the development of knowledge and practical skills with future non-medical health-care workers.

2. The impact of the disease terminal stage on the child and its his/her family

The terminal illness in a beloved person and subsequently his/her death is an enormously painful experience for all involved. A witness of the suffering in someone who is very close relative to us represents a demanding challenge that confronts each of us with the questions related to life and death. If the dying person includes a child, his relatives face a lot of factors that make this challenge even more demanding (Ralbovská, 2009; Ralbovská, Knezović et al., 2011).

The child begins to perceive the issue of death in a more realistic way, as an irreversible fact about 11 years of life. In terminally ill children, death does not resonate in verbal communication, instead, the child often transfers his thoughts to drawings. The number of heterogeneous problems in the terminally ill child results not only from the oncological disease itself and its symptomatology, but also from confronting a child with a wide range of very unpleasant diagnostic and therapeutic procedures resulting from his/her leaving the family and social environment, in older children, especially from the uncertain illness prognosis.

Loss of autonomy and destruction of life plans due to terminal illness can be staggering for adolescents, either in terms of provocative behaviour, increasing anger and reluctance, or some adolescents become depressed and go to retreat and reduce their self-esteem. A patient having been in major depression should be given the quickest possible psychological or psychiatric intervention (Greydanus, Pratt, 2016, pp. 282, 286).

The death of a child is a devastating and tragic event for all those involved, including family members and healthcare providers. Sometimes the people closest to the child refuse negative progression of the disease and, consequently, do not recognize terminal illness and death as real and imminent issues to be addressed; as a result, children are subjected to unrealistic decisions and treatment choices. More frequently, although fully aware of the

reality of the situation, they try to protect the child from a truth that they consider too difficult and painful to cope with by avoiding it in conversation, justifying it as the price to pay for an imaginary better future or, despite the obvious state of affairs, blatantly denying it (Benini, 2017, p. 33).

A physician must be sensitive but, at the same time, truthful in informing the child's parents about his/her health condition and diagnostic and therapeutic procedures, while taking into consideration alternative treatments which some parents often think about. In particular, caution is required to communicate about the prognosis of the disease

During the period of long-term incurable disease in a child and afterwards his/her death, the parents have to cope with the immense psychological trauma but, at the same time, they are confronted with certain life tasks which have arisen in connection with the illness and consequently the death of their child (Dohnalová, 2010; Dolista, 2010, p. 52).

In this direction, invaluable help is provided by hospices and other organizations which help family members, especially during the first year after the departure of their child, at the time of mourning.

3. Palliative care as part of complex care for a terminally ill child

Currently, the progress of medicine makes it possible to treat many of the incurable or deadly diseases, enhanced medical methods and the development of resuscitation techniques allow the life of a human individual to extend and relegate the moment of his/her death. As a result, the quality of life and loneliness and suffering of the dying person, both the patient and his/her close relatives and those who care for him have often not been taken into account. The duty to respect and protect the dignity of all fatally ill and dying persons is derived from the inviolability of human dignity in all periods of life. The expression of respect and protection resides in providing the appropriate environment, which allows a dying person to die dignified (Munzarová, 2005, pp. 77-79).

Palliative care is the overall care of the patient at a time when his/her illness no longer responds to causal treatment, i.e., treatment aimed at removing or affecting the cause of the disease. These are incurable diseases that progress despite the use of all the treatments. In palliative care, it is not a cure; instead its goal is not to return to health but to accompany the patient. The quality of accompaniment verified by patient satisfaction and his/her quality of life perceived subjectively co-determine achieving the goal in this area (Slamková, 2017, p. 129).

Specialized Palliative Care Facilities are those that deal with palliative care as their core business. They must employ trained staff capable of providing a patient with support

anywhere – both at home, hospital, nursing home, day care centre, outpatient care or in a specialized department of palliative care (Marková, 2010, p. 21).

The goal of palliative care is not only to optimize the child's quality of life and to enable the family to care for a terminally ill child, but also to provide care for the family itself. It is necessary to realize that hospital care is not always best suited when providing palliative care to children therefore most families often prefer home care (O'Connor, 2005).

Care of dying children and adolescents is an emotive „roller” for patients, families, healthcare professionals and hospital staff. Many young patients die at home, but many of them die in the intensive care units of the hospitals. These patients deserve the satisfaction of rights based on respect for dignity, peace and pain relief. They deserve the staff who is fully involved in the care and the workers striving for professionalism despite all the circumstances (Greydanus, Pratt, 2016, p. 288).

The care for terminally ill children mainly takes place at the hospital in-patient departments, where the team of paediatricians and child nurses (or sisters) perform the care in cooperation with physiotherapists, psychologists, special pedagogues, priest, etc. The so-called health clowns (the so-called red noses) also play a positive role in helping children overcome maladaptation-related illnesses, especially pain, anxiety and fear and they bring an atmosphere of genuine joy among child patients.

Once the health condition is stabilized, most parents wish the child to be discharged from the hospital to home nursing care. Many parents are trained which allows them to handle several professional interventions resulting from the child's health condition by themselves – re-bandaging, feed probes, oxygen therapy, positioning and the like. The team of mobile baby hospices often help the parents (there are two in Slovakia: Plamienok and Svetielko nádeje). A bed hospice for incurably sick children is an exception. The discussions on this topic are being conducted in several countries; however, the hospices providing comprehensive care for incurably sick adults are still preferred.

In some European countries, for example Switzerland, the centres with full competencies are being set up to implement palliative care for children.

The Competence Centre for Paediatric Palliative Care has a significant impact on the care for children requiring such care and their families. It is recognized and offers a wide range of support for children and their families as well as for professional teams visiting families of terminally ill children. It brings attention to team leadership, disease symptom monitoring and coordination of the care provided. It also provides the so-called respite care, which is seen as an urgent matter for families looking after a child with long-lasting chronic illness (Bergstraesser, 2013, p. 111, 117).

The Hospices and Centres represent a preventive tool for legalizing active euthanasia in children, allowed in two European countries, in Belgium, virtually since the child birth, and Netherlands, since 12th year of the child's life.

Palliative care in the Foster Home

Terminally difficult and heterogeneously affected children, who do not have parents or their parents (mother) abandoned them, are placed in Foster Homes providing palliative care. A multidisciplinary team consisting of a physician, nurse, physiotherapist, psychologist, curative, and special pedagogue implements comprehensive child health care and its psychomotor development. The nurse must have law-defined education and appropriate specialization.

Act 364/2005 on the extent of nursing practice provided by a nurse alone and in collaboration with a doctor and the scope of the midwifery practice provided by a midwife alone and in collaboration with a physician specifies the competencies in nurses in the Foster Home in the field of palliative care. A nurse in the Foster Home carries out health care without the presence of a doctor, i.e., she is responsible for her decisions in life-threatening situations and the chronic condition aggravation. A general practitioner for children and adolescents regularly visits children, assesses their health condition and the level of psychomotor development. During emergency situations, the nurse calls emergency service or Child Emergency Services (Spišiaková, 2015, p. 40).

The frame content in the nurses in the Foster Home in the area of palliative care represents the following activities:

1. Providing comprehensive, medical-preventive care for children along with training.
2. Monitor the child's physical, mental and health condition and inform competent workers thereof.
3. Assessment of child psychomotor development, making records.
4. Preparing and accompanying a child for examination.
5. Preparation, implementation and observance of the daily plan of activities with children.
6. Participating in provision of curative nutrition.
7. Participate in the necessary purchases – dressing, food, hygiene, etc.
8. Collaboration with all team members (Spišiaková, 2015, pp. 42-43).

4. Ethical approach of health care workers to terminally ill children

A contact with parents aimed at communicating the diagnosis associated with infancy prognosis appears the most difficult moments in a doctor's work among others. However, the basic ethical requirement is to give hope for cure or eliminating difficulties or ensuring at least a relative quality of life for each child. The situation becomes even more demanding when the disease progresses irreversibly, the child's health condition becomes irreversible and

the doctor is required to inform the parents thereof. Whilst communicating with a little children, we emphasize the emotional side of the personality, in pubescents and adolescents there is a need to communicate with the emphasis on their rational side because opinions and questions on their part are more refined and the view of the disease is more pragmatic. These circumstances place higher demands on the approach of professionals to this age group of patients. According to Glasa and Šoltés (2004; Gulášová, 2010, p. 104) „not only a child is sick, but also all members of the family in the same sense. The family is experiencing tension and fear”.

The awareness of the fact that a child needs an individual approach with an emphasis on his/her age and mental maturity belongs among the most important aspects of nursing care for a terminally ill child. For the students preparing for the nursing profession or another profession within the non-medical health care professions, who acquire the theoretical knowledge on the subject of lectures from vocational subjects – nursing process and patient needs, clinical psychology, paediatrics and paediatric nursing, oncology and oncology nursing, palliative and hospice care and practice clinical practice in the children university or faculty hospitals and children departments, in Foster Homes or they cooperate with mobile Foster Home staff – it is important to adopt this aspect.

In a difficult situation, it is most important for a child to perceive interested and support, not only on the part of their family but also on that of the health workers, i.e. people who seek to restore his/her somatic, psychological and social balance and, if that is not possible, try at least to get closer to this balance. In addition to professional approach and effective communication as part of the personal equipment of every doctor and nurse working mainly on childhood oncological diseases, the different forms of psychotherapy, relaxation techniques implemented within the competency of a psychologist, clinical psychologist, psychiatrist and therapeutic pedagogue can be used in the psychological and psychotherapeutic support and help to terminally ill children (Grežd'ová, Ralbovská, Knezović, 2010, p. 21).

Both medical and nursing care have been aimed at eliminating the suffering, pain and other symptoms accompanying the serious illness and those conditional on life quality in the sick. A group of paediatric cancer patients also requires an adequate ethical approach based on respect for human dignity as the main proof of the ethical achievement of all those concerned with these patients (Rapčíková, Harabišová, 2014, p. 189).

Parents of terminally ill children feel helpless, but nurses can be helpful because they are capable of estimating the needs and goals of the family and can encourage parents by offering the tools for better communication and expression of love for the terminally ill child. This tool primarily includes understanding the issue and to be aware of that the age, experience and, last but not least, the religiosity of the family influences the death understanding by the child. In the role of advocates, the nurses' fundamental role: is to educate the parents and engage them in discussions on aspects (Nielson, 2012, p. e64).

It is suggested that caring in ethically demanding situations can be facilitated through presence, atmosphere, self-knowledge and time. This challenge does not demand highly technological solutions; these assets are readily available no matter where on earth (Furingsten, 2015, p. 185).

In 2007 and 2009, Dohnalová, Czech Republic, conducted a research study in which the target group included the parents of terminally ill children who had suffered an anticipated loss of the child due to various diagnoses, not only the oncological ones. The study included the children aged 4 months to 24 years and parents 1 year after the death of the child.

Parents' opinions on the care provided during their terminal stage of illness to their children were as follows:

- the majority of respondents have positively expressed their opinion on the professional healthcare provided, however, at the same time, they declared the impersonal approach of many doctors and nurses to children and parents – „medical staff were busy, everything was so fast”,
- psychologist or psychiatrist provides either negligible or almost any help for a child and parent,
- in particular, parents contacted each other, established associations, and were mutually supportive,
- social workers continue to completely fail.

Satisfaction of spiritual needs and the importance of spiritual help did not solve the research but a lot of Children's Hospitals provide this kind of support.

5. Conclusion

The life quality in terminally ill children should form the basic criterion for comprehensive care. Nurses and other health professionals should strive not only to meet the full spectrum of the child's needs, but they also shall create an atmosphere of trust, respect, esteem and maintaining the dignity of a child patient in health service. This approach will also positively resonate with the parents of the child as a factor allowing the grief over losing the child to be eliminated either completely or at least partially.

Health care workers must always remember to touch a person's life even if for a moment, but create a lasting impression. A family may not remember whether you gave their child the medication or were very skilful. But surely they will remember health professionals who supported them through probably the biggest tribulation of their life (Braganza, 2014, p. 367).

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