

Decision-Making in Pediatric Palliative Care



Ian Anderson Continuing Education Program
in End-of-Life Care



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A Patient's Story



***Daniel** is a 3½ year old boy who lives 1-hr drive from tertiary care centre with his parents and 6-mo sister. Investigation of an abdominal mass confirms neuroblastoma with stage IV involvement of multiple bones and bone marrow.*

Reflective Question

- What would you consider to be the unique and major challenges of decision-making during the care of children and adolescents with life-limiting or life-threatening illness?



Objectives

This module aims to improve your knowledge about:

- I.** the ethical principles underlying healthcare decision-making
- II.** the major challenges to decision-making in pediatric palliative care
- III.** the various participants in such decision-making
- IV.** the decisions themselves
- V.** the process of discussing options and reaching consensus decisions, and
- VI.** methods for resolving conflict within this process



I. Ethical principles

Beneficence: Considering “best interests”

- substitute decision-makers (usually the parents) required for most pediatric patients
- substitute decision-makers and clinicians expected to act in the best interests of the child, BUT
- no universally agreed upon definition of “best interests”
- leads to the majority of disagreements and conflict between parents and clinicians



I. Ethical principles

Respect for the principle of autonomy:

Assessing capacity

- competence or capacity, rather than age or life experience, is becoming the standard when deciding an individual's ability to make healthcare decisions
- has led to increased involvement of children and adolescents in health care decision-making
- capacity can change with time, the physical, cognitive and emotional effects of illness on the child, and with the nature of the decision



I. Ethical principles

Disclosure, understanding, and informed choice

- Informed decision-making is best achieved through an ongoing process of disclosure and family education, along with mutual exploration of expectations, perceptions, misperceptions, beliefs, and values
- Informed choices can be achieved through this process, even if it occurs quickly during a rapidly progressive illness



II. Challenges

- Demographics:
 - huge variety of life-threatening or life-limiting illnesses
 - often great uncertainty concerning prognosis
 - often great uncertainty re: likelihood/timing of death
- Societal perspectives: our inherent need to do everything possible for a child can lead to consideration of any technology or intervention, simply because it is available



II. Challenges

- When and how to integrate palliative care: there should be early discussion about the goals of care and palliative care options, aiming to provide accurate and realistic information without eroding hope
- Clinician's grief: the experience of caring for a dying child can be extremely stressful and grief-ridden, which can impact on decision-making



III. Who is involved?

Families – Balancing autonomy and paternalism

- A parent speaks:
They treated me as an active member of the treatment team. They would definitely listen. Before they made a decision they would always ask for my input. And they were honest about not knowing how it was going to go, but they would do everything they could to keep her within the comfort zone. That was so important to me. And the fact that they acknowledged that this is a situation that is not going to have a good outcome.
- A relationship of mutual respect and trust with the family can help during difficult decisions and times of turmoil
- Involve families without giving them the full burden of responsibility



III. Who is involved?

Children

- Some too young or ill to participate in decision-making
- Some have the capacity to make own decisions
- In-between, there is a large group who can express wishes and should be involved in discussions even if their parents or others will be making the final decisions
- Challenges:
 - Children's variable understanding of death
 - Cognitive deficits related to the illness
 - Families' wish to protect the child from details of illness
 - Children's wish to protect their parents from difficult thoughts and feelings

III. Who is involved?

Children:

- You can use creative methods to involve children in decisions by expressing their feelings and thoughts

Mandala by 11-year-old, describing her reaction to being diagnosed with cancer (Sourkes, 1995):

“Red is for *shock* – it’s like coming to a stoplight, or like being hit by a bolt of lightning. *Anger* is black because it’s a very, very dark feeling. You feel *scared* all the time of what is going to happen to you (purple). *Alone* is blue, for tears, because you are so *sad*. I chose yellow for *hope*, because it’s a sunny color, with a lot of light. *Helpless* (green) is little in my drawing, because that’s just how you feel – tiny and scared. I made *confused* a mixture of all the colors together. You’re just confused about everything going on and how this could all be happening to you.”

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III. Who is involved?

Children:

- Adolescents face particular challenges when involved in decision-making:
 - Co-existing usual adolescent challenges of establishing identity, autonomy from family, body image, etc.
 - An illness that challenges growing independence and identity can be particularly difficult
 - If judged capable of making their own decisions, some adolescents make choices that do not agree with their parents and healthcare providers



III. Who is involved?

Children:

- Suggestions for starting difficult discussions with adolescents:
 - *I think you may find if we spend some time on this now, it will be helpful in at least a couple of ways. (Pause...)*
 - *It can help us to know how we can best care for you, particularly if you become sicker. (Pause.....)*
 - *It would also help us both later if I could have some idea now about how you would like to be cared for if we got to a point where we didn't think we'd be able to get you through it. (Pause and wait for patient's response.)*



III. Who is involved?

Substitute decision-makers

- When parents are unable, unwilling or not capable to act as decision-makers
- Step-wise approach to appointing a substitute – details differ by jurisdiction
- Little literature in this area, but can create difficult situations and disagreements, especially if parents continue to be involved without being the designated decision-makers



III. Who is involved?

Healthcare team

- Wide variety of skills and professions often involved
- Team often constructed ad hoc to meet patient and family needs
- Excellent collaborative interdisciplinary work required
- Clinicians can have markedly differing opinions concerning appropriate interventions for a given patient
- Attitudes influenced by clinician's factors



III. Who is involved?

Attitudes influenced by clinician's

- Age
- Country of origin
- Length of professional experience
- Seniority
- Number of intensive care beds in their institution
- Importance of religion in their lives



IV. What decisions?

Goals of care

- Prioritize when pursuing multiple goals simultaneously:
 - Cure
 - Slowed progression
 - Remission
 - Contribution to research
 - Prolonged life span
 - Achievement of life goals
 - Maximizing normal life experience
 - Maximizing periods of lucidity
 - Maximizing comfort
 - Maximizing family access
 - Having care and/or death occur in a preferred location



IV. What decisions?

Ameliorating or curing disease

- When the possibility of ameliorating or curing disease is small and the burden of treatment high, decisions can be very difficult
- Keys:
 - First meet as a healthcare team & identify *reasonable* options
 - Then sit down with the patient and family & focus discussion on these reasonable options
 - Openly discuss rationale for presented options – reduces later conflict
 - Some families benefit emotionally from having “everything possible” done, even for a brief period
 - There are often differences of opinion when making decisions about such treatments



IV. What decisions?

Potentially life-sustaining treatments

- Decisions regarding forgoing potentially life-sustaining treatments should be part of caring for all pediatric patients with life-threatening illnesses
- Such treatments most often address mechanical ventilation and the use of vasopressors, but may also include organ transplantation, dialysis, antibiotics, insulin, chemotherapy, artificial nutrition and hydration, and others
- These decisions can be the most difficult and controversial
- Recognition of the probable premature death of the patient is an important prerequisite
- Although continued hope can be an important coping mechanism, lengthy denial of the realistic prognosis can lead to delays in the implementation of appropriate palliative options



IV. What decisions?

Potentially life-sustaining treatments

- Decisions to avoid instituting a treatment (“withholding”) and decisions to discontinue an ongoing treatment (“withdrawing”) are ethically and legally equivalent but may feel very different on an emotional level
- Trials of interventions on a time- or outcome-limited basis are invaluable when definitive decisions are not possible
- A decision to forgo a specific treatment should not lead to abandonment of all active therapy but may lead to careful review of all current and planned interventions
- All patients and families should be reassured that they will continue to be cared for and supported if they forgo potentially life-sustaining treatment



IV. What decisions?

Resuscitation decisions

- Discussion regarding “do not attempt resuscitation (DNAR)” and “allow natural death (AND)” orders are often not undertaken until death is close at hand
- This may not allow sufficient time for discussion with the family
- This, in turn, can lead to guilt and regret that extend long past the death of the child
- Early discussion can lead to better understanding, fewer inappropriate CPR attempts, and improved family coping



IV. What decisions?

Artificial nutrition and hydration

- We have an instinctual need to feed dependent children and the prospect of withholding food and water can evoke strong emotions – from family and clinicians
- Artificial nutrition and hydration are invasive interventions which do not appear to lengthen survival and may cause additional suffering by:
 - Adding discomfort and bodily invasion
 - Limiting the ability of patients to be held and comforted
 - Side effects including infection, obstruction, metabolic derangements, nausea, vomiting, and diarrhea
- Limiting food and water during the final stages of life may:
 - Be more comfortable for the patient
 - Decrease respiratory secretions, coughing, and GI symptoms
 - Preventing the hunger sensation associated with partial feedings



IV. What decisions?

Relieving symptoms

- Symptom relief should be a goal of care throughout the treatment of an ill child, regardless of prognosis
- Key considerations when making decisions about symptom relief therapies:
 - Degree and duration of relief anticipated
 - Potential physical and emotional distress associated with the therapy
 - Child's expressed wishes
 - Parents preferences
 - Child's proximity to death
 - Location of potential treatment options
 - Alternative approaches: availability and efficacy
 - Financial implications



IV. What decisions?

Sedation at the end of life

- Sometimes, near the end of life, function cannot be maintained without compromising patient comfort
- When this occurs, medications including sedatives and analgesics should be titrated to adequately relieve symptoms, even if this means that cognitive, respiratory or cardiac function becomes compromised as a result
- This approach can be easily misunderstood as an active hastening of death or euthanasia
- Clearly communicate to family that these medications are given to relieve symptoms and may have a secondary, unintended, effect of shortening life by a few hours or days



IV. What decisions?

Planning for the last days/hours of life

- Advance decision-making about the type and intensity of therapy during the final stages of life requires:
 - Full understanding of the patient's medical situation, and all the possible events and decision points that may arise
 - Careful consideration of the patient's wishes, best interests, beliefs, and goals – as well as those of the family
 - Recognition of prognostic uncertainty and the inevitability of unanticipated situations and decisions
- Although not frequently used in pediatric palliative care, advance directives or living wills can be a useful tool
- The best method of preparing for the unexpected is for the designated decision-maker(s) to have frank discussions with the patient, while he/she still has capacity, regarding his/her wishes, values, and beliefs



IV. What decisions?

Location of care

- Various factors can influence the location chosen for end-of-life care and death:
 - Child's physical needs
 - Ability of family to provide daily care
 - Availability of help in the home setting
 - Past experience with death in the hospital/home/hospice
 - Emotional functioning of the family and individual family members
 - Socioeconomic and cultural factors
- Overarching principles in all cases:
 - There is no right setting for all families
 - Any choice that the child/family makes is reversible at any time



V. How to proceed?

The basics of communication

When communicating with patients & families:

- Use open-ended questions
- Respond with empathy
- Use the language chosen by the child, family
- Make use of opportunities to address misperceptions
- Provide information in small packages
- Evaluate/re-evaluate priorities & decision options



V. How to proceed?

The basics of communication

Health professionals should be aware that:

- they have their own beliefs, fears, practices, & expectations
- their values may differ from the patient, family &/or their colleagues
- their healthcare culture is not innately known to patients & families
- this culture shapes
 - how information is shared
 - how children & families are involved in decision-making



V. How to proceed?

The basics of communication

Respecting ethnicity, spirituality & culture

- Explore, acknowledge, & respect the cultural, spiritual, & ethnic beliefs/values
 - of the family
 - the individuals within the family
- Some ethnic/religious groups have a shared sense of meaning & traditions regarding illness/death/dying
- Avoid stereotyping – as variability exists between individuals as well as groups
- Gently inquire about each individual's beliefs & values



V. How to proceed?

The basics of communication

Approaches to discussing cultural issues

- When meeting a new family, try & find out as much as possible about how they make decisions
- Find out if there is anyone that they may want to talk with about the decisions to be made
- Understand that different people have different beliefs about medical treatments
 - It is helpful to know about these beliefs **before** they may be needed to be used in care



V. How to proceed?

Helping families communicate

***Derrick** is a 12 yr-old with relapsed lymphoma & immune deficiency, whose father starts a difficult conversation by saying: "We are very worried about you. We are worried about how sick you are....."*

Reflective Questions

- What do you think the child with a life-limiting/life-threatening illness wants to hear from:
 - Their family? Their friends? Their extended family?
- What do you think the parents of a child with a life-limiting/life-threatening illness want to hear from:
 - Their child? Their family? Their friends?



V. How to proceed?

Helping families communicate

Setting the scene for communicating with children

- Ask questions about how the child and brothers/sisters
 - usually communicate
 - usually like to receive information (ie: details or “just the basics”)
- What does the child/siblings understand about how ill they are/their brother/sister is
- Ask the parent what kinds of questions are being asked by the child/their brothers/sisters



V. How to proceed?

Helping families communicate

Communicating with a child as family member

- Children with a dying sibling/parent have similar communication/information needs as the seriously ill child
 - Accurate age and developmentally appropriate information
 - Encouragement to express their fears & feelings
 - Support & love
 - The freedom to ask questions



V. How to proceed?

Helping families communicate

Supporting parents in talking with siblings

- Provide parents/family members with examples of age-appropriate language to use about illness/death
- Provide guidance about what type of questions & reactions to expect
- Discuss creative ways to communicate - as in play
- Provide opportunities for talks with other parents of children with similar illnesses
- Provide reliable resources for the parents
 - Websites
 - Books
 - Chat rooms



V. How to proceed?

Helping families communicate

Communicating with the broader community of family & friends

With the child/family's permission:

- Convene a meeting with family & friends
- Organize a meeting at child's school/other community venue
- Highlight what the broader community can do to support the child/family
 - including having a "designated" communicator for the family
- Provide information on supportive resources for themselves



V. How to proceed?

Helping families communicate

Sharing information with the broader community

With the child/family's permission:

- Information can be shared via tele-health conferencing – video or audio
- Share a video-tape of the family meeting
- Provide info sheets that contain appropriate summaries of the illness, genetics, resources, etc.
- Provide reliable resources for further information
 - Web-sites
 - Books
 - Organizations



V. How to proceed?

*Speaking the unspeakable:
Earlier rather than later*

Jennifer is a 13 yr-old with advanced lung disease from Cystic Fibrosis, who has expressed vague anxieties about her illness.

Reflective Questions

- Do you believe that end-of-life related discussions can rob the child/family of the hope of getting better?
- Do you believe it possible to take away hope for a miracle?
- How have you talked about “hoping for the best but preparing for the worst”?



V. How to proceed?

Speaking the unspeakable: Earlier rather than later

Why have difficult discussions **before** they are needed:

- Earlier physician & parent recognition of the probability of the child's death has been associated with
 - Earlier integration of palliative care interventions
 - Improved quality of life for children in the palliative care phase (Wolfe – NEJM – 2000)
- The child may have opportunities to express their wishes, achieve goals, including
 - Expressed preference for location of care
 - Meaningful & reassuring discussion with friends/family
 - Preparing special mementoes, going on a special trip, etc



V. How to proceed?

Speaking the unspeakable: Earlier rather than later

Why have difficult discussions **before** they are needed:

- May allow discussion when the child is most physically/ mentally able to participate
- Can help in later discussions/decision-making
- Contributes to a trusting/collaborative relationship
- Provides time to the family to process & integrate information with their values & beliefs



V. How to proceed?

Speaking the unspeakable: Earlier rather than later

Language to start a hard discussion – some examples:

"I would like to take a few minutes to talk about some decisions about treatment for Maia that may come up in the future."

"Some families have told me that it can be very difficult to think and talk about decisions relating to dying when they are still hoping for a cure. Families whose children have died have also told me that when the time came, they were very glad they had taken the time to think and talk about those decisions beforehand."



V. How to proceed?

Speaking the unspeakable: Earlier rather than later

Antenatal palliative care discussions

- New diagnostic techniques have led to the need for some difficult discussions well before birth
- Are quite similar in content to discussions that occur following the birth of a compromised infant
- Can prevent the need for urgent decision-making in the delivery room
- Can help to clarify expectations, reduce subsequent remorse/guilt



V. How to proceed?

Speaking the unspeakable: Earlier rather than later

Factors in antenatal palliative care decision-making

- The gestational age at the time of diagnosis
- The nature of the abnormality detected
- The nature & extent of any accompanying abnormalities (*eg.*, the severity of cardiac involvement in a child with a chromosomal abnormality)
- The degree of certainty concerning the diagnosis/prognosis
- The parental wishes



V. How to proceed?

Framing decisions and building consensus

Consensus building is easier when those involved are:

- Willing to be involved in an open discussion
- Well informed about the potential benefits, burdens, & risks of the available options
- Aware of their own values & beliefs that may influence their weighing of the options
- Emotionally & mentally capable of participating



V. How to proceed?

Framing decisions and building consensus

Factors influencing palliative care decision-making

Parents' Perspectives

- Recommendations/info of health professionals
- The child's current QOL, pain, discomfort
- The child's expressed wishes re: continued treatment
- The child's chance for improvement/survival
- Concerns re: adverse effects of Rx options

Physicians' Perspectives

- Expressed patient/family wishes
- The probability of survival, predicted QOL
- The availability of potentially effective Rx
- Info from other members of the healthcare team
- The presence of unrelenting pain/other symptoms

QOL = Quality-of-life



V. How to proceed?

Framing decisions and building consensus

Framing decisions

- Present the options within the illness context/reality
 - Certain Rx's are not feasible because of the pattern/rapidity of disease progression
 - Legal/ethical/resource issues may make certain options less feasible/appropriate

- An example of language for framing a decision:

"I think sometimes we believe we have decisions to make that we truly have choices, that by deciding one way or the other we can make something happen or not. I think Sara's illness is actually deciding for us. Because she is so sick, we have few if any options, that would make her better. What we do have are options like....."



V. How to proceed?

Framing decisions and building consensus

Evaluating options

- Consider the likely benefit/burden/risk for each option with questions like:
 - How realistic is it that this will cure the disease?
 - If not able to cure the disease, will it prevent progression of the disease?
 - Will it improve the way the child feels?
 - Could it make the child feel worse? If so, for how long?
 - What will it be like for the child to go through this?
 - Will it change the outcome for the child?
 - What is the likely impact of this decision on us as a family?



V. How to proceed?

Framing decisions and building consensus

Parental involvement in decision-making

- Parents vary in how much they want
 - to be involved
 - the decision to be shared
- Majority of parents
 - Want an active role
 - Want honest info, including the most difficult topics
 - Are able to understand/work through complex medical information
- Some parents may feel
 - An additional burden if the decisions have a negative outcome
 - Want the physician to make decisions on their behalf



V. How to proceed?

Framing decisions and building consensus

Obligations of the clinician to the decision-maker

- To involve the patient and/or the designated substitute decision-maker in all decisions
- To provide carefully considered recommendations
- To approach these discussions with sensitivity & compassion
- To be prepared to respond when the decision-maker requests the decision be made by the clinician
- To consider the long-term comfort with the decisions to be made



V. How to proceed?

Framing decisions and building consensus

The dynamics of urgent decision-making

- The parents are often disoriented, sleep-deprived, isolated from usual supports
- Little time to foster rapport/build trust
- Time constraints compound misunderstanding/anxiety
- Apply the same principles as with other decision-making
 - Attend to the family's informational/emotional/practical needs
 - Encourage discussion of options ASAP
 - Ensure consistency of messages from the healthcare team
 - Provide private space, telephone, food, fluid
 - Offer to contact a support person
 - Document discussions/decisions



V. How to proceed?

Maintaining continuity

- Continuity helps patient & family feel supported & reduces the risk of their feeling abandoned
- Continuity requires a conscious effort to maintain communication
 - between care settings/services
 - among health professionals
 - Between patients/families/health professionals



V. How to proceed?

Maintaining continuity

Practical suggestions for maintaining continuity

- Hold a meeting with key individuals from both teams, patient, family at times of care transition
- Clarify the healthcare team's ways of working & maintaining continuity (ie: explain the on-call service, family rounds, team meetings)
- Build a schedule that incorporates patient/family at rounds
- Provide consistent information
- If able, have 1 continuous professional as key info source
- Agree on when discussions & decisions are reviewed



V. How to proceed?

Maintaining continuity

Practical suggestions for patients & families

- Keep a “log-book” of lab results, symptoms, side-effects, decisions, etc
- Request health professionals regularly up-date rest of team (can be via e-mail, telephone)
- Have 1 individual as info gatherer/coordinator
- Tape record important meetings
- Videotape unusual symptoms/events if a health professional is not present



VI. Working through Conflict

Risk factors for conflict include when the patient/family:

- Has pre-morbid internal conflict
- Is experiencing a critical illness/severe-unexpected event
- Is facing prognostic uncertainty
- Have a large number of health professionals involved
- Has previous experience with the same illness or perceptions about the illness
- Perceive inadequate communication
- Perceive unprofessional behavior by health professionals
- Perceive that decisions made without their input
- Have certain religious beliefs
- Have differing cultural beliefs/values
- Lack a shared language or access to translators
- Lack knowledge about the rights of emancipated minors



VI. Working through Conflict

Preventing conflict

- Be aware that disagreement is inevitable with difficult care situations
- Disagreement is not synonymous with conflict
- Maintain open, respectful communication
- Return for further discussion at an agreed-upon time
- Name the emotional distress



VI. Working through Conflict

Facing conflict – use a systematic approach

1. Express interest in resolving the conflict
2. Express a willingness to be accepting of differences of opinion
3. Allow emotional expression
4. Respond empathetically
5. Seek an agreement to focus on the decisions at hand rather than the emotions
6. Seek detail from each party about their understanding, beliefs/values, degree of uncertainty



VI. Working through Conflict

When faced with lack of agreement about how to proceed:

- Work to agree on a smaller, initial step by breaking the process down into smaller stages
- Seek agreement to
 - a 2nd opinion
 - a time-limited or outcome-limited trial
- Involve other professionals if not already involved (ethics consultants, spiritual advisors, etc.)
- If remains un-resolvable
 - Continue care and consider (especially if withholding/withdrawing would result in death):
 - 1/ Transfer care
 - 2/ Bring the issue to court for help in resolution



VII. Training & supporting clinicians

Training in pediatric palliative care decision-making

- Role plays & simulated patients modeling difficult situations
- Reflective practice through writing exercises, discussion groups
- Trainee involvement in case conferences, family meetings, discussions with children & adolescents, clinical decision-making
- Trainee involvement across care settings including hospice, home, in-patient palliative care
- Trainee involvement in multi-disciplinary “de-briefings”
- Provide list of resources - books, reputable on-line info, etc



VII. Training & supporting clinicians

Supporting clinicians

- Regular multi & uni-disciplinary group discussion
- Reflective practice – journal writing, art, music
- Access to 1-on-1 counseling
- Awareness of the necessity/benefits of self care
- Mutual support from colleagues, including coverage when becoming over-burdened
- Institutional support
 - Extra staff around the time of a child's death
 - Providing leave for funerals, memorials
 - Acknowledgement of staff's role in excellent care