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**Medyczne i etyczne aspekty decyzji o zaniechaniu uporczywej terapii u dzieci z chorobami prowadzącymi do przedwczesnej śmierci w Białostockim Hospicjum dla Dzieci**

**SUMMARY IN ENGLISH**

To protect the dignity, good, autonomy, and rights of children incurably or terminally ill is an important ethical issue of modern pediatrics. The use of overtreatment, which sustains life in this group of patients leads to the iatrogenic consequences in the form of children suffering consisting of pain, fear, loss of insecurity and intimacy, isolation in the hospital, deprivation of information, and participation in decisions and other rights, e.g. a choice of palliative care and dignified death. Therefore, the question arises: when a terminal phase can be recognized at them not to implement or refuse the intensive treatment? This problem concerns of course all children with diseases leading to a premature death, i.e. genetic defects, metabolic diseases, defects of the brain, failure of lungs or multiple organs.

 **The main goal of the study** was the attempt to verify the current definition of persistent therapy (overzealous treatment) and possibly a demand or an attempt to formulate a new definition.

 In order to achieve this objective, following research tasks were put:

1. Analysis of medical and ethical problems, legal provisions and ethical standards associated with the persistent therapy in children with chronic disease leading to premature death.
2. Analysis of attitudes of those involved in the care of patients in the terminal phase: persistent therapy, palliative care, and euthanasia.
3. Analysis of clinical and ethical aspects of the decision of parents and guardians to take or not, abandonment, refuse the persistent therapy to children with disease leading to premature death, patients at Hospice for Children in Bialystok in 2009-2014.
4. Getting to know the opinion of parents of children from Hospice for Children in Bialystok on the application and the refuse of persistent therapy.
5. Determination of the possibility of terminal phase diagnosis in children with chronic disease limiting their life.
6. An attempt to define the rules of applicable methods of persistent treatment or to refuse it if determination of the terminal phase is impossible.

 The research was approved by the Bioethics Committee at the Medical University of Bialystok R-I-002/165/2015.

**The first stage of the study** was the initial phase involving the analysis of personal data and the clinical diagnoses of patients from Hospice for Children in Bialystok located at the headquarters of the “Help Them” Foundation for Children with Cancer and Hospice for Children. Based on the analysis, it was found that under the care of hospice in the period 2009-2014, 43 patients died (including one after discharge from hospice care - the death occurred in the hospital), 21 children died of cancer, while the remaining 22 due to non-cancerous disease leading to premature death. For ethical reasons, thus too short time after death and possibly experiencing the intense grief over the loss of a child, children who died in 2015 were not taken into account in the selection of the research sample.

**The second stage of the study** consisted of a thorough analysis of medical data, available medical records (observations of doctors, nurses and other hospice stuff), archived information cards of previous treatments, additional tests, consultations, and analysis of death summaries.

 **The third relevant stage of the study** consisted of interviews with parents/guardians of the dead children. Parents or legal guardians of all children who died from the disease leading to premature death, which were under the care of the Bialystok Hospice for Children within 2009-2014 were asked to participate in the survey. It was a group of parents/guardians of 22 children. Mother of one patient expressed no desire to talk, and in connection with the delicacy of the problem, no pressure was expressed during the phone call and an interview with her was given up.The survey was conducted in each family only once by means of a qualitative in-depth structured interview based on the interview scenario specially developed for testing purposes. Mainly mothers were involved in interviews, because of the fact that they usually exercised actual custody of the child, and they took decisions on the child's treatment. However, some number of fathers also attended the interview (as marked in the description of the interview). The interview was based on a scenario by asking following questions: Was a specific diagnosis was set with a projected survival? If so, was it important or did it help to make a decision upon quitting the persistent therapy? Have you already taken care of a dying person? Have you seen death of a person subjected to persistent therapy? Who decided to give up the persistent therapy? Who helped in making decision on refusing the persistent therapy? Was decision to quit the persistent therapy difficult? How much? What were the reasons for such a decision? What specific treatments or activities, I considered persistent (ventilator, tube, injections?) Was there a specific moment, when you recognized the therapy as persistent? Was the decision made at the right time? Do you now regret such a decision?

The analysis results were subject to the following rules: for recording-information part: the problem of interview was cleared, the goals of the study were explained, the interview was characterized, date and duration of interview was placed, conditions under which it was proceeded were described; for relevant part: meaning of a respondent’s narration was quoted, no questions asked to the respondent were quoted, the language was simple, but strict; for evaluation part: it was verified whether all the planned information was obtained, whether there were gaps, the reliability of achieved data was rated and atmosphere during the interview was described.

 **The fourth stage of the study** consisted of undertaking the attempts to formulate a new definition of persistent therapy for use in the law.

The results allowed for drawing the following conclusions and demands:

* The parents were aware that their child is seriously ill, and they knew that the disease is incurable leading to premature, inevitable death, but they could not clearly say when the death will occur.
* When parents recognized that their child has no chance of life or cure of the disease leading to premature, inevitable death, but only to extend the life, usually confined the consent to treatment (from minor to radical restrictions), taking into account the excessive suffering of their child, treatment failure, lack of opportunities for life, and desire to ensure their child a decent ill and dying conditions.
* In the opinion of parents, the most important limitation to treat children with the disease leading to premature death, related to contention for hospitalization, mainly due to the application treatment that is strenuous to their child, including respirator-therapy and a significant reduction in contact with the child.
* All parents of patients under the care of a home hospice did not express the consent to the use of a respirator, and most of them wanted their child to die at home and not in a strange place (like in the hospital), recognizing it as one of the elements to provide a decent dying.

I therefore postulate to introduce to the definition of persistent therapy, the terms “disproportionate therapy” (cost vs. effect) and “small chance of life” (both in quantitative and qualitative terms), and during assessing the proportionality and opportunities for life, both objective and subjective criteria should be taken into account.