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Review Article

Pediatrics

Medical Ethics of Pediatric Care

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Abstract

Clinical research ethics is founded on a few well-known rules and papers. The criteria differ from country to country, but the ideals of respect for humans, beneficence, and fairness remain consistent. These values are expressed in criteria for obtaining free and informed consent, minimizing risk or damage, and without disproportionately burdening or disadvantageous specific people. In hospitals, physicians frequently confront ethical difficulties that need appropriate abilities and the capacity to detect and manage. For research to be ethical, it must also be of such high quality and performed in such a way that it produces known and usable knowledge. Youngsters have a reduced ability for comprehension and may be more susceptible to compulsion. As a result, kids are seen as a particularly vulnerable demographic, and specific provisions for children are included in many standards. The level of risk permissible for minors participating in research is an important topic in these clauses. While it is widely acknowledged that children deserve special care due to their fragility, there is growing concern that children in general should not be disadvantaged by a lack of information because of decreasing research activities. The purpose of this study was to examine the ethical issues faced by physicians and nurses with medical education and pediatric care responsibilities, as well as whether those issues are related to their workplace, medical specialty, and area of clinical practice, as well as the primary role of parents and children in adhering to these ethics.

Keywords: Ethics, Pediatric Care, Decision-Making, End of Life, Ethical Issues.

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INTRODUCTION

Medical ethics is a set of moral rules that govern how values and judgments are used in the practice of medicine. Although the historical origins of Western medical ethics may be traced back to Hippocrates' writings on the obligations of physicians to rabbinic and Christian teachings, the American Medical Association approved the world's first formal national code of medical ethics in 1847, which acted as a set of rules and regulations for the medical profession [1]. Concerns about human experimentation and the availability of new technology have resulted in a growing role for ethical analysis in medicine since the mid-twentieth century, as seen by the increased usage of institutional review boards, hospital ethics committees, and the development of the function of clinical ethicists [2, 3]. The respect for patient autonomy and shared decision-making has grown at the same time that medical decisions are becoming more complex. As a result, medical ethics has to change from being a theoretical, philosophical defense of moral principles to a practical strategy for addressing common conflicts in clinical treatment [2]

Such quandaries are especially prevalent in critical care due to the complexity of issues concerning supply and demand mismatches between the health care system's resources and the demands of the public, disagreements between the health care team and the patient/surrogate decision maker over whether lifesustaining devices should be employed, and acceptable use of experimental therapies in heroic attempts to preserve a life. Technical developments have enabled us to extend life, but values influence judgments about what quality or length of life is worth maintaining at what expense of pain on the part of the patient or of resources on the part of society. More and more children are surviving chronic diseases in pediatric critical care [4], and some of these children require continuous or frequent intensive care and technology assistance. As a result, these inquiries are expected to

increase in frequency over time, making it even more crucial to establish agreed objectives amongst all parties [2]. Also, Since 1987, the American Board of Pediatrics (ABP) Certifying Test has included ethical decisionmaking [5]. Doctors encounter ethical issues, and the Accreditation Council for Graduate Medical Education (ACGME) recognizes that ethical norms must be followed by trainees as part of their professions [6]. The ACGME mandated a formal curriculum in medical ethics for all pediatric residency programs in 1997 [7].

Notwithstanding these criteria, surveys of pediatric residency program directors have found a wide range of approaches to teaching ethics and professionalism in pediatric residency programs. A 2009 study of pediatric program directors found that 80% of respondents utilized lectures to teach ethics and 72% used seminars based on real-life scenarios to teach ethics. Yet, just 29% of respondents said they were well-versed in the themes addressed in their ethics curriculum. According to a 2013 study of pediatric program directors, many respondents were unaware of options for teaching ethics and professionalism [8]. The ethics of medical decision making was particularly mentioned in the General Pediatrics Subject Outline for the in-training examination in 2017 [9]. This area encompasses essential topics such as capacity, informed consent, teenage assent and dissent, parental authorization, and surrogate decision-making criteria for pediatric patients. Pediatricians face these ethical notions and frameworks on a regular basis. Regrettably, this component of medical ethics has also been highlighted as an educational need, and regardless matter how prevalent these situations are, they may become a source of moral anguish when physicians feel ill-equipped to deal with them. Instructors and students in a variety of medical specialties have recognized medical decision-making ethics as an area in which more education is needed [10, 11].

There are continuing initiatives to expand ethical training in pediatrics, particularly the ethics of medical decision-making, there is a dearth of published curricula to fill this need. The American Academy of Pediatrics (AAP) issued a bioethics teaching guide for pediatric residents in 2011. Sections on Informed Consent and Assent in Pediatrics, Minors as Decision-Makers, and Pediatrician-Parent-Patient Relationship: Duties of Veracity, Fidelity, and Confidentiality are included in the curriculum. Unfortunately, the application and efficacy of this curriculum have received little attention, and it lacks a strict structure for implementation. Nevertheless, some published pediatric ethics courses focus largely on the incorporation of the ethical concepts of beneficence, non-maleficence, autonomy, and justice into pediatric practice but do not explicitly address medical decision-making [12, 13].

This review provides an overview of the broad issue of medical decision-making ethics in specific

pediatric clinical contexts. As well as, the wider curriculum, address both the training and comfort gaps observed by doctors and pediatric trainees, as well as the scarcity of published curricula and ethics materials. It also explains the situations in which medical ethics are needed like decision-making standards and end of life decisions in pediatric cases. The article was successfully integrated as part of a typical medicalreport structure. Given how frequently such difficulties arise in clinical practice, modules dedicated to the ethics of medical decision-making in the juvenile population are a significant addition.

Decision-Making Standards in Pediatrics:

Most institutions have procedures in place that are in accordance with applicable state legislation regarding who is the next acceptable surrogate if a parent is either absent or an unfit decision maker [14]. Extended family or court-appointed guardians are two more options for surrogates. Even if the medical team considers that a parent is untrustworthy as a surrogate (for example, in situations of suspected child abuse), a certain legal process must be followed before that parent's decision-making powers can be removed. While any such legal procedure is ongoing, the team should continue to keep the parent informed and involve them in decision-making [15, 16]. Parents, on the other hand, do not have complete control over everything that occurs to their children. Although parents have wide responsibility over their children's upbringing, education, and medical treatment, courts have concluded that parents cannot create martyrs of their children, and parental authority is occasionally overturned when there is a risk of immediate harm to a child. When a medical team secures a court order to transfuse a kid with blood against the desires of a parent who is a Jehovah's Witness and so objects to blood transfusion on religious grounds, this is an example of parental authority being overturned [17]. Overriding a parent in such a situation is frequently appropriate when the denial of therapy would almost certainly result in serious damage or death and the giving of the therapy provides evident benefits with few or short-term costs. Choices become more difficult when the benefit is uncertain, or the therapy is protracted. The medical team can act as a safeguard to ensure that any decision made by a parent is within a range of acceptable possibilities in comparable instances. In general, an ethical committee or the courts do not need to consider a decision further if the team and a parent concur that it is suitable [2].

Balancing children's, parents', and caregivers' goals:

Children, in general, desire to be engaged in decisions about their bodies and health. They also understand their role in decision-making as entwined with that of their parents and value and respect their parents' advice [18], especially when they consider a situation to be more dangerous. Most youngsters do not expect to make their own decisions, but rather to be included in the process and have their ideas acknowledged. Collaborative decision-making assists youngsters in clarifying their beliefs and preferences [19]. Although most children favor cooperative decision-making with their parents, many do not feel that parental or physician decisions should be absolute. This underlines the significance of parents assisting their children in recognizing their own skills and responsibilities as part of the process that results in meaningful consent [18].

The AAP recommends that clinicians assess each child's potential for consent on an individual basis. Children are urged to "give agreement to care whenever feasible" based on their developmental stage (American Academy of Pediatrics, 1995). Assent, according to the AAP, is a process that should include cooperative decision-making by all participants. The Academy believes that dialogue contributes to the establishment of a meaningful relationship between a child and a physician, and that this part of consent is critical to the process. Doctors should make every attempt to give parents with the skills they need to help their children think for themselves. This helps youngsters to make reasoned and logical, age-appropriate decisions, knowing that their parents will back them. Through experience and reliance on people they trust, children learn to make excellent, sensible judgments. Parents and children may not be aware of the extent to which their connection may impair a child's capacity to make free or spontaneous decisions. As a result, it is the physician's obligation, as the child's advocate, to act as a facilitator and ensure that this process takes place [20].

When it comes to medical decisions, children, parents, and physicians do not need to be equal in status, but it is critical that each stakeholder has the chance to express his or her preferences and concerns. Parents must realize the significance of listening to their child's voice and considering what the youngster says. Children must understand that decision-making is a collaborative effort, and that while their opinion will be included in the ultimate choice, it is not theirs alone to make, nor is it necessarily binding. Hence, by setting ground rules and acting as needed, the physician may share part of the load and alleviate what can be a difficult and stressful period for both children and parents [20].

Ethics of End-of-Life Decisions in Pediatrics:

Every year, over 50,000 children die in the United States. Although there is some indication that more children are dying at home, many of these fatalities still occur in hospitals, and most frequently in the intensive care unit (ICU) [21-23].

Handling pain and other symptoms near the end of life, as well as providing emotional support to patients and families during the dying process, are thus key clinical competencies for pediatric intensivists. Because many life-limiting pediatric illnesses occur before the age of one year, shared decision-making approaches are unworkable. Until recently, there was just one systematic approach for dealing with terminal pediatric patients, and it was limited to meningomyelocele repair as a futility treatment. The "Groningen Protocol," devised in 2002 by a group from the Netherlands, is a systemized way to dealing with pediatric euthanasia difficulties in the newborn era. This approach stressed five factors for determining if euthanasia, or in many circumstances, cessation of care, is a viable option: The baby must have a specific diagnosis or prognosis. He or she must be in hopeless and excruciating pain. Criteria 1 and 2 must be validated by at least one independent doctor; both parents must provide informed permission; and the operation must be carried out according to accepted medical standards. The goal of this approach was to alleviate the suffering of juvenile kids born with "hopeless" disorders, or prognoses in which the quality of mental and physical life would be severely compromised or death would be near. This procedure drew harsh criticism both locally and internationally, but it was innovative in its goal of offering a systematic approach to challenging end-of-life choices in newborns.

The Groningen protocol positions the physician in a role of discussion leader or moderator, a framework for discourse while still addressing the issue of "parental permission" [24].

This strategy moved the perceived context of decision-making from sole parental consideration to consensus between medical providers and parents, an approach that is effective for addressing religious and cultural concerns in end-of-life and general medical treatment [25]. Notwithstanding the accusations, the Groningen Protocol's purpose was not to "murder infants," but rather to emphasize the quality of life of patients who lacked agency over the ability of technology to prolong life [26].

Managing Symptoms at the End of Life and the Principle of Double Effect:

Dying patients commonly experience discomfort or dyspnea, which need medical attention [27, 28]. Physicians at the bedside may be concerned that pharmacologic therapies designed to alleviate such pain could expedite death, and such worries may lead to symptom under-treatment [29]. The concept of twofold impact supports administering whatever amounts of medication are required to alleviate such agony, even if death is accelerated. This principle distinguishes between an action's intentional and unforeseen negative consequences. An act can be justified if the following conditions are met: the intended impact is beneficial, only the good effect is intended, the negative effect is

not a method to achieve the good effect, and the good effect must outweigh the bad effect.

In practice, judging intent is challenging, but drugs that are titrated to effect can be justifiable even when extremely large dosages of such treatments are required [30]. In most cases, dosages of opioids and benzodiazepines are not linked with time to death after mechanical ventilation removal if the quantity given is aimed at pain alleviation [31, 32], therefore doctors should be comforted that appropriate therapies seldom hasten death. Large dosages may be required to treat pain or dyspnea in patients who have built tolerance to these drugs over time, and doses may rightfully be raised higher than the customary quantities when necessary. The idea of twofold impact also explains why some drugs should not be used near the end of life [33]. Neuromuscular blocking medications, for example, do not reduce pain (and may interfere with the clinician's ability to identify pain in the patient) and induce death by paralyzing the breathing muscles. Neuromuscular blockade should never be given when removing a ventilator or to a dying patient who is spontaneously breathing. Similarly, drugs like highdose potassium chloride, whose primary purpose is to hasten death rather than ease pain, are unsuitable [2].

Social Responsibility:

The subject of social responsibility was highlighted as the necessity for nurses to be recognized as good professionals, recognized for the quality of their care and their position as care process mediators [34]. Several significant findings resulted from Albuquerque Quiroz's study [35], which investigated the experiences of nurses caring for critically sick children and their families. They discovered that social responsibility and solidarity are significant parts of nursing care for the non-biomedical features experienced by children and families based on an examination of the relevant themes. They discovered that through their experiences, nurses got a deeper sense of self and reflected more on their own beliefs, boosting their capacity to care in a more compassionate and holistic manner. The study by Srlie et al. demonstrated how crucial this feature is for nurses to be regarded good professionals, but nurses must also be rewarded for the quality of their job when it meets nursing norms and duties. They need societal confirmation as well as self-confirmation. It was critical for these nurses to remember their patients and to take good care of them. This is a type of ethical memory, and nurses felt "emotional distress" when they realized they had not paid enough care to their young patients. Andrade et al. emphasized the importance of nurses as mediators in the child-care process, acting as a form of agent who respects, protects, and defends children's health, supports their families, and communicates with healthcare providers [34].

Ethical problems in pediatric care:

The ethical concerns encountered in the everyday care of children involve topics that should be prepared for and addressed in pediatrics courses. Certain difficulties were more unique to specific workplaces, such as those linked to end-of-life care circumstances in hospitals and socioeconomic challenges and health policy in primary care. The fact that many stories concerned the physician-patient connection demonstrates the importance that this subject should be given in medical school. It is generally acknowledged that these connections should be compassionate, founded on ethics, and that they are heavily impacted by the moral values of persons participating in this process, culture, society, and the way the health care system is constructed. The American Academy of Pediatrics (AAP) has created eight components of professionalism to teaching and assessment in pediatrics in order to attain the optimum quality of this interaction. Six of these (honesty and integrity, dependability and responsibility, respect for others, compassion and empathy, communication and cooperation, and altruism and defense) directly connect to the attitudes and values required of the doctor in regard to the patient, while the other two (selfimprovement and self-awareness and understanding of boundaries) relate to the specialty-specific abilities of the doctor [36].

Ethical issues affecting the behavior of health professionals arose in all of the situations studied. Situations in this category, such as differences in personal and professional behavior and challenges protecting privacy, highlight the significance of enhancing negotiation skills and relationships with all members in the health care network. Delany et al. define "allied health" in Pediatrics as individuals from a variety of specialized health professions who operate in the pediatric area as part of a health care team, attending to children and adolescents with acute and chronic illnesses or impairments. Because of their conflicting viewpoints on what constitutes the best interests of the child, which depend on what the authors call "disciplinary paradigms of care or operational philosophy," the connection between physicians and these professions may lead to ethical dilemmas. According to these writers, the professional who attends the pediatric age group must be conscious of his position as a moral actor, of his professional obligation, and of the influence of his actions on the lives of children and their families when referring the patient to allied experts [37].

Another ethical problem of end-of-life care were those that were more intimately tied to the influence of technology advancement in health, which necessitated ongoing reflection on the ethical elements. Some important subjects in the teaching of Ethics in pediatrics should be emphasized in this area, such as the limits of prematurity, advanced life support in children with severe disabilities and malformations, do-notresuscitate orders, therapeutic futility and palliative care, technology-dependent children, and the use of offlabel medications. Prior studies addressing these concerns, conducted in various contexts, indicate the difficulties experienced by hospital workers, particularly those in pediatric subspecialties charged with the treatment of critically sick children. They emphasize the need of physicians having the abilities to deal with these circumstances so that their decisions are in the best interests of the patient [38-41].

The socioeconomic background and public health policies are complicated and an inseparable aspect of medical activity, since they are closely tied to medical practice, especially for those who attend pediatric patients, due to the child's eco-dependence. Issues of this nature are connected to Social and Community Pediatrics, which DeWitt regarded as the largest problem for educational activity planning for over a decade, as it necessitates the integration of topics related to fairness in child health and social justice. The student gets the chance to connect with the socioeconomic determinants of health in the community setting, to advocate preventative action at many levels, and to develop an interest in safeguarding children's rights [42, 43].

CONCLUSION

In pediatric critical care, ethically sensitive situations are widespread. Although most circumstances are handled with minimal dissent within the medical team or between the team and patients/families, it is critical to practice with a constant awareness of areas where dissent might arise. At Basic Health Units, ethical challenges related to socioeconomic conditions and public health policies that impact patient treatment, care, and child safety are increasingly common. To prepare medical students and professionals for pediatric practice in hospitals, educational initiatives to help in decision-making and ethical reflection on end-of-life care circumstances in pediatrics should be addressed. The ethical difficulties surrounding socioeconomic issues and public health policies must be addressed and fully explored in pediatrics, particularly in relation to the teaching of pediatric primary health care and community practice.

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