

Ethical Conflict at the End of Life

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Outline

- Dilemma #1 – Medical Futility
 - Case Presentation, Role for Law, Ethics and Values
 - Audience and Panel Discussion of Case and Issues

- Dilemma #2 – Parents Refusing Medically Recommended Treatment
 - Audience and Panel Discussion of Case and Issues

- Conclusion

When Parents and Health Providers Disagree

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Family-Centered Care

- Dependent pediatric patient
- Dependent siblings
- Parents
- Issues that you've probably heard:
 - "parent-directed care?"
 - "treating the family, not the patient."
 - Who speaks for the child?
 - Whose decision is it, anyway?

When parents request therapy
health providers view as “futile”

An Ethical Dilemma (#1)



When Parents and Health Providers Disagree: Is There a Role for Law?

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Why talk about law?

- locates decision making authority
- legal framework provides the basic level of rights, liberties, obligations
- may establish limits on action
- reflects basic social values about children and the family; importance of family as a significant social institution

What does law say about decision-making

- who should make decisions?
- how should they be made?
- what standards should be used?

Potential Decision-Makers

- parents
- health care professionals
- health care administrators
- ethics committees
- government institutions (legislatures, courts or social service agencies)

Legal status of family as decision makers

- law protects parental autonomy and family privacy & integrity
- courts recognize parents as appropriate decision-makers, do not like to “meddle” in parents’ decisions

What about health care professionals?

- specialized knowledge
- familiar with treatment options
- experience with complex cases
- no personal conflict of interest
- but . . . do not live day-to-day with results of their decisions
- no legal status apart from emergencies

Ideal decision-making strategy

- health care professionals recommend
- parents decide

What standards should be used?



General Legal Principles

- All persons are inviolable and are entitled to their physical integrity: civil & criminal law
- Parents must act in the “best interests” of their children
- Health professionals must act in the “best interests” of their patients: physician’s fiduciary duty
- Every decision concerning a child shall be taken in light of the “child’s interests” and the respect of his rights (art. 33 C.C.Q.)

What does “best interests” mean?

- standard of ‘reasonableness’: the best option is one that most rational people of goodwill would choose after full consideration of all factors that influence the situation (Canadian Pediatric Society)
- “best interests” generally supports a balance of potential benefit over potential harm, discomfort or distress resulting from a given treatment or non-treatment choice


How is “best interests” applied?

- no easily interpreted and applied substantive standards for decisions about critically ill children
- “best interests of the child” locates the interests, but does not interpret them

Best interests

- how does one determine what is in “the child’s interests”
- cannot “know” what is in every child’s interests, especially infants
- “construct” what will serve the particular child
- determine what is contrary to the child’s interests
- legal standards of care are based (for the most part) on standards set by the medical profession

What factors have courts considered to determine “best interests”?

- value of life: laws to protect & maintain life
 - child’s right to health
 - current and future situation of the child – “subjective interests” of the particular child
 - quality of life with/without an intervention
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Factors considered?


- probability of success an intervention
- results of withholding / withdrawing it
- requirement for many “risky and painful” interventions in the future
- nature of the intervention: how “commonplace” is it?
- does withholding constitute discrimination?

Factors considered?

- physical pain
- preservation and restoration of physical, sensory, emotional and cognitive functioning
- degree of humiliation
- dependence and loss of dignity resulting from the condition and treatment
- quality of life
- life expectancy
- prognosis for recovery without treatment
- futility of continued treatment

In re Christopher (2003, California)


Regard of courts re role of parental interests:

- parental concern considered by many courts
 - a few take account of effect of treatment family and social milieu on the child
 - courts recognize parents as appropriate decision-makers, do not like to “meddle” in parents’ decisions
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Courts are conservative/protective

- important role in protecting those unable to protect themselves
- historical role in preservation of life
- in hard cases, they tend to favour life / treatment

Conclusions

- law establishes boundaries
 - law recognizes important societal values
 - law requires interpretation for the individual case
 - legal analysis informs, but does not replace ethical analysis
 - “hard cases” remain difficult
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When Parents and Health Providers Disagree: Ethics and Values in Conflict

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Conflict in End of Life Decision Making

Health care providers have an ethical obligation to provide good end of life care, including helping patients and families make decisions regarding life-sustaining treatment. Occasionally, conflict may arise when life and death decisions must be made for a child. These situations cause distress for patients, families and health care providers.

Examples of conflict include:

- A patient or parent requests treatment be initiated or continued that health care providers believe is futile
- A health care team believes life sustaining treatment should be initiated or continue, where parents believe life sustaining treatment should be withheld or discontinued

Sources of conflict include:

- Different assessment of the child's best interests and/or quality of life
- Different views about the longer-range goals for the child
- Different understanding and appreciation of the nature and meaning of the child's health condition

Sources of conflict include:

- Tension between different values/belief systems

E.g. health care providers who practice evidence-based medicine may view things differently from families who follow alternative health care practices, or hold certain religious beliefs

1st Example of Conflict

A patient or parent requests treatment be initiated or continued that health care providers believe is 'futile'.

'Quantitative' vs 'Qualitative' Futility

Will it work?

- Treatment physiologically ineffective
- May be appropriate to consider this a medical decision

Is it worth it?

- Treatment may be physiologically effective but not believed beneficial (i.e. disagreement about objectives)
- Not only a medical decision (involves values, beliefs, etc.)

Conflict most often focuses on ...

... not whether or not it will work, but whether or not it is worth it. In both cases, patient's life may be prolonged by aggressive medical intervention.

- Are the burdens imposed on the patient proportional to the potential benefits?
- Whose assessment of 'burden' and 'benefits' should prevail when there is conflict?

- When resources are limited, are there other patients who will *clearly* benefit more? How does this (*how should this*) affect our moral reasoning?

Is the Language of 'Miracles'
a Problem?



- The 'futility problem' remains unresolved socially, professionally, institutionally, and legally
- Responding with skilled communication, negotiation, and compassion is often successful in resolving disagreement
- Rare cases that are not resolved should not set the standard for all cases

2nd Example of Conflict


A health care team believes life sustaining treatment should be initiated or continue, where parents believe life sustaining treatment should be withheld or discontinued

What is the problem?

For us ... a child is not receiving the health care intervention(s) we think will benefit him/her.

For the parents ... Treatment is perceived as nonbeneficial, or the child's suffering is perceived as unbearable, or the child's quality of life is seen as intolerable

What are some causes of these conflicts?

- Lack of information
 - Misunderstanding
 - Different interpretation of facts
 - Lack of trust
 - Practical problems
 - Different values
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In the case of parents refusing potentially life saving surgery

Health care team ...

May focus primarily on potential for survival

May assess of quality of life factors from a dispassionate, detached point of view

May have experience with many children and families under similar circumstances

Parents ...

May be influenced by grief, overwhelmed by emotions

Will consider child's best interests within the context of their family

May have a broader perspective on quality of life considerations

Dilemma #1: Questions to Consider

- When parents request 'futile' treatment, in your role what would you do?
- A mother asks: "How could anyone think they were in a better position to identify a child's best interests than his mother?" How would you respond?
- Is the language of 'miracles' a problem?

An Ethical Dilemma (#2)



Questions to Consider

- Which scenario is more difficult from your perspective ... being asked to provide therapy we deem “futile”, or not providing therapy we deem more beneficial than parents do?

Things That Help Staff

- Ethics consultation and education (e.g. rounds, inservices)
- Conflict management guidelines and training
- Debriefing sessions, and strategies for managing moral distress

Things That Help Parents

- Access to consultation with social work, chaplaincy, palliative care and/or ethics
- Time limited trials of therapy
- Opportunities for second opinion and/or transfer of care

These sorts of conflicts challenge our commitment and responsibility to provide care that is both family-centred and in patients' best interests.

Thank you!

The image features a solid blue background. In the bottom right corner, there are several concentric, light blue circular ripples, resembling water droplets or a ripple effect, which are partially obscured by the text.