

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



Symposium 2 speaker

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Sarosh Saleem is a physician ethicist from Pakistan. Dr. Saleem is currently pursuing Doctorate in Health Care Ethics from Saint Louis University, MO, USA. She is Assistant Professor of Bioethics and founding head of Bioethics Department at Shalamar Medical & Dental College, Lahore, Pakistan. Dr. Saleem has a keen interest in Clinical Ethics Consultation, Cross-cultural ethical issues, Pediatric end of life and research. In 2021, Dr. Saleem received Hans Joachim Shwagger Award at ICCEC 2021 as acknowledgement and encouragement of efforts in developing Clinical ethics Consultations in Pakistan. She has a Masters in Bioethics from Aga Khan University, Karachi, Pakistan and Fellowship in Pediatric Bioethics from Children's Mercy Hospital, Kansas City, MO, USA. She plans to continue teaching and training Bioethics and especially Clinical Ethics in Pakistan on completion of PhD in Health Care Ethics.

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Presentation title: Reclaiming Interests: Centering Children in Pakistan's Pediatric Ethics Discourse

Abstract

Pakistan is a low-middle-income country with nearly half (45%) of its total population under the age of 18. Social, cultural, and financial challenges have a direct impact on pediatric care and the decision-making process in pediatrics. Additionally, political and legal inconsistencies exacerbate the socio-cultural and economic challenges within pediatric clinical care. The social and legal obstacles encountered in pediatric clinical practice have subtle yet significant implications for pediatric research.

In this presentation, my objective is to raise questions within the normative discourse that affect decision-making in pediatrics. I aim to initiate a normative discourse rooted in Pakistan's ethical landscape within the field of pediatrics. The primary challenge revolves around determining the locus of moral authority for decision-making. Parents and families bear the responsibility for their children. When personal, spiritual, cultural, and financial factors influence parental or familial decision-making, it raises the question of the moral authority clinicians possess to intervene. Safeguarding the rights of children is responsibility of the state. However, in the absence of clear legal benchmarks and limited state protection, defining the limits of harm and the boundaries of interests for a child becomes a daunting task. Pediatric clinical research in Pakistan predominantly adheres to international research ethics guidelines. I argue that given the limited involvement of children in pediatric clinical decision-making, involving them in research for the purpose of obtaining assent can be detrimental. The concept of assent is morally grounded in the principles of respecting individuals and ensuring non-maleficence, which are derived from the notion of informed consent. It is also considered an engagement tool to empower, engage, and educate children in research. However, I contend that both of these foundations encounter challenges in Pakistan due to deeply ingrained social and cultural practices of respect and obedience to authority figures, whether they be parents, family elders, or clinician researchers. Clinicians, ethicists, researchers, and research institutions bear the added responsibility of safeguarding the interests of children in research in Pakistan and protecting them from harm that can result from insensitivity and a failure to respect cultural differences.

The most significant question we all must address is: Are we doing enough to give voice to all the unheard voices of our children?