

Pediatric Palliative and Hospice Care – An Overview

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Presentation Outline

- Overview of Pediatric Palliative Care
- The Butterfly Program – Palliative and Hospice-Based Program at TCH
- Models of Pediatric Palliative and Hospice Care in the US
- Colorado Medicaid Waiver for Pediatric Palliative and Hospice Care

Current Death Statistics in US

- In the US in 2000, 53,728 children and adolescents died between birth and 19 y
- 52% of these deaths occurred in infants
 - 50% of these deaths occur within first week of life
 - 50% of these deaths occur after 1st week up to 1st birthday

Children Living with Special Needs and Health Problems

- Many children with special needs now alive due to medical and clinical advances
- More ventilator dependent children surviving longer; more TPN dependent children
- Over 12 million children in US with special needs who have conditions that are not expected to lead to death in childhood
 - Nearly 400,000 of these children will need long term care at home or elsewhere

WHAT IS PEDIATRIC PALLIATIVE CARE?

- Comprehensive approach to the needs (physical, emotional, spiritual) of those with a life-threatening illness
- Concept emerging as a service necessary from the time of diagnosis of a life-threatening illness as per recommendations from AAP and IOM Report
- Family centered and interdisciplinary
- Allows patients and their families to increase their options of care by stating their desires for end of life care through advance planning, if appropriate
- "Add life to the child's years not years to the child's life"

LIFE-LIMITING DISEASES IN CHILDREN WHO COULD BENEFIT FROM PPC

- Diseases for curative treatment may be feasible but may fail - cancer
- Diseases in which premature death is anticipated but intense treatment may prolong good quality of life : CF, AIDS
- Progressive diseases for which treatment is exclusively palliative but may extend over many years: mucopolysaccharidoses
- Conditions with severe neuro disability that lead to vulnerability and complications likely to cause premature death: severe CP

Pediatric Palliative and End of Life
Care at The Children's Hospital,
Denver:
The Butterfly Program



History of The Butterfly Program

- Identification of a need for outpatient pediatric palliative care/hospice care services
- Key players brought together in 1998 at time during health care consolidations and mergers
 - The Children's Hospital
 - The Children's Hospital Home Care
 - Porter Hospice/Centura Home Care and Hospice (adult focused agency)

History of The Butterfly Program

- Evaluation of data regarding pediatric end of life care
 - # patient deaths/year/inpatient
 - # patient deaths/year/outpatient
 - # expected and unexpected deaths
 - Review of deaths by diagnosis, age, and demographics
 - Review of family experiences regarding end of life care for their child

History of The Butterfly Program

- Palliative care program sketched out with 50/50 support from each organization
- Palliative care clearly a part of each organization's mission
- Stakeholders identified that would be responsible for creating infrastructure, investment and support: Home Care, Social Work, Foundation, Family Representative, Hospice, Chaplains, Administration, and Marketing
- TCH to provide medical/home care expertise and Porter/Centura to provide emotional support (social work, spiritual bereavement)
- Began accepting patients on an outpatient basis in June 1999

PHILOSOPHY OF THE BUTTERFLY PROGRAM

- Pediatric palliative/hospice care does not have to follow the same guidelines as adult end of life care
- Parents may have a difficult time stopping treatment modalities at end of life
- Families may also want to continue supportive measures to assist in quality of life
- Consistency of caregivers is important
- Program seeks to work with the existing primary care team

ORIGINAL CRITERIA FOR ADMISSION

- Patient has a life expectancy of less than 12 months
- Continued curative approach to the disease is allowed
- Supportive care modalities such as blood product transfusion, IVF, TPN are acceptable
- A DNR may or may not be in place
- Continued contact with PCP/Primary Care Team

Expansion of Butterfly Services

- Slow accrual first two years
 - Similarity to CHI PACC model meant changing a philosophy with respect to caring for patients with life limiting illnesses
 - "Turf issues"
 - Promote an understanding that primary care providers would not be replaced but be offered additional support if desired
- Grant support
 - Colorado Trust Grant (2000-2002)
 - CHI PACC Grant (2002-2004)

Expansion of Butterfly Services

- Outcomes of grant support
 - Creation of Supportive Care Network
 - Aggressive marketing program
 - Creation of inpatient consultative service
 - MD, PNP/Inpatient coordinator, Chaplains
 - Outreach Program
 - Educational programs in Denver metro area
 - 1915c waiver based on CHI-PACC model of care

THE BUTTERFLY TEAM

- Inpatient Coordinator
- Outpatient Coordinator
- Medical Director
- Home Care Nursing
- Spiritual Support (Inpatient and Outpatient)
- Social Work
- Bereavement
- Pharmacy/PT/OT/Dietary
- Art Therapist
- Volunteers

PATIENT DEMOGRAPHICS

- Program has accepted over 375 patients to date (outpt and inpt)
- Program enrolls 40-45 pts/year
 - 73 patients enrolled in 2008
- Average Daily Census – 60 patients (almost all outpatient)
- Patient diagnoses - Oncology (32%), Neurologic (33%), Muscular Degenerative Disorders (20%), Cardiac/Pulmonary (15%)
- Length of Stay – 0 days -4.5 years

Bereavement Programs Unique to TCH

- Grief Packets
 - Newborn, child, Spanish newborn & Spanish child
 - Selected reading materials
 - Some designed/ written by TCH staff
 - Given by staff to parents when death is imminent or after death has occurred
 - Kept in ED, NICU, PICU & Family Services Office
- Precious Prints

Bereavement Programs Unique to TCH

- Bereavement Council
 - Interested staff
 - Bereaved parents
 - Community members
- Goals:
 - Family support
 - staff support

Bereavement Programs Unique to TCH

- Family support
 - Colors of Healing Bereavement Programs
 - Condolences card
 - Parent Grief Support Groups -2 times/year
 - Annual Memorial Service
 - Annual Family Conference-"A Family Day Together"
 - Library
 - Holiday gathering
 - Coordinator

Bereavement Programs Unique to TCH

- Staff support
 - Invited to Annual Memorial Service
 - Good Grief at Noon
 - 4th Tuesday at noon, Lecture Hall (lunch!)
 - T.R.E.E. Time (Time to reflect, express & energize)
 - Before Good Grief at Noon begins.

Unique Aspects of The Butterfly Program

- The Butterfly Program Outreach
- The Cocoon



What Makes Colorado Unique?

- The Children's Hospital is the only free standing tertiary pediatric hospital in CO
 - Within CO many patients come from rural areas where peds palliative/EOL care services are limited
- Catchment area for the hospital is vast

WHY CONSIDER AN OUTREACH PROGRAM?

- Geographic referral region for The Children's Hospital, Denver comprises 6 states including Colorado, Wyoming, Montana, and portions of South Dakota, Kansas, and Nebraska
- Patients and their families may face limited pediatric experience in their hometowns including pediatric palliative and hospice care
- For patients with life-limiting illnesses, important to arrange for care in hometown if possible given emotional and family support available

DESIGN OF OUTREACH PROGRAM

- Initially conceived as a goal of initial Colorado PACC grant
- Concept to involve on-site visits to hospice programs outside the Denver metro area in Colorado, Wyoming, and Montana to provide an extensive seminar program on various aspects of pediatric palliative/EOL care
- 10 hospice programs contacted
- Grant funds to be used for costs of travel and educational materials

SEMINAR CONTENT

- Hospice programs sent follow-up letter requesting program to decide on topics of interest
- Presentations on following topics offered
 - Overview of pediatric/EOL care available through The Children's Hospital
 - Pain and symptom management
 - Child's concepts of death and dying
 - Nursing aspects of caring for a child at end-of-life
 - Nutritional issues at end of life
 - Spiritual issues at end of life from pediatric perspective
 - Emotional/family issues
 - Bereavement

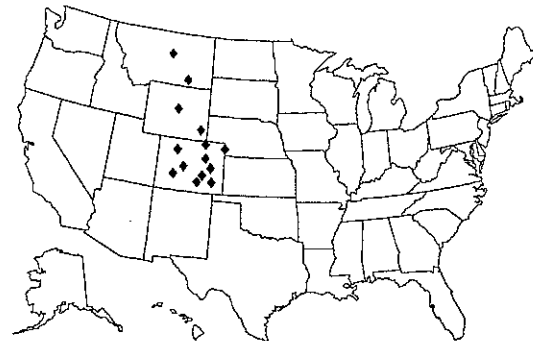
THE BUTTERFLY PROGRAM OUTREACH TEAM

- Medical director
- Inpatient coordinator
- Social worker
- Chaplain
- Bereavement coordinator
- Above includes staff from both The Children's Hospital and Centura Health at Home/Porter Hospice

SUCCESS OF OUTREACH PROGRAM

- First outreach site in Montana; "urgent visit"
- To date, 14 sites have been involved with the program and include Colorado Springs, Pueblo, Fort Collins, Greeley, Sterling, Durango, Grand Junction, Alamosa, Vail, Wray(CO), Cheyenne, Buffalo (WY), Lewistown, Montana
- Most recent site visit to Billings, Montana; program teleconferenced to other sites in Montana

BUTTERFLY PROGRAM OUTREACH



ACCOMPLISHMENTS OF PROGRAM

- Feedback from programs visited overwhelmingly positive
- Increased level of comfort on part of hospice programs participating in outreach with respect to caring for pediatric patients at end-of-life
- Creation of network to assist with pediatric palliative/hospice care for children and their families cared for by The Children's Hospital with The Butterfly Program as center of expertise
- The Butterfly Program Outreach Program source of education for pediatric palliative/hospice care issues

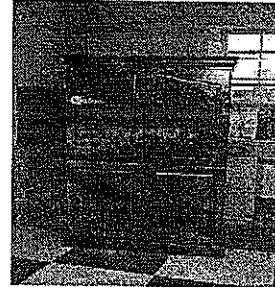
The Cocoon

- The Children's Hospital does not have rooms solely dedicated to end of life care
- Inpatient rooms, while kid friendly, are not like home
- Idea for The Cocoon came from the mother of an oncology patient who was dying from progressive disease
- Project completed with support from both TCH and Porter Hospice

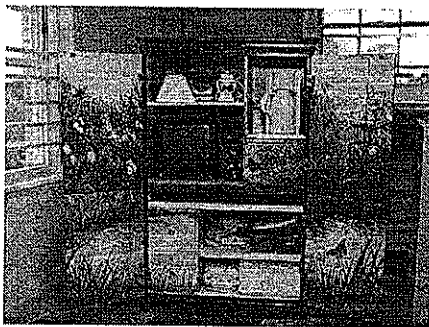
The Cocoon

- Turns patient room into home-like environment
 - Soft sheets
 - Flannel pj's
 - CD player
 - Coffee machine
 - Soft light/soft kleenex
 - Toiletries for parents/sibs
 - Toys/puzzles for sibs
- Can be requested by staff to Pastoral Care
- Built in cocoon in ED Family Room

Cocoon



Cocoon



ONGOING CHALLENGES

Acceptance of the Need
for a Pediatric Palliative
Care Team

Tip of the Iceberg...

- The Good News – Steady number of referrals to the program each month
- The Bad News – Many patients who could benefit from services offered by The Butterfly Program are not referred
- Ongoing need to show benefit of pediatric palliative care to primary care givers and subspecialists

ONGOING CHALLENGES

Sustainability

Funding The Butterfly Program

- Given that The Butterfly Program's philosophy does not follow the adult hospice model all outpatient emotional support can not be billed for and costs are absorbed by partner institutions; implementation of Medicaid waiver will alleviate some of this burden
- Hospital funds part of chaplains', inpatient coordinator's, medical director's salary as well as some secretarial support
- Foundations of each organization committed to look for sources of future funding

SUCCESSSES

- Successfully changed hospital's culture and acceptance of pediatric palliative care
- Lectures on palliative and end of life care integrated into pediatric residents' lecture series
- Several stories in media on Butterfly patients has allowed community to get to know the program
- Recipient of Circle of Life Citation of Honor (2005) given by The American Hospital Association
- Recipient of The Denver Business Journal's Champion's of Health Care (2007 Outreach Award)
- Invited to participate in National Network Consortium for Pediatric Palliative Care (2009)

Institutional Models of PPC

- Children's Mercy Hospital PACCT Program- Kansas City, Missouri
- Harriett Lane Compassionate Care – Johns Hopkins University - Baltimore, Maryland
- St. Mary's Health Care System for Children – Bayside, New York
- Seattle Children's Hospital Palliative Care Consulting Service – Seattle, Washington

Children's Mercy Hospital

- PACCT – Pediatric Advanced Comfort Care Team
- Consultative service based in the hospital only (no home care)
- Team members
 - MD
 - Nurse Clinician
 - Chaplain
 - Social worker
 - Case managers
 - Pain management specialist
 - Psychologist
 - Child life specialist
 - Medical director
 - Community hospices

Children's Mercy Hospital

- Average daily census – 120 patients (inpatient and outpatient)
- Population served
 - Acute life threatening
 - Life threatening
 - Life limiting
 - Life style limiting

Children's Mercy Hospital

- Service delivery
 - Referrals via medical personnel and parents must be in agreement
 - Nurse clinician meets with patient and family within 48 hours of referral
 - PACCT coordinator determines composition of team to provide necessary support
 - Team members come from staff assigned to specific departments or specialties of outpatient clinics
 - No consistent continuity
 - PACCT information, Comprehensive Comfort Care Tool, Do Not Attempt Resuscitation documents given to family if they agree to participate

Children's Mercy Hospital

- Team meets with family to discuss CCCT document and develop plan which is signed by family
- PACCT coordinator monitors family as needed on inpatient/outpatient basis
- Bereavement provided by a separate hospital team which is not part of the PACCT program

Harriett Lane Compassionate Care

- Main focus is to provide education and support for the inpatient and outpatient staff
- Emotional support for the inpatient team to allow for a reconnection for "meaning" for what they are doing
- Consultation to staff on pain and symptom management, psychosocial and spiritual support, advance care planning, and bereavement

Harriett Lane Compassionate Care

- 4 member team
 - Program director (RN)
 - Medical director
 - Family care coordinator (social worker)
 - Bereavement coordinator
- Referral made to program by member of inpatient team
 - Member of team acts as a facilitator at Patient Care Conference
 - Parents not invited
 - Goals of patient care discussed and documentation tool completed
 - "High density" areas (Oncology, PICU, NICU, ED) request majority of consults
 - Second conference occurs with parents but member of team invited on case by case basis

Harriett Lane Compassionate Care

- No outpatient services for pediatric palliative care
- Home care available but not for hospice care services
- Strong link with community hospice

St. Mary's Health Care System for Children

- Hospital specializes in post acute care for children with special needs
 - HIV
 - Genetic/metabolic disorder
 - Complications of prematurity
 - Traumatic brain injury
- Pediatric Palliative Care Program is over 25 years old
- Inpatient palliative care service which consults throughout hospital
- Team members
 - Administrator
 - MDs
 - Manager
 - Director of Complementary Therapy
 - Pastoral Care
 - Social workers

St. Mary's Health Care System for Children

- Developed Palliative Care Pathway which is a care map for providing PC
- Referrals come from inpatient medical service
- Well established outpatient program
- Program has defined 3 levels of care which reflect the severity of illness and life expectancy
- Palliative Care Pathway outlines care components, outcomes, and outcome measures

St. Mary's Health Care System for Children

- Peaceful Dying Plan completed when patient is terminally ill and reflects both parent's and patient's wishes
- Doula Program
 - Volunteers assist patients and families during the dying process
 - "Dying coaches"
- Social worker visits family 2 weeks after death of patient to give family a memory box and visit with sibs
- Home care component in place
 - RNs, Social Worker, Chaplain

Seattle Children's Hospital

- Inpatient palliative care program
- Team Members
 - MD
 - RN
 - Social worker
 - Chaplain
- Provides care coordination and indirect medical care
- Referral Process
 - Following physician referral, consultant assigned to case
 - Consultant meets with providers and coordinator of program schedules care conference with parents and health care providers
 - Consultant facilitates communication and shared decision making

Seattle Children's Hospital

- Decision Making Tool (DMT)
 - Completed by consultant
 - Contains information on meeting discussion and action plan
 - Consultant follows up with all those listed on action plan
 - Completed DMT goes into front of patients chart and becomes tool for continuity of care

Colorado Medicaid Waiver for Pediatric Palliative and Hospice Care

State Medicaid Waiver

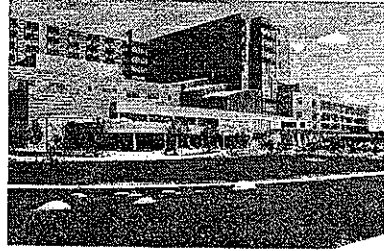
- The Butterfly Program along with Colorado Medicaid began working on waiver in 2001 to provide pediatric palliative care services to Medicaid eligible patients from time of diagnosis
- Based on Children's Hospice International Program for All-Inclusive Care for Children and Their Families
- SB 206 signed by Governor Owens in June 2004 authorizing HCPF to craft waiver
- Waiver approved by CMS in January 2007 and implemented April 2008
- 1st 1915c Home and Community Based Waiver for pediatric palliative and end of life care in U.S.
- California's 1915c waiver approved earlier this year

State Medicaid Waiver

- HCPF estimated 4000 Medicaid eligible children could benefit from waiver
- Introduction of pediatric palliative care earlier in the course of a life limiting illness estimated to save \$20,000/child/year
 - Decrease unnecessary ED visits and hospitalizations
- 200 slots available in current waiver
 - 70 slots filled to date

1915c Home and Community Based Waiver

- Medicaid eligible children with a life threatening diagnosis
- Services available from the time of diagnosis of the illness
 - Child must be at risk of hospitalization
 - Curative therapies may continue
- Services include nursing, counseling, spiritual support, respite, complementary therapies such as art and music therapy, anticipatory grief therapy



The New Children's Hospital

Questions?

