

Moral issues of paediatric palliative care

Moralne zagadnienia pediatricznej opieki paliatywnej

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Abstract

The aim of the article is to describe the moral obligations in the context of the pediatric palliative care. The practical aim is to answer the question about proper attitude of the family and the medical staff toward a dying child. The answers take into account the right of the child to the true information about his or her physical state, the possibility of taking part in the decision making process and the spiritual care of the dying children. The theoretical reflections are confronted with the empirical survey among the physicians. The answers for the twelve questions of the questionnaire illustrate the practice of the doctors who deal with the sick children and their families.

Streszczenie

Pytania o właściwą postawę wobec umierającego człowieka wprowadzają w obszar zagadnień związanych z etyką komunikacji międzyosobowej. Problematyka ta odkrywa swoją szczególną specyfikę w sytuacji pediatricznej opieki paliatywnej. Zagadnienie uczestniczenia dziecka w procesie podejmowania decyzji związanych z terapią, a także udostępnianie mu informacji dotyczących niekorzystnej diagnozy medycznej, rodzi szereg specyficznych pytań natury moralnej. W dużej mierze są one związane z pytaniem o to, na ile dziecko potrafi wziąć świadomy udział w dyskusji dotyczącej jego stanu zdrowia, podejmowanej terapii, czy konsekwencji leczenia. Inną kwestią jest to, czy dziecko posiada emocjonalną stabilność pozwalającą zasymilować informacje w sposób, który nie będzie dla niego szkodliwy? Zagadnienia te są osadzone w kontekście relacji rodzinnych, w których rodzice są prawnymi opiekunami dziecka i w dużej mierze określają granice tego, na ile dziecko w sposób świadomy i wolny przeżywa swoją chorobę i umieranie. Rozważania natury teoretycznej zawarte w tym artykule będą konfrontowane z wynikami badań empirycznych. Badania te zostały przeprowadzone w oparciu o ankietę zawierającą 12 pytań. Pytania dotyczyły postaw personelu medycznego wobec dzieci ciężko chorych i umierających oraz ich rodzin. Grupę badaną stanowili lekarze różnych specjalizacji, czynni zawodowo, pracujący w warszawskich szpitalach i przychodniach. Są oni katolikami praktykującymi swoją wiarę i należącymi do różnych grup duszpasterskich.

Key words: pediatric palliative care, ethical aspects of autonomy; truth telling to patients, patient as a person

Słowa kluczowe: pediatriczna opieka paliatywna, etyczne aspekty autonomii dziecka, prawo pacjenta do informacji prawdziwej, pacjent jako osoba

Introduction

Affirmation of patient dignity, *inter alia*, requires the respect of their rights to true information and accepting subjectivity in therapy. This assumption is rooted in the natural law and reflected by the Church teaching, documents of medical deontology and is quite commonly recognised. In special situations these rules may, however, be variously interpreted, which may bring about a number of moral dilemmas. Such special situations include paediatric palliative care. Many questions as to the respect of children's right to true information after unfavourable medical diagnosis and their independence in therapy arise in this context. These matters are characteristic of the fact that they are rooted in the context of family relations, parents' rights and obligations towards their children.

Theoretical deliberations on the issue have been operationalised in questions of a questionnaire completed by 94 professionally active doctors of various specialisations, who declared believing in God. The aim of this article is to present the results, to display the convictions of the medical staff on the ethical aspects of the communication in paediatric palliative care and attempt to provide them with ethical commentary.

Execution of ill children's rights to true information

Deontological codes, studies in bioethics and documents produced by the Church entitle patients to true information about their health. Medical law obliges doctors to inform persons aged 16 and over about their diagnoses. None-

theless, this law strictly relates to the patients' well-being and their ability to constructively use this knowledge in therapy. Each situation is different and depends both on the psychological, family, medical conditions and on the level of risk of patient's death. A routine system of medical personnel and patient communication cannot therefore be established. Next to the knowledge of the basic rules, the attitude characteristic of "great flexibility and openness, considering the very widely-understood time and place determinants" [1] is necessary.

Family is a natural environment in which a child may receive what it needs the most at the time of severe disease and death. The experience of unconditional love, affirmation of subjectivity, respect, understanding and trust can be most implemented in close family relations. Integrity of personality and relations with the loved ones is a significant element of dignified death [2]. Close cooperation of the medical personnel and the family involves communication to a large extent. Thanks to the parents and siblings a child is able to accept the truth of its health and experience unconditional love in a manner more adjusted to its cognitive skills [2]. Children respect the standards of recognising their health developed by their parents to a large extent and expect their parents to present them with a vision of worldly life and life after death.

Family members are privileged in the group of people taking care of a child suffering from a terminal disease. This assumption is confirmed by the opinion of doctors. Positive reply was given by 82% of the respondents to the question *whether a family is the best intermediary to inform the child of its health*. "Definitely yes" was replied by 42% of the respondents, 20% said "rather yes" and 20% gave a "yes" answer. The reply "rather no" was given by 13% and further 7% had no opinion. These opinions relate to primary school children. In the case of secondary school children 61% of doctors claim that family is best to describe health status to a child and 29% of the respondents are of a different opinion, saying "rather no".

The majority of parents assume that they know what their children need best, what is the best for them and what decisions will meet their expectations. However, the problem arises when the parents do not want to or cannot inform the child of the fact that it should prepare for death.

In respect of primary school children, 33% of doctors asked *if informing a child about its health should be limited to the boundaries estab-*

lished by its parents replied "yes", where only 10% answered "definitely yes". It is maintained by 67% of the respondents that doctors may cross the boundaries drawn by parents if the child's good requires so. As regards secondary school children, the majority of doctors claim that parents should refrain from establishing such boundaries; 42% said "no", 20% answered "rather not" and 8% said "definitely not". The opinion that parents have such right in respect of secondary school children is maintained by 30% of the respondents.

In the case of impending death, 70% of doctors maintain that a primary school child should be informed of its health condition by the medical personnel if it asks this question itself. Similar results were obtained for secondary school children. "Medical personnel should not inform primary and secondary children of the risk of death" is assumed by 28% of the respondents. It seems that this group of doctors leaves the decision to the family or some other person to decide in this case. When a child is dying and does not ask about its health condition, 30% of the respondents maintain that the medical personnel should inform the child of the fact, regardless of whether it is a primary or secondary school child. The doctors replied (72%) that a child not asking about its health should not learn about the diagnoses or be informed of its health. A "rather not" answer to the question was given by 50% of the respondents.

The above mentioned replies seem to have been accompanied by a conviction that it is the family who should care to inform the child of its health condition. However, if parents are unwilling to inform a child of an unfavourable diagnosis in the case of direct risk of death and the lack of such knowledge would involve the child's spiritual harm, doctors maintain that the medical personnel is authorised to provide the child with such information. Twenty two percent (22%) of doctors claim they "definitely have" such a right, 50% maintain that they "rather have" such a right and 28% are of the opinion that they "have" such a right. The same ratio is maintained for primary and secondary school children.

To prove the right of informing children about death, one may quote the results of research carried out in Japan in 2006. The research covered children having cancer and being subject to palliative care [3,4,5,6]. The said results have shown that informing a child about the possibility of death did not effect nervous breakdown, i.e. depression. Other research car-

ried out by *Karolinska Institute* proves that none of the 147 parents who discussed death with their children regretted their decisions later on. On the other hand, 69 in 258 parents who concealed the truth from their children regretted not having discussed death with them [7]. It turned out that the majority of parents who regretted their decision were aware of their children's sensing the approaching death. Wolfe, referring to these findings, concludes that children worry more about their family and about the way their parents and siblings will cope with the problem than about themselves. Therefore, children are often aware of this problem, they know considerably more than the adults think, and refrain from discussing the matter due to a uniquely understood well-being of the family [8].

Active child participation in the therapy of decision-making process

The question of whether the medical personnel should take into account the child's opinion depends on three factors. Firstly, it should be borne in mind that the way children perceive the disease, the forms of therapy, prognoses depends on whether the family and the medical personnel discuss the disease and therapy with them in an honest and open manner. Secondly, the level of emotional and intellectual capabilities of children depends on the extent to which their psychological and spiritual needs in relation to the family and friends are met. Finally, age, disease advancement, emotional balance and personal skills that allow for a positive absorption of information about the health condition, are important determinants [8].

The majority of the responding doctors claim that children are emotionally and intellectually prepared to actively participate in the decision-making on their therapy. Seventy per cent (70%) of the respondents claim the above mentioned fact is true for primary school children, where 20% maintain that children are absolutely mature in this respect, whereas 50% claim that children at this age are rather emotionally and intellectually competent in this regard. Thirty per cent (30%) of the respondents maintain that such children are not completely prepared to such participation and 80% of the respondents considered secondary school children ready to take part in the decision-making process; however, only 20% were absolutely certain about their opinion) maintained that the secondary school children rather lack such competences.

It is worth mentioning that allowing a child to participate in the decision-making process is

determined by whether the child chooses a solution that is good for its well-being.

If the child's decision is not focused on its well-being, the majority of doctors claim that the child's opinion cannot be taken into account. This view is shared by 74% of the respondents. A surprisingly high percentage of doctors claims that even in the above mentioned situation, when the child's opinion is not good for its health, it should be considered. This view is shared by 26% of the respondents. The same answers were provided in the case of primary and secondary school children.

Religious and spiritual matters

Parents often go through extreme and conflicting moods in view of their child's terminal disease. On the one hand, they might feel being abandoned by God who let the innocent child suffer. On the other hand, they hope that God will allow the child to live after death and in a way still be with them [9]. Interestingly, the hope of eternal life is similar among the practising believers, those who don't practice, atheists and agnostics. This is connected with experiencing sorrow in grief that can be called a child's sorrow because it is accompanied by inability to express pain, longing, by accusing oneself. These experiences are characteristic of childhood [10].

Moral dilemmas related to children's religious independence may also occur in this context. They appear in situations when children's and parents' views on religion differ and when the family disagrees in their religious beliefs. It is natural that parents raise their children in concordance with their own religious beliefs. It may, however, turn out that a child wishes to die in a spirit of faith which parents reject as a protest or outlook on life. Such a situation may take place when children are introduced to the articles of faith outside the household, e.g. at school during the religion lessons. The question arises whether the believing medical personnel is morally entitled to exert indirect or direct religious impact on the child when the parents do not wish so. Does the child's independence in the religious dimension precede the parents' right to raise the child?

Research has shown that catholic doctors are quite unanimous in their opinion on spiritual support they are obliged to in respect of dying children. When asked: "*Should the medical personnel talk to the children about their faith, fears, anxieties*", they all replied affirmatively. This relates to both age groups. Among this group of doctors, 42% considered this need defi-

nite. This view is, however, accompanied by the conviction that they are not ultimately prepared to hold such conversations. Only 27% of them claim that the medical personnel is prepared to carry on conversations on the spiritual and religious aspects of life, while 73% maintain that it is “not” or “rather not” prepared. It turns out that three in four doctors face a certain dilemma resulting from the sense of responsibility of having such conversations and experience of lack of competences in this respect.

The last two questions related to the situation of difference in faith between a child and its parents and the fact whether the medical personnel is allowed to give witness of faith in such situations. All the respondents gave affirmative replies to the question “*if the medical personnel should give witness of their own faith in God and eternal life when parents reject believing in God and the child asks questions of its life after death*”. Fifty nine percent (59%) of the respondents maintained that doctors and nurses had definite right to do that. The opinion is identical in respect of primary and secondary school children. Doctors hold that children are independent from their parents in respect of religion. This is confirmed by replies to the next question: “*Should the hospital’s chaplain pay visits to a child on its request despite the fact that parents do not wish so?*” As regards secondary school children, all the answers were positive, where 81% of the respondents voted “yes” and “definitely yes”. Similar replies were expressed in respect of primary school children, though 12% of the respondents replied negatively, claiming that the chaplain should rather not visit a child in such a situation.

Conclusions

Children subject to palliative care should be treated with due dignity, respect and honesty. As regards functional families, parents are the best witnesses of such attitude to children. Parents know their children and are thus appropriate intermediaries to communicate the truth about their children’s health, therapy initiated and possible consequences. Children should be allowed, if they wish so, to openly discuss such matters. Experience shows that children, noticing their parents’ reactions, subtle body language, mimicry and voice tone as well as behaviour of the medical personnel, can sense the approaching death and expect such conversations. Dishonesty to small patients or concealing the truth may result in the sense of alienation, loneliness and lack of understanding. Parent’s

desire to spare their children the sense of unease related to the risk of death in similar situations may have opposite outcomes than expected.

In principle, it is the family which should determine the scope of information to be provided to a child as parents can best establish the dynamics with which the child can be informed about its health and the parents are familiar with the child’s ability to assimilate the truth in an unharmed manner. Communication within a family is not always appropriate, though. Crises often intensify problems and the disease disintegrates the family system. In such situations it is not only a child that is a patient but also the whole family.

Children are often aware of which spiritual and religious topics can be discussed freely with parents and siblings. It is often easier for a child to hold such conversations with non-relatives and discuss matters freely. It therefore seems that in some situations a child may be provided with information about its health or the issues of faith by the hospital’s personnel even if parents refuse to agree to that because of fears, prejudices or troubles with coping with the situation. It thus seems that when a family is unable to fulfil its function the medical personnel may provide the child with information about its health, in particular in the case of the risk of its death. Such truth should, however, be communicated progressively and the dynamics of informing about the unfavourable diagnosis should be determined by the patient. Many doctors claim that children can be told any truth, even the most severe one. Yet the way the truth is told should be adjusted and the child should be allowed to decide on what and when it wants to be told by asking questions.

If a child refrains from asking questions about its health and if life is at risk, it may mean that the child non-verbally demands particular attention and care. It should, however, be borne in mind that the child’s suffering due to awareness of upcoming death is difficult to imagine for the medical personnel. The phenomenon of the child’s calmness and courage in the face of death is frequent. It does not necessarily mean that the child fails to experience it deeply and in pain. Such calmness may be misleading and should not encourage to “forcibly” burden it with unfavourable diagnosis, subsequently leaving the child to itself. The fact that patients are not fully competent to constructively accept the truth about their health and consciously participate in therapy may indicate the need of particular care of an interdisciplinary team, composed of a doctor and a confessor or a psychologist [11].

Children may to some extent – which is always an individual issue – participate in taking decisions about therapy on the condition that they are competent. The patient's independence should, however, be subject to the generally understood interest of a child. If children's decisions are not aimed at their spiritual and bodily well-being, parentalism would be perfectly justified.

The medical personnel failing to make effort to fulfil the child's spiritual needs does harm to such a child. If children are not spiritually supported by the loved ones, the scope of obligations of the medical personnel increases. It should be borne in mind that spiritual concern is as important for therapy as bodily concern. Despite the difficulties and negative emotions which may arise from the discussion of spiritual matters, it should be pointed out that faith of children facing death is frequently characteristic of deeper confidence in continuation of life after death. Children in such situations may be more open to discussions of life after death than their parents.

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