



Pediatric Palliative Care: Lessons From the Seattle Experience

ANMC
Grand Rounds
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Death in Childhood 1997 U.S.

~43,000 infants
~27,000 1-19 years

35,000 pediatricians
2-3 deaths/pediatrician/year

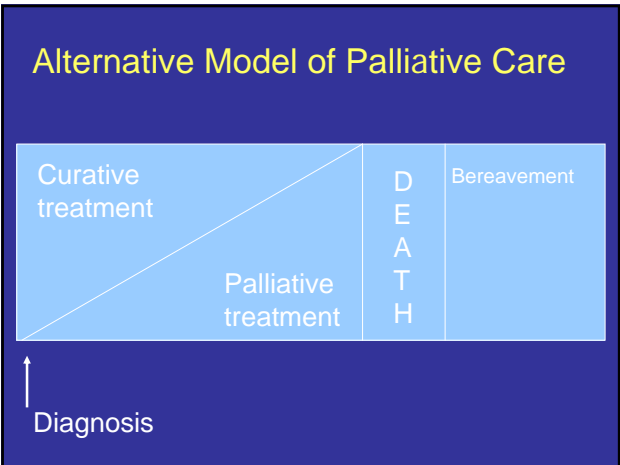
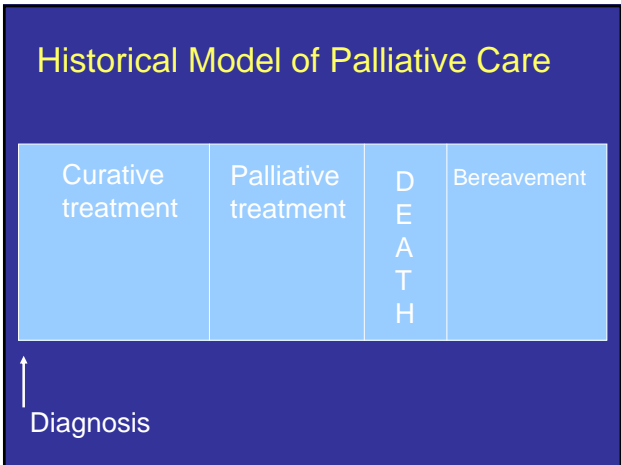


- ### GENERALIZATIONS ON EOL CARE IN THE UNITED STATES
- Over-treatment of Dz/Under-treatment of Sx
 - Technological Imperative/Biologic Reduction
 - Lack of Meaningful Patient-Physician Discussion
 - Inability to identify terminal illness and make timely hospice referrals

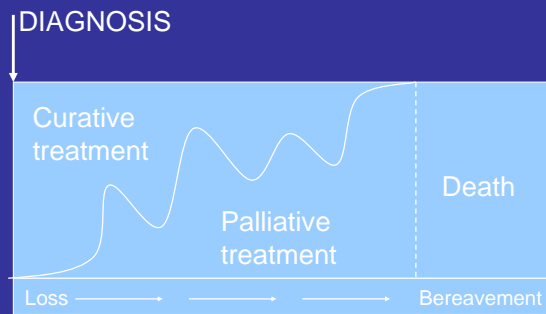


**“It should be just as natural
to die as it is to be born.”**
 -Sir Francis Bacon

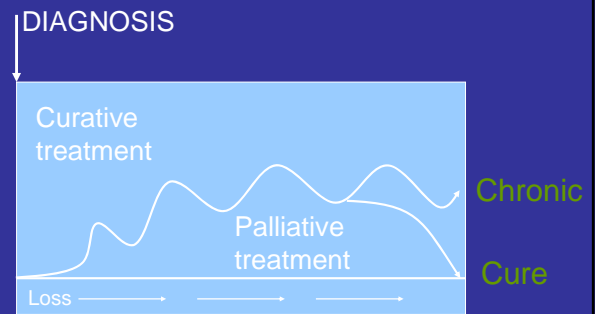
- ### Pediatric Palliative Care Barriers
- Cultural denial
 - Lack of education
 - Hospice based on adult model
 - Restrictive admission policies
 - Health insurance benefits are limited



Pediatric Model of Palliative Care



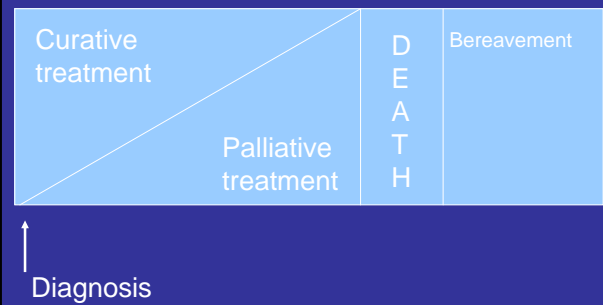
Palliative Care



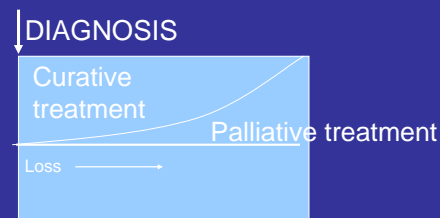
Integrating effective palliative care, from the time a child's life threatening medical problem is **diagnosed** will improve care for children who survive as well as children who die - and will help the families of all of these children

Institute of Medicine Report, 2001

Alternative Model of Palliative Care



What is The "Leading Edge of the Wedge?"



Pediatric Palliative Care in Seattle

What We Have Learned

Seattle Children's Palliative Care Consulting Service Chronology

1994-1995 Center for Children with Special Needs statewide survey of families and providers caring for children with potentially life-limiting conditions.

1998 Robert Wood Johnson Foundation awarded three-year demonstration grant to Center and Hospital team to develop program.

2001 Families and providers expressed increased satisfaction with care. Children's Hospital agreed to continue the program in palliative care as a Consulting Service of the hospital.

1994-1995 Center for Children with Special Needs statewide survey of families and providers and children with potentially life-limiting conditions.

- Better physician-patient communication
- Better transitions from hospital to community
- Help with decision-making
- Improved reimbursement for end of life care
- Case management, case management, case management

Improved Communication

JSW Decision-Making Communication Tool

Medical Indications	Patient Preferences
Quality of Life	Contextual Issues
Discussion	
Plan	
Physician Signature	Date

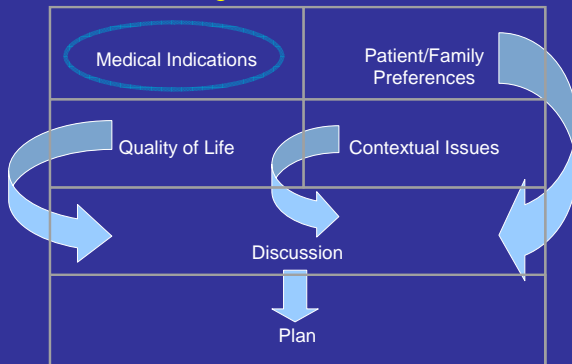
The **Decision-Making Communication Tool (DMT)*** is an excellent format to follow in planning health care for any child.

DMT Care Planning

- Is ethics based
- Integrates the problem list with other important decision-making elements of a family's life
- Establishes a balanced partnership in decision making between the family and the health care team
- Is updated at regular intervals as well as in response to a new problem.
- Creates a comprehensive action plan, signed by the physician.

*Developed by the Pediatric Palliative Care Consulting Service at Children's Hospital and Regional Medical Center, Seattle, and adapted from an ethical decision-making model developed by Albert Jonsen, Mark Siegler and William Winslade, in their book CLINICAL ETHICS (McGraw-Hill, 2002, fifth edition).

Decision-Making Communication Tool



Less Restrictive Health Plan Reimbursement

- Flexible administration of the existing health plan benefits package
- Partnership with the Blues
- Soft cost analysis

Home Health Care/Hospice Agency Co-Case Manager

- Manages medical care plan in the home
- Coordinates home visits by other members of the health care team
- Supports quality of life issues
- Negotiates health plan coverage with insurance co-case manager
- Oversees pain and symptom management

Health Plan Co-Case Manager

- Collaborates with other providers to create care plan
- Responds to care goals by flexibly administering benefits
- Participates in long term care planning

Partnership with Health Plans: An opportunity for

- Collaborative effort across many health services
- Health plan case managers playing an integral part in care planning
- Showing that quality care can be cost-effective care
- Development of Palliative Care Benefit

Soft Cost Analysis

17-yr-old with liver cancer with spinal mets. Was hospitalized early in month for pain management. Increasing declining symptoms including pain, abdominal distention and emesis precluded discharge. Health plan agreed with hospice to fund special high-priced suction machine at \$300/mo above hospice rate, as likely that patient might only go home for a few days before she expired, and the rental would overwhelm any hospice reimbursement. This agreement supported home plan and allowed patient to die at home.

Pre-Intervention

Inpatient pain management	\$6300
MD visits	\$520

Post-Intervention

Automatic Intmt. suction device	\$300
Hospice care	\$784
Infusion services	\$525

TOTAL \$6820

TOTAL \$1609

Research Supports the Model

Improvements in Patient and Family Satisfaction with

- Overall care
- Pain and other symptom relief
- Emotional support received
- Quality of information received
- Quality of providers' communication, ability to listen and answer questions
- Provider's sensitivity to needs
- Ease of getting needed care and coverage from health plan
- Understanding insurance benefits

Research Supports the Model

Improvements in Provider Satisfaction with

- Comfort in communicating findings and care options related to life-limiting conditions
- Working with hospice and home health to coordinate care
- Communicating with hospice and insurance case managers
- Knowledge of effective pain management
- Knowledge of methods to obtain needed information from children

Research Supports the Model

Improvements in Quality of Life (PedsQL4.0)

- Statistically significant improvements in the emotional well-being measure

Pediatric Palliative Care Which Children?

1. For which cure is possible but may fail.

Cancer

2. For which there is no known cure, but where treatment may prolong quality and quantity of life.

Muscular Dystrophy

3. In which treatment is palliative from the beginning.

Trisomy 18

4. That are not progressive, but render children vulnerable and susceptible to life-limiting complications.

Severe Anoxic Brain Injury

Pediatric Palliative Care Which Children?

1. For which cure is possible but may fail.

Jackie

2. For which there is no known cure, but where treatment may prolong quality and quantity of life.

Jordan

3. In which treatment is palliative from the beginning.

David

4. That are not progressive, but render children vulnerable and susceptible to life-limiting complications.

Kara



David Scares
the Hell Out
of Us



PEDIATRIC PALLIATIVE CARE BENEFIT COMPONENTS

- 130 home visits by RN, Aide, PT, OT, ST and MSW
- 120 hours respite care (may be skilled nursing level of care)
- Mental health benefit: Home or off-site visits by a licensed therapist or counselor for patient, family members, or others close to the patient
- “Home visits” to a pediatric patient’s school or other setting
- Patient need not be homebound
- Hourly care to the maximum of the SNF benefit
- Renews annually
- Pay per visit



Jackie Takes Charge

JSW Decision-Making Communication Tool

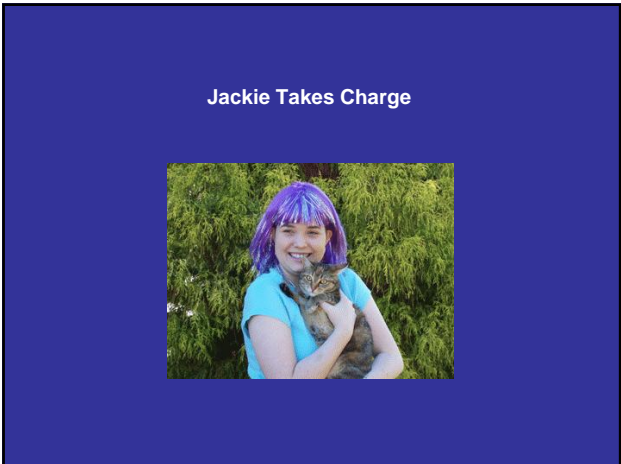
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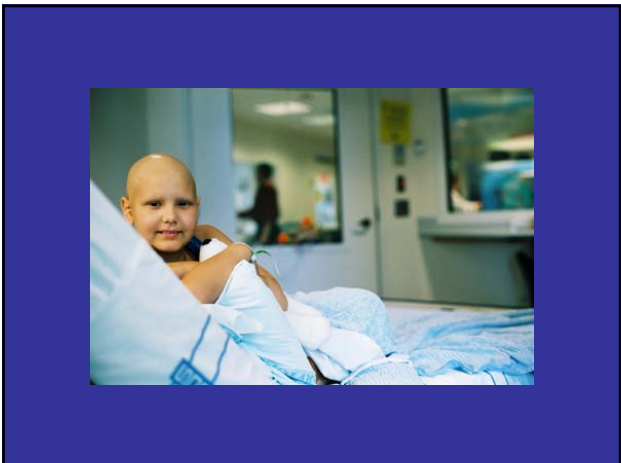
Identify Many QOL Issues	<p>Medical Indications Diagnosis: MDS Treatment Option: Bone Marrow Transplant with HLA identical Sibling Donor Benefit: 60% chance it will cure Jackie's MDS Risk: 40% chance it will not cure MDS. 20% chance of transplant Related mortality</p>	<p>Patient Preferences Both Jackie and her parents Are in favor of moving ahead With transplant Dignity conserving care is Important to Jackie she does not want a male nurse if possible</p>	DMT # 1
	<p>Quality of Life Being at Home Being a Mother Orlando Bloom God Zelda - my cat My mom Jonathan - my brother My picture of Orlando Bloom My stuffed animals My baby blanket My quilt my grandmother made My Nintendo</p>	<p>Contextual •Jackie is 3rd of 5 children •Her sister, Jenny, 8 - bone marrow donor •She lives in Wenatchee •Her mom is a former BMT nurse •Jackie is active in her church •Excellent community Support •Enjoy good family support</p>	



	<p>Medical Indications</p> <p>Diagnosis: 120 Days post transplant Jackie has relapsed with AML</p> <p>Treatment Options:</p> <ol style="list-style-type: none"> 1. Supportive Care:Hospice 2. Palliative Chemotherapy -10% chance of survival 3. Remove immunosuppressants- may induce GVL effect. 4. Reinduction chemotherapy with second transplant 	<p>Patient Preferences</p> <p>Jackie does not know what she wants to do right now.</p> <p>She thinks she will probably want to remove the immuno-suppressants first.</p> <p>Jackie is not sure she wants to go through the transplant process again.</p>	
	<p>Quality of Life</p> <p>To be with my brother as much As possible</p> <p>Being at Home</p> <p>To talk with other teens who Have relapsed</p>	<p>Contextual</p> <ul style="list-style-type: none"> •Jackie is 3rd of 5 children •She lives in Wenatchee •Her mom is a former BMT nurse •Jackie is active in their church •Excellent community Support •Enjoy good family support 	



	<p>Medical Indications</p> <p>Diagnosis: Relapsed AML post transplant. Status post Reinduction chemotherapy</p> <p>Treatment Options: Second transplant with TBI</p>	<p>Patient Preferences</p> <p>Jackie is the primary decision Maker, her parents want to Honor her decisions.</p> <p>Jackie is "not interested in extending her life, she "wants a cure." She wants the second transplant</p>	
	<p>Quality of Life</p> <p>Being at Home as much as possible</p>	<p>Contextual</p> <ul style="list-style-type: none"> •Jackie's siblings have Returned to school in Wenatchee. •Jackie's parents are taking Turns staying with her on The weekends. 	



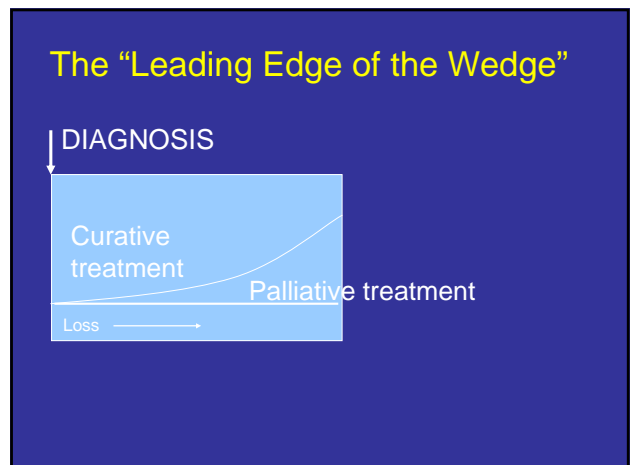
Expanding QOL Issues	Medical Indications Diagnosis: status/post 2 nd transplant. AML has relapsed. Treatment Options: Supportive Care	Patient Preferences Jackie is the primary decision Maker, her parents want to Honor her decisions.	DMT # 4
	Quality of Life Receive care at home Receive blood products at home Spending time with friends & family. Going to the movies Completing make-a-wish trip to Disney Land. Redecorating bedroom New hobby - miniature dollhouse Kit. - Furnishing doll house Reading	Contextual •Jackie's primary care Dr. Is willing to manage her care at home. •Hospice services available In the community Home health agency willing to give blood products at home.	



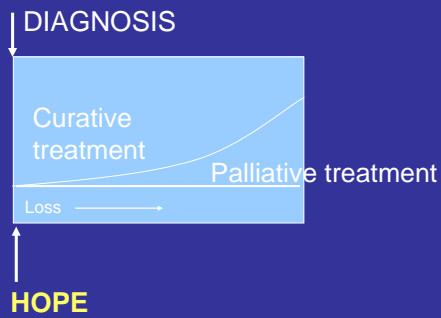
Kara
Every Step
of the
Way

Admission 49 weeks
 4 discharges/readmissions
 32 attendings
 57 house staff
 G, J, G-J, D tubes,
 42 formula changes
 TPN 3 central lines
 PIV's too numerous to count
 6 surgeries
 4 PICU admissions
 21 service transfers

- “Parents want to sit in the driver’s seat and let the physicians be the GPS navigational system.
 - Physicians want to drive and have parents sit in the back seat.
 - Kara’s doctors and I were able to take this ride together.
 - Palliative care was our chauffeur.”
- Shari Charlot



The "Leading Edge of the Wedge"



HOPE

The "Leading Edge of the Wedge"

DECISION MAKING
providing a service:
the DMT

HOPE

The "Leading Edge of the Wedge"

DECISION MAKING
providing a service:
the DMT

RELATIONSHIP
continuity and added
level of support

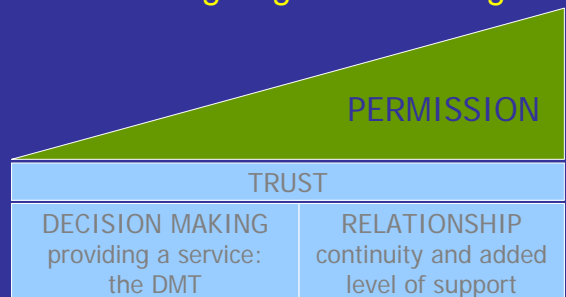
HOPE

The "Leading Edge of the Wedge"

TRUST	
DECISION MAKING providing a service: the DMT	RELATIONSHIP continuity and added level of support

HOPE

The "Leading Edge of the Wedge"



HOPE



Jordan is
Going Home

