

2018-08

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Kirsch, RE

<http://hdl.handle.net/10026.1/10763>

10.1097/pcc.0000000000001488

Pediatric Critical Care Medicine

Lippincott, Williams & Wilkins

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Pediatric Critical Care Medicine
Supplement issue: Death and Dying in PICU
Accepted 3 January 2018

Ethical, cultural, social and individual considerations prior to transition to limitation or withdrawal of life-sustaining therapies

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Financial Support: No financial support was utilized for the creation or completion of this manuscript.

Keywords (6): bioethics, pediatric critical care, withdrawal of life-sustaining therapies, best interests, end of life, conflict resolution

Copyright form disclosure: Dr. Larcher received funding from ICON Clinical Research for work as Ethics consultant on Joint Data Monitoring Committee for an international multi agency trial on Long Acting Broncodilator Agents (LABAs) (did not involve consideration of any subjects relevant to current contribution) and from an Ejoint meeting of EAPS in Geneva October 2016 (guest lecturer; accommodation, registration, and travel paid). The remaining authors have disclosed that they do not have any potential conflicts of interest.

Abstract

Objective: To review ethical, cultural, and social considerations for the bedside healthcare practitioner prior to engaging with children and families in decisions about limiting therapies, withholding, or withdrawing therapies in a pediatric intensive care unit.

Data sources: Medical and bioethics published literature. Expert opinion.

Data synthesis: Clarifying beliefs and values is a necessary pre-requisite to approaching conversations about limiting or withholding life-sustaining therapy. Striving for medical consensus is important, but if professional disagreements remain, discussion, reflection and ethical analysis may determine a range of views that may reasonably be respected. Parental decisional support is recommended and should incorporate their information needs, perceptions of medical uncertainty, child's condition, and their role as a parent. Child's involvement in decision making should be considered, but may not be possible in younger children and those with advanced critical illness. Culturally-attuned care requires early examination of cultural perspectives before misunderstandings or disagreements occur. Societal influences may affect expectations and exploration of such may help frame discussions. Hospital readiness for support of social media campaigns is recommended. Consensus with family on goals of care is ideal as it addresses all parties' moral stance, and diminishes the risk for superseding one group's value judgments over another. Engaging additional supportive services early can aid with understanding or resolving disagreement.

Conclusion: There is wide variation globally in ethical permissibility, cultural, and societal influences that impact the clinician, child, and parents. Thoughtful consideration to these issues when approaching decisions about limitation or withdrawal of life-sustaining therapies will help

to reduce emotional, spiritual, and ethical burdens, minimize misunderstanding for all involved, and maximize high quality care delivery.

Article Tweet: Practical guide to important considerations prior to decisions about limitation or withdrawal of life-sustaining therapy in pediatric patients #PedsICU #Pedsethics

Introduction

Decisions about limitation of therapy or withdrawal of life-sustaining therapy involve several considerations. In a pediatric intensive care unit (PICU) limitation or withdrawal of life-sustaining therapies may entail a range of medical directives (table 1). This article will focus on the ethical, cultural, and social considerations framing decisions about limitation or withdrawal of life-sustaining therapy in the PICU setting (table 2).

Ethical Permissibility

Withholding or withdrawal of life-sustaining therapies (WLST) are considered morally [and legally] equivalent and accepted in many countries including Canada, United States, Europe, and Australia (1-9). In other countries, some permit withholding but not withdrawal of life-sustaining therapies; some permit both, and some permit both *and* hastening of a foreseeable death (1,10). In countries where withdrawal of life sustaining therapies is allowed, the ethical justifications are:

- 1) when continuing life-sustaining therapy (LST) cannot achieve its intended benefits e.g. death is imminent, irreversible organ failure;
- 2) when burdens of disease and or its treatment outweigh benefits so that continuing or starting LST is no longer in the patient's best interest (10,11);
- 3) when patient makes competent informed voluntary choice to forgo LST, even if efficacious or life-saving (2,4,5,12,13).

These approaches can be defended by application of deontological (no duty to give LST to those who cannot benefit since the sanctity of life is not absolute) or utilitarian (consequences are

better as determined by overall burden/benefit analysis) moral theories (1). They can also be defended by balancing the four ethical principles of respect for autonomy (right to individual views/choices/actions), beneficence (providing benefit to others), non-maleficence (avoidance of inflicting harm), justice (fairness, access) (10,13,14). An overarching principle is that all treatments should be in the child's best interests.

In the PICU setting the patient's preferences cannot be known due to critical illness, unconsciousness, cognitive limitations, age, developmental level or lack of prior discussions with the child. In these scenarios, clinical decision making is based on best interests. Determination of best interests is complex and widely used in decision making for those who lack capacity. Best interests are determined by weighing the risks and benefits of ongoing treatment. This process accepts that the sanctity of life principle, though carrying great weight, is not unquestionable. It may be appropriate to stop a therapy when potential for benefit is exceedingly low and the potential for ongoing suffering is high (2,4,5,10). Best interest determinations should take account of family beliefs and values and the social, environmental and cultural context in which they exist. Best interest determinations are subjective as they include value judgments such as quality of life (QOL) and suffering, that may vary between individuals, cultures and belief systems (4,10,15). For example, some patients value the sanctity of life even in the face of pain, discomfort, or suffering, and others value a minimization or discontinuation of painful interventions to preserve comfort – and these priorities may change over time and the course of a child's illness. Clarifying beliefs and values is a necessary prerequisite to approaching conversations about limiting or withholding life-sustaining therapy.

Withdrawal of Life-sustaining Therapy and Hastening Death

Distinctions between WLST and active hastening of death are based on the *intention* of the actions rather than the actions themselves since both have the same outcome. In WLST, life support is withdrawn with the intent of reducing burden, suffering and loss of dignity associated with these treatments (13,14). Withdrawing life-sustaining therapies allows the primary problem to progress, even to death, and pain and anxiety are treated without artificially hastening death (16,17).

In jurisdictions where hastening death (physician assisted suicide, medical assistance in dying, euthanasia) is legal, the ethical justifications are grounded in the permissibility of actions. In these situations, hastening death is ethically justified as providing an end to suffering or indignities when death is inevitable (18-21). Legal mandates for medical assistance in dying make specific stipulations to regulate the process. Such stipulations commonly require the explicit request of a person with capacity, a diagnosis of terminal illness, and they make allowances for conscientious objection by providers. Not all jurisdictions extend these options to pediatric patients.

Whether undertaking decisions about WLST or decisions about hastening death, the medical team needs to assess capacity of the patient or their surrogate decision maker, explore reasons and values involved in the decision, and ensure legal decisional authority. Capacity determinations ensure the patient is able to understand the information given and appreciate the consequences of all potential decisions. For example, the individual may disagree with a recommendation but retain full capacity – they appreciate the implications of their choice. If there is uncertainty in the ethical justifications or legal rulings, clarification for healthcare

practitioners can be found in resources such as the hospital bioethics department, legal department, and medical board for the region or country of practice.

Medical Consensus

Resolution of conflicts within or between healthcare teams is an important prerequisite for decisions about limitations in or withdrawal of life-sustaining therapies. Striving for medical consensus is important to reduce uncertainty for the team and for patients and families.

Accurate prognostic recommendations allow for consistency and certainty in communicating about WLST with the family. Medical uncertainties may be reduced by investigations, the passage of time, and by obtaining additional opinions. This dynamic process must be balanced against the impact of continuing treatment on the child, any ensuing harms, and it should be responsive to the child's changing clinical circumstances and parental responses to these.

Where possible, PICU professionals should collaborate with others responsible for the child's care to discuss treatment options and limitations prior to PICU admission. For example, daily conversations, and identification of key individuals to share information may minimize later conflicts about life-sustaining therapy (10,11,22,23).

In some instances, it may be impossible to attain complete consensus on what is in an individual patient's best interests consistent with all care providers' beliefs and values. It is important, during consensus building, that all pertinent team members are able to participate and have their views respected. Discordance within healthcare teams may be addressed by: a) agreement of all to accept collective responsibility for the decision made, b) allowing conscientious objection provided that the objector can get their duties covered, c) accepting

the “professional dissensus view” in which the dissenter, after adequate reflection and discussion, is prepared to take over the more contentious elements of the care of the patient (24). Professional disagreements do not in themselves entail that a particular view is right or wrong; rational discussion, reflection and ethical analysis may determine a range of views that may reasonably be respected.

Decisional Authority and Decision Support

In some countries, physician decisional authority is absolute (25,26). In countries where patient or surrogate decision maker input is expected, it is most often the parents for pediatric patients that are the recognized decisional authority for their child (27-29). Family compositions vary and the parental decisional authority may vary including: single parent, biologic parent(s), adoptive parent(s), foster parent(s) or legal guardians. Legal decisional authority should be clarified even though cultural approach to decision making may differ. This should be made transparent early during admission to avoid subsequent confusion.

Even where parental decisional authority is recognized, it is not absolute (14,27). In practice, parental authority tends to be limited at a point of harm to the child, rather than where they diverge from a medically judged singular best interest (27,30-33). Challenging parental determinations of best interest may require court involvement, and may compromise the working relationship between families and the PICU team.

Decision Support

Decisional support is recommended for the parent or surrogate decision maker(s). Several domains have been identified as important in family decision making such as information needs, seriousness of illness, no other treatment options, child’s best interests,

cultural influences, parental characteristics and past experiences, emotional support (29), perceptions of medical uncertainty, trust in care providers, alignment of recommendations with perceptions of the child’s condition, and perceptions of their role in the team and how best to care for their child (25,34,35,36) (Table 3).

Child Involvement in Decision Making

The potential for the child’s involvement in decision-making about limitations of therapy should be considered (10,37,38), but may not be possible in younger children and those with advanced critical illness. Existing research confirms that children prefer to be involved, but to a degree that varies from hearing information to choosing treatment options (38-42).

Conversations should explore cultural, family, and child expectations of the child’s role in decision making. For the child with cognitive limitations, consideration can be given to their expression of what makes them “happy” or provides them a “good life” (45). Pre-emptive conversations with chronically ill children to explore views on treatment burdens, QOL, and suffering can inform future decisions before a crisis occurs (1,39,43,44). Such conversations can be undertaken by the primary medical team, the pediatric palliative care team, by the critical care team, or combinations of these.

Culture

Culture is foundational and shapes all human experiences and social interactions. Rather than narrower definitions linking culture with ethnicity, religion, or spirituality, culture is broadly defined as a membership in a social community that shares values, beliefs and practices

(46,47). Culturally-attuned care requires explicit early examination of families' cultural perspectives, values, beliefs, preferences and practices early, *before* misunderstandings, relational tensions, erosion of respect or trust, or disagreements occur (46). This will happen concurrent with other explorations of values and beliefs, as there is a range of how people seat their values individually, or within their culture.

Different cultures vary in their perception and experience of death and dying (46,47). Cultural models are increasingly integrated into educational curricula for healthcare professionals (e.g. cultural competency, cultural humility, cultural safety) (47-49). Application of this knowledge involves asking patients and families about their beliefs (which may be represented as religion, spirituality, or individual preference) and integrating these constructs into care and end of life decision making.

Healthcare professionals are also influenced by their personal and professional cultural communities (46,47). An individual's background, beliefs and values determine their sense of moral obligation, whether explicitly stated or implicitly acted, and influences their judgments about moral permissibility. Although withholding and withdrawing life sustaining treatment are considered ethically equivalent by most bioethicists, healthcare professionals may find withdrawal more difficult as they may feel they are causing the patient's death through their actions (50). Alternately, a healthcare professional may consider the value of life relative to the scientifically-predicted likelihood of future ability to participate in self-directed activities, and find withdrawal less troublesome than continuing. Recognition and reflection about personal inhibitions or preferences by healthcare professionals, may increase understanding of other

viewpoints, allow discussions to be individualized for each patient and family and mitigate unintended negative impacts.

Societal Expectations

Experience and anecdote indicates that expectations of healthcare from patients and their families are rapidly changing, fueled by both local and global influences (51-54), misleading portrayals of resuscitation and medical miracles on television (51,53,55-58) and hospital marketing campaigns (59). Advances in medical technology have fueled perceptions, especially in high-income countries, that cure is assured or death can be delayed indefinitely (60,61). This may cause patients or families to oppose proposals to stop or limit life-sustaining therapies. Being aware of societal influences and asking questions about expectations can help to frame discussions and clarify impressions of certain success where present.

The Role of Social Media

The use of social media by patients and their families can affect expectations, or augment disagreement and challenge privacy and confidentiality. Use of social media may provide families comfort and education, allowing them to share information and connect with other families experiencing similar situations (62) even though this may disregard the child's confidentiality. Conversely, families may seek treatment or support that their own health care services have deemed inappropriate, they may utilize social media to raise money for alternatives, or to appeal to governmental representatives or push for changes in legislative policy (60, 63-65). The broad and immediate availability of information on social media may

change a private discussion between families and treating teams to a world-stage event that challenges confidentiality, fairness, objectivity, and can lead to a focus on personal or group agendas instead of the child.

Representation of clinical details in media may be biased or one-sided (60,62). Although parents are free to share what they like about their child, clinicians directly involved with the situation are bound by duty of confidentiality, privacy laws, and cannot share their perspectives— whether or not these are aligned or reflective of the media reports. In consequence, discussions about withdrawal or limitation of life-sustaining therapies can become a public debate, that may underplay the complexity of the issues in balance for an individual case (64,66,67). Furthermore, it may sidetrack both family and ICU team from the child at the heart of the debate, and risks distracting from high quality care.

Strategies that mitigate the impact of social media need to be tailored to the individual patient, their family, and societal context. Solutions also need to emphasize respect, trust building, and protection of confidentiality of all involved. Hospitals are tasked with utilizing social media to embrace their mission, promote healthcare education, and engage patients and families (62). However, they need to adapt policies to deal with negative publicity (60,68). Policies to promote proper social media use for staff can help prevent missteps (62). Social media output should be monitored, and a response team (composed of clinical staff, family relations representatives, information services, communications services, public relations, and legal or risk management) should be ready in advance to respond to potential social media campaigns or surge of negative media (60) and support resources should be available and known to ICU teams.

Consensus and Conflict between PICU and Family

There are many potential sources of disagreement between medical teams and parents (Table 4) about limitation in therapies or WLST. Decisions involve both medical considerations and balancing judgments about value of life, and competing interests in the broader context of the child's life. Consensus on goals of care is ideal as it addresses all parties' moral stance, and diminishes the risk for superseding one group's value judgments over another (4,69,70). The consequences of decisions for limitation or WLST will have long standing impact to the family. Achieving consensus recognizes the importance of the child-family unit and contributes to high quality care (4,10).

Understanding the basis of disagreement can help the team to seek additional support for consensus building. Reaching agreement for limitation of therapies or WLST starts at the initiation of technologic support. Clarifying expectations, the limits of therapeutic benefit, and setting timelines for medical markers of recovery or potential for restoration of baseline function can provide bookmarks for future discussions. Conversations of values and beliefs surrounding suffering and quality of life should occur early in a course of therapy so as to provide time for reflection between the healthcare team and family. Regular review of all decisions and willingness to respond to changing circumstance are essential; a time-limited evidence-based trial of treatment may be helpful and ethically appropriate (4,10,33,71). Scheduling regular meetings to check in and review (either with the current care team, or an assigned core care team) can help to prepare families for transition, or realign expectations for change (36, 72).

When divergences appear significant or difficult to reconcile, the PICU team can consider communication approaches that foster bridging, mediation, or reconciliation of disagreements (69,70,73). For example, agreement may be found in focusing on the child central to the conflict and understanding that each party – the family and the medical team – are seeking to do their best for the child. From there, understanding acceptable steps may help to find a path that allows best medical care and does not undermine moral principles of each party.

Support Services

Engaging consultant services, core clinicians the family trusts, social work, chaplaincy, palliative care, or bioethics teams early can aid with understanding and/or resolving disagreement. Additionally, asking the family to identify a cultural or religious authority for the team to communicate with directly can help to clarify the child's situation and permissibility of limitation or withdrawal of life sustaining therapies. Palliative care teams can provide a supportive perspective and assist with understanding family values or preferences, decision making, exploring fears, and can share knowledge about symptom management and what the experience of death may be like (4, 15, 74,75). Bioethicists can clarify ethical justifications of each party, determine potential ethical options, and may help to mediate solutions (4,15,73,75). Choosing the right support service with additional training in end of life communication and conflict resolution will depend on the resources available in any given hospital system.

Conclusion

Attention to the care of the child when life-saving therapies are unsuccessful is critical to respect the life of the child, the burdens associated with PICU therapies, the role of the family in the child's life and the impact that will continue beyond the families' interaction in the PICU. There is variation globally in ethical permissibility, cultural, and societal influences and thoughtful attention to such considerations *prior* to conversations about limiting or withdrawing life-sustaining therapies in the PICU is recommended. An inclusive and thoughtful approach will help to reduce the emotional, spiritual and ethical burdens and minimize misunderstanding for all involved to maximize high quality care.

TABLES

Ethical, cultural, social, and individual considerations prior to transition to limitation or withdrawal of life-sustaining therapies

<p>Table 1: Examples of Medical Directives included in Withholding and Withdrawing Therapies</p> <p>Withholding:</p> <ul style="list-style-type: none"> • withhold all life-sustaining therapies • withhold specific therapies: e.g. do not resuscitate (DNR), do not intubate (DNI), no ECMO, withhold enteral/parenteral nutrition • no escalation of current therapies (limitation of therapy) <p>Withdrawing:</p> <ul style="list-style-type: none"> • discontinue specific technologies: e.g. extubation with no re-intubation, ECMO decannulation with no recannulation • discontinue specific therapies: e.g. discontinue inotropic supports, discontinue prostaglandins <p>Separate orders are not necessarily required for all or any of these actions individually, once an agreement for withdrawal of life-sustaining therapy has been reached. In addition, there may be an agreement for a time limited trial of therapy preceding withdrawal if the therapies are not effective or otherwise beneficial</p>
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Table 2: Considerations Prior to Discussion about Limitations of Therapy or Withdrawal of Life-Sustaining Therapy

<i>Consideration</i>	<i>Description of Consideration</i>
Ethical permissibility	<ul style="list-style-type: none"> Based on applied moral theory surrounding medical interventions, limitations or discontinuation of treatment guided by accepted norms of a society Varies between societies, jurisdictions and cultures
Legal framework	<ul style="list-style-type: none"> Specifies how the roles and accountabilities of health care providers are integrated and operationalized for end of life decisions and processes Varies between jurisdictions
Medical consensus	<ul style="list-style-type: none"> The degree of agreement on diagnosis, prognosis, potential medical interventions and therapeutic benefit of those interventions Higher degrees of consensus may be beneficial in mitigating uncertainty for family and providers alike Various amounts of residual uncertainty often remain, and it is important that this is acknowledged for all involved
Decisional authority	<ul style="list-style-type: none"> In some countries, decisional authority rests solely with physicians In those where patients or families are included in decision-making, parents are most often the decisional authority for their children provided they act in the best interests of the child
Decision maker capacity	<ul style="list-style-type: none"> Capacity requires understanding (of the treatment plan) and appreciation (of the potential benefits, risks, benefits, likelihood of success) Some jurisdictions have stipulations about capacity and how it is determined
Child engagement and involvement	<ul style="list-style-type: none"> Intentional consideration of how the child contributes to the decision making process Involves exploration of the child's and family's expectation of the child's participation, the child's understanding of the illness and treatment, their thoughts on burdens and benefits and what is most important to them
Decisional support	<ul style="list-style-type: none"> Requires asking questions about how decisions are usually made in the family, how patient/family prefer to receive information, what are their needs for emotional/spiritual and pragmatic support (family, community, friends) Ensure that information provided is matched to their self-defined needs and desired processes
Culture of patient/parent(s)	<ul style="list-style-type: none"> Requires asking questions to understand if there is a specific system for decision making (e.g. individual, community, community leaders), if there are beliefs about illness, death, or parenting that are important for the healthcare team to understand and incorporate into the decision making process.
Societal influences	<ul style="list-style-type: none"> Exploration of societal expectations (for expectations of cure, perceptions of childhood death) held by the child, family and team that may frame assumptions and expectations Social media is a pervasive and easily accessed source of societal influences (both supportive and disruptive) and should be discussed with families to provide a supportive and transparent platform to address these influences
Support services	<ul style="list-style-type: none"> Identifying specific services outside of the medical team to support the process of decision-making and for continuing outreach after decisions are determined These include bioethics consult teams, palliative care team, social work, psychology, and chaplaincy and can be within or outside of the organization

Table 3: Factors to consider when assisting parents with difficult decision making (adapted from Allan (29))

<i>Goal</i>	<i>Practice Suggestions- Focus on Child and family preferences</i>
Explore the information needs of parents/child	<ul style="list-style-type: none"> • Explore what is important for them to know at that time; and for ongoing decision making • Do not assume that medical information is prioritized • Explore the level of information required at each point of decision-making • Explore their current understanding of the child’s illness and current state, e.g. “What have you been told about ‘name of child’ illness?” • Ensure information has been received accurately, e.g. “Please tell me in your own words what we have discussed”
Explore how to effectively communicate information	<ul style="list-style-type: none"> • Determine who is best to lead disclosures and follow ups of information sharing • Determine where and how are these discussions are best held • Use appropriate language that is easy to understand • Ensure accurate translation is provided where needed • Literacy and cognition support as required • Consider providing information in multiple forms– written, verbal, pictures, diagrams
Clarify family understanding of the severity of illness and its possible trajectory	<ul style="list-style-type: none"> • Explore how family perceives the child’s condition • Explore what the parents see as indicators or cues about the child’s status • Share the medical team’s indicators and markers of severity of illness
Understand all treatment options or lack of options	<ul style="list-style-type: none"> • Identify a time when parents can listen and understand all treatment options • Understand and discuss upfront if they wish to pursue “experimental” therapies
Understand cultural influences and parental and family characteristics and experiences	<ul style="list-style-type: none"> • Explore parental culture, relational histories and roles, expectations and experiences • Explore parents (or alternate decision makers) religious beliefs in relation to withdrawal of life sustaining therapies • Explore personal beliefs which can influence their views toward their child’s diagnosis • Explore previous experience in ICU, or with other children or family members who have died
Explore views around child’s best interests	<ul style="list-style-type: none"> • Determine parental views of the child’s best interest based on their knowledge, previous experiences, values, beliefs • Share the healthcare teams’ views of best interests for the child
Establish external influences and support structures	<ul style="list-style-type: none"> • Identify - religious leaders, cultural leaders, influential family members, social media, ideally before meeting • Consider including family identified “authorities” as part of meetings • Offer and maintain emotional support from the healthcare team • Consider emotional and practical support from other family members and peer support groups

Table 4: Potential reasons for disagreement for withdrawing life-sustaining therapy and practical recommendations for resolution of conflicts

<i>Potential Reasons for Disagreement</i>	<i>Steps to Aid Solution</i>
<p>Misunderstanding of underlying disease process and prognosis</p> <p>Misunderstanding of the role of technologic support (as curative rather than supportive)</p>	<ul style="list-style-type: none"> • Information gathering and sharing • Early regular scheduled meetings • Clarification about what is known/understood at the start of the meeting • Ensure clear communication of facts
<p>Disbelief of prognostic information given</p> <p>Previous experience of recovery</p>	<ul style="list-style-type: none"> • Early frequent meetings • Referral for greater expertise and/or experience/second opinion • Review and accommodate changing circumstances and opinions • Reflect on similarities and important differences compared to previous experiences
<p>Religious or faith based restrictions</p> <p>Divergent cultural views on the appropriateness of discussion of consideration of death</p> <p>Desire to avoid experiencing the death of the child</p>	<ul style="list-style-type: none"> • Information gathering and sharing • Distinguish between facts and values with mutual respect for differing values • Negotiation of morally acceptable trade-offs • Mutual education • Support Services: religious leaders, spiritual leaders, community leaders, cultural leaders, other family members
<p>Suspicious for lack of concern or care for the child from the health care team or ineffective relationship with team</p>	<ul style="list-style-type: none"> • Explore if any mistrust exists • Establish roles and responsibilities • Regular meetings • Core care team to provide consistent care • Empathy • Mutual respect for differing values • Engage the child’s other regular health care providers e.g. paediatrician
<p>Disagreement that withdrawal of life-sustaining therapy is in the child’s best interests</p>	<ul style="list-style-type: none"> • Discussion and debate; reflective equilibrium • Mediation techniques • Bioethical cases analysis* • Bioethics mediation** • Legal input

*Bioethics Case Analysis: directed substantive process, explores issues and applies ethical principles to facts; may be hierarchical and authoritative

**Bioethics Mediation: uses classical mediation techniques to identify, understand, and resolve conflicts; inclusive, empowering, minimizes power disparities to obtain principled solution

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