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SUBJECT: CARE FOR A TERMINALLY ILL CHILD

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Key words: terminal illness; child.

Abstract

A terminal illness of a child is a traumatic experience for both the child and the family. The illness destroys their current life, The terminally ill patient experiences total pain, which includes not only physical pain caused by lesions, but also psychological, social and spiritual one. The terminal disease of a child is an exceptional experience also for medical staff, for whom it cannot be an ordinary medical case. The terminally ill patient requires an HPC environment, in which the death perspective is inscribed. The whole environment of a terminally ill child, both family and medical staff, should follow the rules of thanatopedagogy, a discipline whose subject is education for good dying, or with respect for the subjectivity and dignity of a person facing death.

HPC, regardless of whether it is performed in home, hospital or hospice settings, it must be closely correlated with support for the closest family of a terminally ill child, especially parents and siblings. Only then it can be an effective support group for the child, a factor raising the quality of life in dying, which is the main goal of HPC.

Introduction

On the town hall clock in Leipzig there is a following Latin sentence: *Mors certa, hora incerta* ("Death is certain, its hour is not") [July 1994, p. 172]. Death is treated in culture as an inevitable component of fate. Mature people are aware that it will come, they do not know only when. However, it is difficult to accept the death, which comes too quickly, especially the death of a child. A particularly traumatic experience is a contact with a terminally ill child.

Discussion of this issue in the context of axiology, goals and tasks of hospice and palliative care (HPC) is the main aim of this study.

HPC is an inherent component of palliative treatment, which in turn is an essential component of symptomatic therapy, and its primary task is to "relieve suffering – alleviate ailments" [Łuczak, Kotlińska-Lemieszek 2011, p. 4]. In the latest definitional terms, HPM is understood as "a comprehensive care for a patient with a progressive and advanced disease, whose prognosis is limited, and the most important goal is to improve the quality of life of the patient and his family" [Kurczewska et al. 2010, p. 93]. It has a holistic nature, both in the subjective and objective dimension. This is because it is performed by an interdisciplinary, professional team composed of a doctor, a nurse, a psychologist, a social worker, a rehabilitator, a chaplain and volunteers, and covers fulfilling all needs of a terminally ill patient, namely "somatic (relieving pain, dyspnea and other symptoms, including rehabilitation and creative therapy), psychosocial and spiritual ones, through early identification of threats and needs, prevention and bringing relief" in the suffering [Łuczak, Kotlińska-Lemieszek 2011]. While in the case of adults the HPC of terminally ill adults is performed in specialized hospice institutions, in the case of children it was institutionalized as a specialized paediatric palliative home care (hereinafter: SPPHC). According to the name, it is performed at home, and covers children with illnesses that significantly limit their fitness and life activity, and is combined with the active participation of parents and other family members in its course [Łuczak, Kotlińska-Lemieszek 2011]. Moreover, it should be borne in mind that HPC of terminally ill children also takes place in hospital conditions during the period of hospitalization of children, e.g. associated with oncological diseases. Therefore, SPPHC requires not only specialist support for parents because of the trauma they experience in connection with the child's illness, but also active participation in alleviating ailments, both somatic and mental ones, which they suffer.

HPC, and thus also SPPHC, moreover – which is worth emphasizing – "respects life and is against euthanasia, [...] opposes the use of intense, persistent therapy aimed at prolonging life at any price" [Kozomaricz 2012, p. 2012]. Its purpose, in other words, is to ensure the highest possible quality of life not only for the terminally ill patient but also for their family. In the case of the patient, it is primarily related to removing or minimizing physical, mental and spiritual suffering that accompany dying, and in the case of the family – to preparing for the death of a close relative [Chmiel et al. 2011].

In addition to general axiological and ethical principles, HPC must consider the specificity of child's death, which apart from the fact that – as it was signalled – arouses opposition because of its perception in terms of a non-culpable harm, is still in the taboo sphere.

Modern knowledge and contemporary culture patterns favour overcoming fears underlying the avoidance of conversations about death. They are most often the result of the fact that adults attribute to children their own view of death as a tragic necessity that cannot be reconciled with. However, children can often create in their psyche various defence mechanisms that allow them to remove the phenomenon of death from the consciousness [Trosińska 2015]. The circumstance that a child perceives their death differently than the surrounding adults must be considered in the care in the terminal phase.

The practice of HPC of a terminally ill child is based to a large extent on the achievements of thanatopedagogy, one of the disciplines of medical (therapeutic) pedagogy. Its main goal is to educate to respect the dignity of a dying child, but also to "educate for good death, respect for life and acceptance of death (becoming accustomed to death as an inseparable element of life)", while the subject of its influences covers “an ill (dying) child and therapeutic work with their parents” [Krzesińska-Żach 2011, p.570].

Thanatopedagogy determines, among other things, the rules of participation in HPC of a terminally ill child of medical staff, psychologists, chaplains, in particular the preparation of the child for death, as well as the rules of caring for the child’s family, which should be supported to cope with the loss of a child.

A terminally ill child

It has already been mentioned that in the face of death a child can, even when, as a teenage child, is aware of the inevitability of their fate, remove the phenomenon of death from their consciousness, and deprive it of importance, if not rationalize, in their own way. Most often, however, it is a mask that they adopt to hide a specific sense of guilt that they hurt their loved ones. It is also the result of a different than the perspective of adults, cognitive perspective from which the child perceives the world. As K. Gerc writes, “the child’s suffering is a kind of existential paradox, considered in an individual and social context. Here, the experience of suffering exceeds the limits of the world of adults, touching people who are located at the threshold of developmental potentiality, while depriving the parents of the possibility and sometimes the hope of protecting the offspring from this experience” [Gerc 2016, p. 46]. It does not change the fact that the experience of a terminally ill child includes both a disease-dependent physical suffering, and a mental, spiritual sense of loneliness against the cruelty of fate that has affected them. In literature, the suffering of a terminally ill child is typified as physical pain (caused by illness and therapeutic procedures), social suffering (caused by adverse changes in the social situation, related to, among others, isolation from the peer group), emotional suffering (associated with fear of effects of the illness, of pain), and spiritual suffering (caused by the experience of death, tormenting question about the meaning of one’s suffering and the feeling of guilt because of the suffering of close relatives) [Białożyt, Haftek 2014]. This syndrome, characteristic especially for the course of cancer, is referred to as total, all-encompassing pain [Winkler 1996]. It has the form of such ailments as, among others, dyspnea, loss of appetite, anger, sadness, anxiety, depression, causing “existential torments, such as negating the meaning of life and a deaf search for the sense of suffering” [Trosińska 2015, p. 56]. In the feedback relationship, these ailments are a source of total pain [Skura-Madziała 2010]. All things considered, “the source of suffering in terminal illness includes all the unpleasant experiences, contacts that lower the quality of a patient’s life, disintegrate the whole of the human being; they concern not only the body (somatic symptoms), but all areas of human existence: thinking, emotions, social ties, financial situation and, above all, wounded spirituality – existential pain” [Skura-Madziała 2010, pp. 145-146].

In this context, the question arises whether a terminally ill child experiences ailments that constitute the total pain with the same intensity. In the light of research, as many as 94% of children suffer primarily from physical pain [Kozłowska-Pietruk 2009]. Its source is both the disease and medication used as part of the conducted therapy. Children who are terminally ill are afraid of pain more than of death. They also cannot understand its meaning, they associate it with the punishment for bad behaviour. This is because, the child, as it has been signalled before, perceives the world from a different perspective than the adult, and the present is more important to them than the future. For this reason, they cannot understand why parents force them to bear pain, especially the one which is associated with therapeutic treatments [Białożyt, Haftek 2014].

The other types of pain manifest differently in the terminally ill child. J. Oppenheim, analysing artistic creations of children with neoplastic diseases, interpreted the symbolism of those works as an indicator of their fear “of loneliness, anonymity, bereavement of their parents, failure to meet the expectations, nothingness or transition into another dimension of existence” [Trosińska 2015, p. 56]. At the same time, however, these children do not reveal these fears in their behaviour. They mask them with optimism or vitality to protect their parents from despair. Only in older children, especially teenagers, depression resulting from a better understanding of the inevitability of the loss of life, appears [Trosińska 2015, p.56]. Younger children are more susceptible to escapism, the escape into the world of their imagination and fantasy. As noted by the previously mentioned Oppenheim, especially younger terminally ill children are happy to draw, because it reduces their sense of danger [Trosińska 2015, p. 56].

In the context of the above remarks, it should be emphasized that a terminally ill child perceives their position differently than an adult. They think less about death, more about physical pain, which they experience most intensively. However, this does not mean that they do not experience social, emotional, spiritual pain or existential despair. Nevertheless, these components of total pain gain in significance only in older, teenage children, when the reflection, including the intellectual one, over the tragedy of one's own fate, becomes more and more conscious and mature.

Family of a terminally ill child

The terminal illness of a child is, as previously reported, also a traumatic experience for their family, especially the closest one: parents and siblings. The reaction to the illness has primarily the emotional dimension. It has the form of fear, anxiety, and a sense of danger [Kozomaricz 2012, p. 2012]. Moreover, it does not manifest fully, but it grows, evolves. According to the literature, the following stages of the reaction of the closest relatives of the child to their illness are distinguished [Baruch, 2013, pp. 136-137]:

1. Denial and isolation. It is preceded by a shock, disbelief, followed by a fearful denial, the conviction that a mistake has occurred, and that it will be quickly explained.
2. Strong emotional reaction of the nature of rebellion. Its behavioural indicators are anger, opposition, rage, irritation, resentment, that fate was so cruel to the child.
3. Negotiation. It is characterized by reconciliation with fate, with underlying hope that not everything is lost yet, that with God, as the only authority that can change anything it is possible to succeed, making a deal in which something will be offered in exchange for the child's recovery. A willingness to sacrifice all the possessed goods (money, properties, even one's own health) in return for the child's recovery appears.
4. Depression. It appears at the advanced stage of the child's disease when there is no longer any doubt that it is present, because there is empirical evidence for it. Its advanced symptoms occur, and a need to reach for more and more advanced

forms of therapy takes place. The basis of depression is the loss of hope to overcome the disease.

5. Reconciliation. The acceptance and hope to overcome the disease come back. Moreover, the confidence in the effectiveness of therapy appears, because apart from its side effects, its positive effects are also visible: improvement of health. The family gets new strength to fight the disease. All this allows them to bear the death of the child more quietly.

Regardless of the intensity with which the family of the ill child experiences successive stages of reaction to the disease, it has a destructive influence on family life, which must be subordinated to it in its entirety. Among the negative phenomena in family life mediated by the disease the following should be mentioned: 1) experiencing pain by family members (especially mental and spiritual one, resulting from empathy for the child and horror resulting from the perspective of losing them); 2) disintegration, resulting from the occurrence of conflicts, mutual blaming, making inconsistent decisions on methods of care and therapy, etc.; 3) the burden of excessive duties, to which professional work and personal aspirations in life must be often subordinated; 4) psychological stress, to not aggravate the social pain resulting from loneliness or rejection in the ill child with one's words and behaviour; 5) negative aesthetic experiences to which physiological reactions of the ill body and consecutive exacerbations of the disease lead; 6) deterioration of the financial situation caused by the necessity of subordinating the family budget to the costs of care and therapy; 7) intensification of the sense of injustice related to the subjectively felt indifference of the social environment and insufficient or incorrectly directed actions of medical staff taking care for the child and conducting their therapy [Łuczak, Kotlińska-Lemieszek 2011].

In general, the terminal disease of a child is a difficult test for the whole family. It experiences stress that can negatively affect the relationships between its members and the external environment. According to A. Baruch, „the more severe the illness of the child and the worse the prognosis are, the greater the stress associated with their chronic illness is. Also, the course of the disease with relapses and periods of remission results in significant fluctuations of emotions and feelings from fear, anxiety to optimism and joy" [Baruch, 2013, p. 134]. In general, the child's illness fundamentally changes the way the family functions, the nature and quality of mutual relations between its members, and deeply verifies previous plans and intentions, often completely reverses the hierarchy of priorities [Baruch 2013, p. 134].

The terminal illness of the child not only disturbs the functioning of the family, but also negatively affects the quality of life of the child. The disintegrated family is not able to support them effectively, it deepens their sense of loneliness, apathy, helplessness and weakens the will to fight the disease. Meanwhile, it is desirable to "shape in parents a proper image of a child's illness and motivate them to actively participate in the treatment. If the parents of the ill child become allies of the specialist, there is a good chance of forming a proper picture of the disease in the child and achieving good cooperation with them in the treatment process" [Krzesińska-Żach, p. 574]. For this reason, it is indispensable to cover the family of the child with the support program in the course of the care, whether in hospital, home or hospice settings. Only then it can be a factor of the improvement of the quality of a child's life in the illness and their ally in the struggle with it, as well as in the building of hope for healing.

Support for the terminally ill child and their family

HPC, as mentioned, is holistic in nature, and includes all the components of total pain experienced by a terminally ill person. In its entirety, this also applies to HPC provided for a terminally ill child.

It should focus on an integral approach to the improvement of the quality of the child's life and support for the family. In this way, the synergy effect is achieved, strengthening the child's chances, if not for healing, then for dignified dying. However, these are not factors sufficient to achieve the goals of care. The fully professional fulfilment of duties by qualified medical staff, especially by nurses, who have the most intense contact with ill children and their closest family is of special importance. Professional approach includes not only medical or psychological knowledge, but also acting in accordance with the principles of professional ethics and deontology. The nurse, not only palliative care one, but this one in particular, should, according to I. Wrońska, remember that the subject of their actions is "a human being who has the right to get information about themselves, the right to participate in decisions that affect their life, health, to benefit from social care, the right to accept or reject care. This is a human being in the whole of the eco-holistic dimension of their personality, or in the system of physical, psychological, social, cultural and developmental and spiritual needs, a human being in various spatial and temporal dimensions of their existence" [As cited in: Kliś-Kalinowska 2011, 43]. As such, they require full respect for their needs and rights, especially the right to inherent dignity. These duties also include respect for the spirituality of the child, and for their practised religion. This in turn requires from the medical, and especially nursing staff, cultural competence, especially in the field of religion and religiosity. This is because the nurse is "a person who supports the patient until the very last moment and prepares them to cross the border separating life from death. Care for dying patients does not end in the physical sphere but also includes the emotional one. The nurse, taking care of the dying patient, should get to know their faith, which is so important for the patient and their family" [Sienkiewicz et al. 2011, 59]. The ill child and their family should be provided with a religious service at any moment. This is one of the fundamental requirements of care for the dying child, in addition to providing pain therapy and personalised treatment [Trosińska 2015].

However, not only professional knowledge or required from the medical staff humanistic knowledge shape their attitudes towards the dying child. The sociocultural context also has a significant impact on this sphere. Research demonstrates that nurses' behaviour towards death is determined primarily by culture – 86% of indications. Medical knowledge is as far as in second position – 57.5%. In further positions there are the following factors: broad medical knowledge about death – 56.5%, experience – 40%, tradition – 20.5%, changes in family – 15%, changes in the organization of life – 12%. Only 7.5% of the respondents were unable to determine which factors affect their attitudes towards death [Paszek et al. 2011, 57].

In the context of the above remarks, it should be noted that in HPC two main perspectives are distinguished: a medical (satisfaction of disease-related needs, associated with the conducted therapy) and non-medical (possibly fullest satisfaction of not disease-related needs, mainly associated with satisfaction of mental needs of closeness, empathy) one [Krzesińska- Żach 2011]. In HPC, a much stronger emphasis should be placed on the latter aspect than in other types of medical care. More precisely, both perspectives should penetrate each other. In practice, in HPC of the terminally ill child, it is required to follow certain general rules. They include [Gerc 2016, pp. 53-54]:

1. Getting to know the child's sensitivity, all that can arouse their anxiety in connection with the disease, hurt them, make them unhappy. The type of child's sensitivity should be considered when taking care of them and selecting therapeutic procedures.
2. Getting full knowledge about the child's illness as an individual case. This allows to better understand the child's needs and better prepare them for the difficulties that may arise in the course of the disease.
3. Taking any measures aimed at reducing the level of child's anxiety. This should be reflected in emphasizing all, even the smallest successes in the fight against the disease. It serves to build the child's sense of security and hope for recovery.

Support for the terminally ill child includes four support levels: 1) emotional (transmitting all verbal and non-verbal messages confirming that someone thinks about them and supports them); 2) evaluative (transmitting messages that they are important and exceptional); 3) instrumental (providing with any particular assistance when it is needed, and the task exceeds the possibilities of the patient; 4) informative (providing all advice and information that allow the patient to solve problems arising in the course of the disease) [Trosińska 2015].

Generally, a terminally ill child should be provided with personal treatment. In order to achieve this, the care for them should be targeted at the most individualized needs, especially the reconstruction of a disturbed sense of security, reduction of anxiety related to illness and prevention of a sense of loneliness [Gerc 2016]. The effectiveness of care for the terminally ill child depends on the quality of support for their family. Care for the ill child and support for their family should be closely related and mutually conditioning activities.

Summary

A terminal illness of a child is a traumatic experience for both the child and the family. The illness destroys their current life, The terminally ill patient experiences total pain, which includes not only physical pain caused by lesions, but also psychological, social and spiritual one. The terminal disease of a child is an exceptional experience also for medical staff, for whom it cannot be an ordinary medical case. The terminally ill patient requires an HPC environment, in which the death perspective is inscribed. The whole environment of a terminally ill child, both family and medical staff, should follow the rules of thanatopedagogy, a discipline whose subject is education for good dying, or with respect for the subjectivity and dignity of a person facing death.

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