

## **CHAPTER - 10**

### **ETHICAL CHALLENGES AND DECISION MAKING IN PAEDIATRIC NURSING**

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#### **Abstract**

Ethical challenges and decision-making in pediatric nursing present complex dilemmas due to the unique vulnerabilities of children, the involvement of families, and the evolving capacity of minors to participate in their own care. This chapter explores key ethical principles—autonomy, beneficence, non-maleficence, and justice—as they apply to pediatric nursing, emphasizing the tension between parental authority and the child’s best interests. Common ethical challenges include informed consent and assent, end-of-life care decisions, cultural and religious conflicts, resource allocation, and adolescent confidentiality. Research highlights that pediatric nurses frequently experience moral distress, particularly in cases involving treatment refusal, futile care, and disparities in healthcare access.

Decision-making frameworks, such as the Four-Box Model and shared decision-making approaches, provide structured methods for resolving ethical conflicts. Case studies illustrate real-world dilemmas, including parental refusal of life-saving treatment, adolescent autonomy in medical decisions, and ethical considerations in neonatal intensive care. Legal and professional guidelines, such as the UN Convention on the Rights of the

Child (CRC) and the American Academy of Pediatrics (AAP) policies, offer foundational support for ethical practice.

To mitigate ethical distress, strategies such as improved communication training, interdisciplinary ethics committees, and institutional support systems are essential. This chapter underscores the need for ongoing education, policy refinement, and advocacy to ensure ethical, compassionate, and equitable care for paediatrics patients. Future research should focus on interventions to reduce moral distress and enhance ethical decision-making in pediatric nursing.

Keywords: Paediatric Nursing, Ethical Dilemmas, Ethical Decision-Making, Informed Consent, Assent in Children, Best Interest of the Child Parental Rights

## 10.1 Introduction

Pediatric nursing involves unique ethical challenges due to the vulnerability of children, the role of parents in decision-making, and the evolving capacity of minors to participate in their own care. Ethical decision-making in this field requires balancing the child's best interests, parental rights, legal standards, and professional nursing obligations.

Pediatric nursing is a specialized field that presents unique ethical challenges due to the inherent **vulnerability of children**, the **role of parents** in medical decision-making, and the **gradual development of autonomy** in minors. Unlike adults, children may not have the full legal capacity to make independent healthcare decisions, requiring pediatric nurses to navigate complex interactions between **ethical principles, parental authority, legal frameworks, and professional responsibilities**.

One of the primary ethical dilemmas in pediatric nursing arises from **balancing the child's best interests with parental rights**. Parents or legal guardians typically have the right to make medical decisions on behalf of their children. However, conflicts may arise when parental choices contradict **medical recommendations or ethical standards**, such as refusing life-saving treatments due to religious or cultural beliefs.

In such cases, pediatric nurses play a crucial role in advocating for the child's welfare while respecting the family's values.

Additionally, the **evolving capacity of minors** to participate in their own healthcare decisions further complicates ethical considerations. While younger children may rely entirely on their parents for medical decisions, **adolescents may demonstrate maturity and understanding** sufficient to express preferences about their treatment. This raises questions about **informed consent, assent, and the appropriate level of autonomy** to grant minors in healthcare settings. In some cases, legal provisions allow adolescents to seek medical care independently, particularly for sensitive health issues such as reproductive health, mental health, and substance abuse treatment.

Beyond ethical and legal considerations, pediatric nurses must adhere to **professional nursing obligations**, including the duty to **provide compassionate, evidence-based, and family-centered care**. They must also manage ethical distress that arises when personal values, institutional policies, or medical constraints conflict with their professional responsibilities. Ethics committees, interdisciplinary collaboration, and shared decision-making models serve as essential tools in resolving these dilemmas effectively.

Ultimately, ethical decision-making in pediatric nursing requires a **delicate balance** between medical ethics, parental rights, and the evolving autonomy of the child. Nurses must **advocate for their young patients** while ensuring that ethical, legal, and professional standards are upheld to provide the best possible care.

## **10.2 Objectives**

### **1. To Identify the Most Prevalent Ethical Challenges in Pediatric Nursing**

Pediatric nursing presents a range of **complex ethical dilemmas** due to the unique vulnerabilities of children, their limited legal autonomy, and the involvement of parents or guardians in decision-making. The most common ethical challenges include:

Ethical dilemmas in pediatric nursing often revolve around complex and emotionally charged issues. One key area is **informed consent and assent**, which involves determining the appropriate level of involvement for children in medical decision-making while balancing the legal authority of parents or guardians. Children, depending on their age and maturity, should be given the opportunity to assent to treatments, even though legal consent is typically provided by adults. Another challenging domain is **end-of-life care**, where decisions must be made regarding the withholding or withdrawal of life-sustaining interventions. These include considerations for palliative care and the implementation of do-not-resuscitate (DNR) orders, often involving difficult conversations between medical teams and families.

**Cultural and religious conflicts** also play a significant role in ethical decision-making, especially when a family's beliefs contradict recommended medical treatments. For example, parents may refuse blood transfusions or other necessary procedures based on their religious values, prompting healthcare professionals to find respectful yet effective solutions that prioritize the child's health. Additionally, **resource allocation** poses ethical challenges when access to limited healthcare resources such as ICU beds or expensive therapies must be fairly distributed. In such cases, ethical frameworks are applied to ensure that decisions are made based on medical need, prognosis, and equity.

Finally, **adolescent confidentiality** is a critical concern, particularly in sensitive areas such as mental health, reproductive health, and substance abuse. While adolescents may legally access confidential care in many regions, healthcare providers must carefully navigate the boundaries of privacy—especially when the adolescent's safety is at risk. Together, these issues underscore the importance of ethical awareness, communication, and advocacy in pediatric nursing practice.

Understanding these challenges allows pediatric nurses and healthcare professionals to develop **ethical guidelines and frameworks** that support decision-making while ensuring **the best interests of the child**.

## **2. To Evaluate Existing Ethical Decision-Making Models and Their Applicability in Pediatric Care**

Ethical decision-making models provide **structured approaches** for resolving dilemmas in pediatric nursing. Evaluating these models helps determine their **effectiveness, limitations, and practical application** in real-world settings. Key models include:

In pediatric nursing, several ethical decision-making frameworks are utilized to guide healthcare professionals through complex and sensitive situations. One widely adopted model is the Four-Box Model developed by Jonsen et al., which organizes ethical analysis into four key areas: medical indications, patient preferences, quality of life, and contextual features such as cultural, legal, and social considerations. This model helps clinicians systematically evaluate all aspects of a case. Another important approach is Shared Decision-Making (SDM), which emphasizes collaboration among the healthcare team, the parents, and the child (when appropriate). This model values the perspectives of all stakeholders and fosters ethical and medically sound decisions through open dialogue and mutual respect.

Additionally, Principle-Based Ethics, proposed by Beauchamp and Childress, is foundational in nursing ethics. It focuses on four central principles—autonomy, beneficence, non-maleficence, and justice—which serve as moral touchstones for evaluating ethical dilemmas in practice. When particularly challenging cases arise, Ethics Committees—multidisciplinary teams composed of healthcare professionals, legal advisors, ethicists, and sometimes spiritual advisors—can offer expert guidance, facilitate conflict resolution, and support healthcare providers in navigating difficult decisions. By understanding and applying these ethical frameworks, nurses can better assess diverse clinical scenarios, select the most appropriate model for each case, and enhance their ethical decision-making skills to provide compassionate, just, and effective care in pediatric settings.

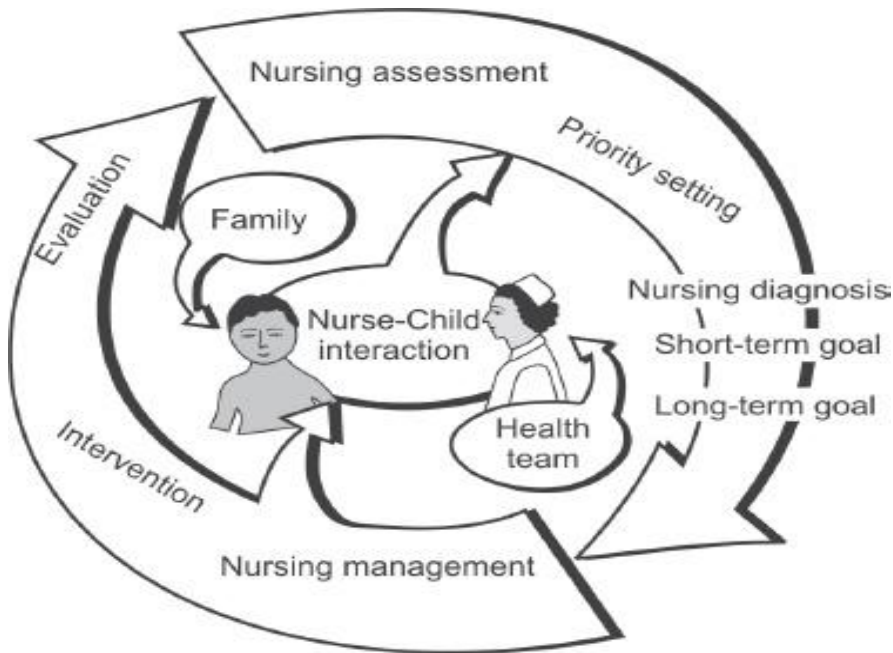
### **3. To Assess the Impact of Moral Distress on Nursing Practice and Patient Outcomes**

Moral distress occurs when nurses feel **unable to act according to their ethical or professional values** due to institutional constraints, parental decisions, legal barriers, or conflicting medical opinions. The consequences of moral distress include:

**Emotional and Psychological Effects:** Anxiety, guilt, frustration, and burnout among pediatric nurses. **Compromised Patient Care:** Nurses experiencing moral distress may struggle with **compassion fatigue**, leading to reduced engagement and suboptimal care. **Ethical Erosion:** Repeated exposure to ethical conflicts without resolution can lead to **desensitization**, where nurses become less likely to advocate for their patients. Assessing the extent and impact of moral distress is essential to **implementing support systems** such as ethical debriefings, counseling, and institutional policies that protect both nurses and patients.

### **4. To Propose Interventions for Improving Ethical Decision-Making and Reducing Moral Distress**

Effective interventions are necessary to **enhance ethical decision-making, support nurses in difficult situations, and reduce moral distress**. Key interventions include: **Ethics Training and Education:** Continuous professional development in ethical reasoning, legal frameworks, and cultural competence to equip nurses with the skills to navigate ethical dilemmas. **Support Systems:** Establishing **ethics committees, peer support groups, and debriefing sessions** to provide guidance and emotional support for nurses facing ethical distress. **Institutional Policies:** Creating **clear guidelines and standardized protocols** for handling ethical conflicts, ensuring that nurses have structured procedures to follow. **Advocacy and Communication Skills Training:** Enhancing **active listening, negotiation, and conflict resolution skills** to facilitate better communication between nurses, families, and healthcare teams.



The figure 10.1 illustrates a comprehensive **nursing care process model in pediatric nursing**, emphasizing the **dynamic interaction between the nurse and the child**, with essential contributions from both the **family** and the **healthcare team**. At the center of the diagram is the **nurse-child interaction**, which is the core of pediatric care. This interaction is enriched and supported by continuous communication and cooperation with the **family** and the **health team**, forming a collaborative care environment.

The process begins with a **nursing assessment**, where the nurse evaluates the child's health status, physical and emotional needs, and overall condition. This step forms the foundation for **priority setting**, where the most pressing health issues are identified in order to ensure that care is directed effectively. Following this, the **nursing diagnosis** is made based on the assessment and prioritized needs.

Once the diagnosis is established, **short-term and long-term goals** are formulated. Short-term goals focus on immediate and achievable outcomes, while long-term goals are aimed at sustained health improvement and developmental progress. These goals then guide the

**nursing management** phase, where strategies and care plans are developed and organized in alignment with the established objectives.

The next phase is **intervention**, where the planned care is implemented. This includes clinical procedures, therapeutic activities, patient education, and psychosocial support. During and after the intervention, **evaluation** is continuously conducted to determine the effectiveness of the care provided. Evaluation results feed back into the care cycle, leading to further assessments or adjustments to the care plan if needed.

This model also shows how the **family** and **health team** are integral to every stage of the process. The family provides emotional support and relevant background information about the child, contributing to personalized and culturally sensitive care. The health team, comprising doctors, therapists, and other healthcare professionals, collaborates closely with nurses to ensure a multidisciplinary approach to treatment.

In summary, the figure represents a **cyclical, patient-centered approach** to pediatric nursing that emphasizes **continuous assessment, collaborative goal setting, intervention, and evaluation**, with the child's well-being at the center of a strong support system involving both family and healthcare providers.

## **Core Ethical Principles in Pediatric Nursing**

Four fundamental ethical principles guide pediatric nursing:

- i. **Autonomy** – Respecting a child's developing capacity to make decisions (assent).
- ii. **Beneficence** – Acting in the child's best interest.
- iii. **Non-maleficence** – Avoiding harm (e.g., overtreatment or neglect).
- iv. **Justice** – Ensuring fair and equitable care for all children.

**Autonomy** – Recognizing and respecting a child's developing capacity to make decisions. While younger children may lack full decision-making capabilities, their assent (agreement) should be sought when appropriate. Adolescents, especially those deemed mature minors, may have the legal and ethical right to make certain healthcare decisions independently.



**Beneficence** – Acting in the child’s best interest by providing interventions that promote health and well-being. Pediatric nurses must consider both short-term and long-term benefits of treatment, advocating for care that enhances a child’s quality of life.

**Non-maleficence** – Avoiding harm, including physical, emotional, and psychological distress. This principle requires careful consideration of treatment risks versus benefits, ensuring that children do not suffer due to overtreatment, medical errors, or neglect.

**Justice** – Ensuring fair and equitable access to healthcare services for all children, regardless of socioeconomic background, race, or disability status. Nurses play a key role in advocating for healthcare policies that reduce disparities and improve health equity.

The topic of **parental authority versus a child’s rights** in healthcare presents complex ethical and legal challenges, particularly in pediatric settings. Traditionally, parents are responsible for making medical decisions on behalf of their children, operating under the assumption that they act in the child’s best interest. However, conflicts can arise when parental decisions are perceived as harmful—for example, refusing life-saving treatments due to religious beliefs or requesting unnecessary procedures that may distress the child.

As children grow older, their ability to participate in healthcare decisions also evolves. While younger children rely fully on parental guidance, adolescents often develop the maturity to understand medical procedures and make informed choices. Many legal systems acknowledge this by distinguishing between **assent**—the child’s agreement to care—and **consent**, which is usually provided by parents. In some circumstances, particularly with **mature minors**, adolescents may have the legal right to consent to their own treatment. This is especially relevant for **confidential services** related to reproductive health, mental health, and substance use, where adolescents may legally seek care without parental involvement.

When parental authority conflicts with a child's rights, healthcare providers face the critical task of balancing ethical and legal considerations. Their primary obligation is to uphold the **best interests of the child**, ensuring health and safety while also **respecting parental beliefs**. This often involves engaging in open, empathetic dialogue with families to reach mutually acceptable decisions. However, when a child's well-being is at serious risk—such as in cases where parents refuse essential, life-saving care—providers may need to pursue **legal intervention**, including seeking court orders to override parental decisions. In such scenarios, the legal and ethical duty to protect the child takes precedence, reinforcing the need for a careful and compassionate approach to resolving these sensitive issues.

### **10.3 Common Ethical Challenges in Pediatric Nursing**

Ethical considerations in pediatric nursing encompass a wide range of complex and sensitive topics. One primary area involves **informed consent and assent**, where parents or legal guardians typically provide informed consent for medical interventions. However, children should also be involved in decisions through the process of assent, based on their age and level of understanding. Ethical dilemmas can occur when a child refuses a treatment that parents want to proceed with, requiring careful negotiation, communication, and ethical review to balance autonomy and best interests.

**End-of-life care** presents another significant challenge. Decisions to withhold or withdraw life-sustaining treatments such as mechanical ventilation or artificial nutrition involve both ethical and legal dimensions. Healthcare teams must weigh the benefits of **palliative care**, which focuses on comfort, against **aggressive interventions** that may prolong suffering. Disagreements often arise between medical teams and families, particularly when families push for treatments the healthcare providers

view as futile. In such cases, ethics consultations and compassionate mediation are essential to prioritize the child's quality of life and dignity.

**Cultural and religious conflicts** can further complicate pediatric care. For example, some religious groups, such as Jehovah's Witnesses, may refuse life-saving procedures like blood transfusions for their children. Similarly, families may prefer **faith healing** over evidence-based medical treatment, creating ethical tensions when the child's health is at serious risk. Addressing these issues requires cultural sensitivity, legal understanding, and a patient-centered approach.

In times of medical crises, **resource allocation** becomes a pressing concern. Limited ICU beds, ventilators, and high-cost treatments pose ethical challenges when not all patients can be treated equally. Healthcare providers must rely on ethical frameworks to **prioritize cases** based on medical urgency, prognosis, and fairness, often making heartbreaking decisions in resource-constrained environments.

Another crucial area is **adolescent confidentiality**, especially in issues related to sexually transmitted infections (STIs), mental health, and substance abuse. While adolescents may legally access care confidentially in many jurisdictions, nurses must be prepared to **breach confidentiality** when the adolescent is at risk of suicide, abuse, or severe harm. Striking a balance between privacy and protection is key in such situations.

Lastly, **genetic testing** in pediatric patients introduces ethical questions about autonomy and future implications. Testing children for **adult-onset conditions**—such as Huntington's disease or certain cancers—can reveal information that may not benefit the child during childhood but could impact their future. This raises concerns about **informed decision-making and autonomy**, as children may later prefer not to have known such information. These ethical dilemmas highlight the need for a thoughtful, patient-centered approach in pediatric nursing that respects legal standards, family values, and the child's evolving rights.

## **1. Decision-Making Models in Pediatric Ethics**

### **A. The Four-Box Model (Jonsen et al.)**

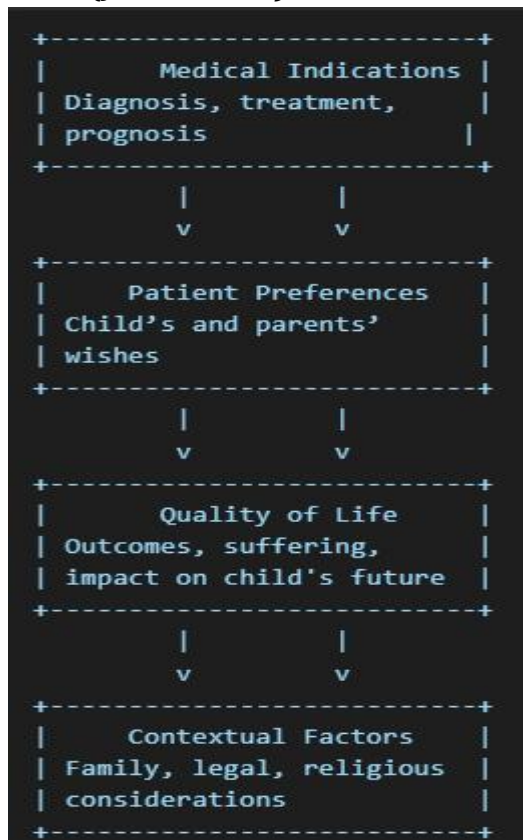


Fig 10.2 illustrates Medical Indications – Diagnosis, prognosis, treatment options, Patient Preferences – Child’s and parents’ wishes, Quality of Life – Potential outcomes and suffering, Contextual Factors – Family, religion, legal issues.

### **B. Shared Decision-Making**

Ethical considerations in pediatric nursing encompass a wide range of complex and sensitive topics that require careful navigation to ensure the well-being and rights of young patients. A primary concern is informed consent and assent, wherein parents or legal guardians typically provide consent for medical interventions. However, involving children in the decision-making process through assent—appropriate to their age and level of understanding—is also essential. Ethical dilemmas arise when, for

instance, a child refuses a treatment that parents insist upon, requiring thoughtful communication and ethical deliberation to balance the child's autonomy with parental authority.

End-of-life care introduces further challenges, particularly in decisions regarding withholding or withdrawing life-sustaining treatments like mechanical ventilation or artificial nutrition. These choices carry ethical and legal implications, demanding a balance between comfort-focused palliative care and potentially distressing aggressive interventions. Conflicts often occur when families insist on treatments deemed futile by medical teams, making ethics consultations and mediation necessary to uphold the child's dignity and best interests.

Cultural and religious beliefs can also complicate care. Certain religious groups, such as Jehovah's Witnesses, may reject blood transfusions even when they are life-saving. Some families may choose faith healing over conventional medicine, which can pose risks to the child's health. Addressing such conflicts necessitates cultural sensitivity, legal awareness, and a respectful, patient-centered approach to care.

In resource-limited settings, ethical issues related to allocation become prominent. Scarcity of ICU beds, ventilators, and expensive treatments demands prioritization, often forcing difficult decisions. Medical professionals must rely on ethical principles such as fairness, urgency, and prognosis to determine which patients receive care.

Adolescent confidentiality represents another crucial ethical area, especially in cases involving mental health, substance abuse, and sexually transmitted infections. While many legal systems permit adolescents to access care confidentially, nurses must be prepared to break confidentiality when there is a risk of suicide, abuse, or serious harm, balancing the need for privacy with the obligation to protect the adolescent's safety.

Lastly, genetic testing raises concerns regarding future autonomy. Testing children for adult-onset conditions—such as hereditary cancers or Huntington's disease—can reveal information that may not be immediately relevant but could affect the child's future decisions. Such testing brings into question whether it is ethically appropriate to disclose

information that the child may have preferred to learn later in life. These dilemmas emphasize the need for ethical sensitivity and a balanced, child-centered approach in pediatric nursing, ensuring care that respects legal frameworks, family dynamics, and the evolving autonomy of young patients.

An ethics committee consists of **diverse professionals** to ensure balanced perspectives:

Member	Role in Decision-Making
Pediatric Nurse	Advocates for patient-centered care, provides clinical insights.
Physician	Offers medical expertise on treatment options and prognosis.
Social Worker	Assesses family dynamics, cultural concerns, and support systems.
Legal Advisor	Ensures compliance with healthcare laws and regulations.
Ethicist	Provides guidance on ethical principles and frameworks.
Chaplain/Spiritual Advisor	Supports families with religious or spiritual considerations
Patient Advocate	Represents the child's best interests and rights.

The table 10.1 outlines the key members involved in pediatric healthcare decision-making and highlights their specific roles in ensuring comprehensive, ethical, and patient-centered care. The **pediatric nurse** plays a crucial role as a patient advocate, providing clinical insights and ensuring that the child's needs and comfort are prioritized. The **physician** contributes medical expertise, offering guidance on treatment options, prognosis, and overall clinical management. The **social worker** evaluates family dynamics, cultural values, and available support systems, ensuring that care plans are both practical and respectful of family circumstances. A **legal advisor** ensures that all decisions comply with relevant healthcare laws and regulations, particularly in complex or contested cases. The

**ethicist** helps navigate moral dilemmas, offering guidance grounded in ethical principles and frameworks. The **chaplain or spiritual advisor** addresses the family's religious or spiritual needs, providing comfort and guidance aligned with their beliefs. Lastly, the **patient advocate** represents the child's best interests, ensuring their rights are respected throughout the care process. Together, these professionals form a multidisciplinary team that collaborates to provide holistic, ethically sound, and legally compliant pediatric care.

## **10.4 Case Studies**

### **Case 1: Religious Refusal of Treatment**

The case of a 6-year-old child diagnosed with severe anemia who urgently requires a blood transfusion presents a significant ethical dilemma when the parents refuse the treatment due to their religious beliefs. This situation exemplifies the ethical conflict between the parental right to make medical decisions based on personal or religious convictions and the child's fundamental right to life and health. From a nursing perspective, ethical principles such as autonomy (respecting parental rights), beneficence (acting in the child's best interest), and nonmaleficence (preventing harm) must all be considered. Legally, in many jurisdictions, healthcare providers have the authority to seek court intervention to override parental refusal when a child's life is in danger. Effective communication is vital in such cases, with an emphasis on respectful dialogue and the potential involvement of religious or community leaders to bridge understanding. Typically, courts prioritize life-saving interventions and may permit the blood transfusion under emergency provisions, ensuring the child receives the necessary care.

In another scenario involving a 16-year-old adolescent diagnosed with leukemia, the ethical landscape shifts. The adolescent refuses chemotherapy due to concerns about its side effects, while the parents strongly support continued treatment. This case presents a conflict between adolescent autonomy and the best-interest standard. Although legally still a minor, the adolescent may possess the maturity to participate meaningfully in healthcare decisions. Ethical principles such

as respect for emerging autonomy, beneficence, and the best-interest standard come into play. Some legal systems acknowledge the mature minor doctrine, granting decision-making rights to competent adolescents. A multidisciplinary approach, including ethics committees, psychologists, and child life specialists, is often adopted to support both the teen and their family. Depending on the jurisdiction and the adolescent's demonstrated competence, courts may uphold the teen's decision or proceed with treatment based on best-interest considerations.

Legal and professional guidelines further inform pediatric ethical practice. The UN Convention on the Rights of the Child (CRC) affirms children's rights to health, protection from harm, and the opportunity to participate in medical decisions aligned with their maturity. The American Academy of Pediatrics (AAP) promotes the best-interest standard, advocating for evidence-based interventions and collaborative decision-making. Additionally, the American Nurses Association (ANA) Code of Ethics emphasizes the nurse's responsibility to advocate for pediatric patients, prioritize ethical standards, and deliver culturally competent care.

To uphold ethical nursing practice in pediatric settings, several strategies are crucial. Effective communication, including active listening and empathetic engagement, helps build trust with children and families while promoting clear, age-appropriate understanding of medical care. Nurses must also address moral distress, which can arise during ethical conflicts such as treatment refusal. Participating in debriefing sessions, seeking ethics consultations, and joining peer support groups are essential coping mechanisms. Lastly, advocacy is a vital nursing role—protecting children from harm, educating families, and intervening when necessary to ensure that care decisions align with the child's best interests, even when it means challenging parental authority.

## **10.5 Conclusion**

Pediatric nurses face complex ethical dilemmas requiring a balance of compassion, legal knowledge, and ethical reasoning. Ongoing education,



interdisciplinary collaboration, and ethical frameworks are essential for upholding the rights and well-being of child patient.

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