Inaugural Asian Paediatric Ethics Conference
2nd and 3rd October 2023

Symposium 1 speaker

Professor Ilhak LEE
Yonsei University, South Korea

Professor Ilhak Lee, MD., Ph.D., is an Associate Professor in the Department of Medical Humanities and Social Sciences at the College of Medicine, Yonsei University. His primary research areas include 1) end-of-life care with a particular focus on medical ethics consultation and 2) the ethics surrounding innovative medical research. Dr. Lee has held esteemed positions as an expert committee member for both the Korean National Bioethics Advisory Committee and the National Hospice and Palliative Care Committee. He is current Chair of ELSI Committee for Korean National Bio Big Data Project, National Institute of Health, ROK.

His recent publications are, “Public perceptions and attitudes of the national project of bio-big data: A nationwide survey in the Republic of Korea” (2023), “ Public perceptions and attitudes of the national project of bio-big data: A nationwide survey in the Republic of Korea (2023)”, and “Ethical Principles and Considerations concerning the Use of Artificial Intelligence in Healthcare” (2023)

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Presentation title: When Is It Enough?: Ethics of Novel Interventions for Critically ill Children

Abstract

In situations where death or serious disability is feared, rational and integrated understanding is not only a very difficult task, but there are many limitations that inevitably accompany the decision-making process that integrates ethical values and medical indications. Meanwhile, in evaluating decision-making, more of consideration is needed not only for the product of the decision but also for the appropriateness of the process. Formal requirements of decision-making such as information provision, voluntary deliberation, and clear expression of intent must be met, but a decision-making process that can address the motives and unseen purposes and needs of families, children, and medical staff participating in the decision-making process is needed.

In this presentation, we will examine the conditions to permit attempting unproven treatments for seriously ill pediatric patients.
The permission condition for medical interventions will be "to voluntarily choose a treatment method that has a reasonable expectation of contributing to the realization of the best interest after sufficient consideration". However, there are factors that cannot easily meet this condition in the decision of treatment targeting critically ill children who are at risk of life.

The biggest issue is the decision-making ability of pediatric patients. Because they are growing in physical and mental aspects, it is not easy to evaluate the decision-making ability of these patients. In other words, the preferences of these patients exist at different levels depending on (1) cases where it is difficult to expect that preference ever existed (for example, genetic diseases manifesting symptoms after birth or brain damage due to childbirth accidents), (2) children whose decision-making ability is not fully mature, and (3) mature minors who have decision-making ability but are not legally recognized. Because it is difficult to recognize them as the subjects of decision-making, parental consent is considered an important requirement in research involving children.

Parental consent is justified not because they are the legal guardians of the child, but because they have an interest in the best interest of the child and the motivation to realize it. However, additional considerations are needed to ensure the best interest in the situation we are discussing. For instance, the best interests of the parent and the child are often understood in a way that is difficult to separate. Also, new treatments, such as gene therapy, have different development mechanisms and verification procedures from traditional compound-based drug trials, making it difficult to distinguish between therapeutic and research purposes. Therefore, it is not easy to consider the implications of the so-called therapeutic misconception. This means that decisions must be made by overcoming considerable uncertainty.

I will examine the points to consider in the decision-making process for the implementation of therapeutic interventions. For example, the additional risks to health posed by the intervention, the existence of clinical equipoise between existing treatments and new interventions, and the nature of the disease are such points. This is why a deep approach to counseling and decision-making processes is requested to sufficiently address these factors in determining the implementation of interventions that have both therapeutic and experimental characteristics.