Overcoming Barriers to Successful Implementation of Pediatric Palliative Care

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Objectives

1. Describe two successful models of pediatric palliative care: one in the community and one inpatient model among children with heart failure.
2. Identify strategies to analyze and overcome barriers in program implementation.
3. List the main outcome measures to document quality of care.

Objective 1

• Describe two successful models of pediatric palliative care: one in the community and one inpatient model among children with heart failure.
TLC clinic: What?

- Integrated pediatric heart failure and palliative care clinic.
- TLC = Total Life Cardiac to signify ‘quality of life’ rather than ‘planning for death’

TLC clinic: Why?

PPC consultation, recommendations and follow up for pediatric cardiac patients:

- With life-threatening illness and limited treatment options
- Who need help with understanding complexity and preferences
- Who need help with advance care planning
- Who need end-of-life care recommendations

TLC clinic: Who?

- Palliative care team:
  - Ilanit Brook MD (palliative care)
  - Bethany Korzer PNP (palliative care)
  - Linda Rodbell PhD (psychology)
  - Helene Morgan MSW (social work)
- Cardiology heart failure team:
  - Lucy Bautch RN (heart failure nurse)
  - Jondavid Menteer MD (cardiologist)
  - Sarah Badran MD (cardiologist)
  - Susan Fusaro MSW (social work)
  - Melissa Morales RD and Stephanie Sanborn RD (nutrition)
TLC clinic: Where?
- Pediatric cardiology clinic space, CHLA
- Familiar space to family and patient
- Familiar space for testing (echocardiogram, labs, x-ray, EKG)
- Multiple simultaneous rooms available

TLC clinic: When?
- One afternoon per month
- Friday afternoon where clinic space available in cardiology clinic

TLC clinic: How?
- Pre-clinic:
  - Patients identified by cardiologist
  - Clinic concept presented to patient/family by cardiology
  - TLC team informed; co-ordination by heart failure nurse
TLC clinic: How?

- Clinic day:
  - Patients check in, complete testing
  - Team discussion immediately prior to clinic
  - Cardiologist sees patient first
  - Palliative team care meets patient as a group the first visit
  - One-on-one time with specific team member as needed
  - Group discussion follows; ‘whole patient’ assessed
  - Needs, referrals, follow up established and delegated

Excellus

LIFETIME CARE

CompassionNet

Excellus

Five Regions

Watertown

North Country

Genesee

Central

Western

Southern Tier

Ulster

Rome

Tri-Cities

- Rochester region
- Southern Tier region
- Syracuse region
- Ulster region
- Western region
Purpose:
- To assist children with life-threatening illnesses to live as normally as possible
- To support the independence and functioning of the family unit by providing full access to services and resources that sustain effective coping and positive family dynamics.

Eligibility Criteria
- Birth to 21 years of age
- Families with High Risk Pregnancies are also eligible
- Member of Excellus/Univera Insurance plan
- Physician believes that the child is at significant risk to die before the age of 21.
- This may include an acute exacerbation of a chronic illness placing the child at risk to die before reaching adulthood

Components of CompassionNet
- Views the Child and Family as Unit of Care
- Provides consistency and coordination across all settings
- There is ongoing assessment of the family’s physical, psychosocial, emotional, spiritual, and financial needs.
- Families may seek both life-prolonging treatments and palliative care
- Massage therapy and expressive therapies such as art therapy, child life specialist, music therapy are offered as needed.
Components of CompassionNet (Continued)

- Pain and Symptom Management
  - Pediatric Nurse Practitioners and Palliative Care Certified physicians are available for home visits.
  - Alternative and complementary methods of pain and symptom management are discussed and incorporated into care of the child as appropriate
- Existing community resources will be identified and used whenever possible
- Bereavement services are provided to the surviving family members and/or significant others for extended period of time

CompassionNet Care Team

- Patient
- Family
- CompassionNet Case Manager
- Pediatric/Family Nurse Practitioner
- Palliative Care Certified Physician
- Child Life Specialist
- Chaplain
- Primary Pediatric Home Care Nurse
- Hospital Representative
- Primary Physician
- Music Therapist
- Home Care Social Worker
- Home Health Aide Dept.
- Hospice Volunteer Dept
- Hospice Bereavement Dept
- Parent Representative

CompassionNet Utilizes the Village

- Reimburse family expenses
- Provide in-home services
- Advocate for reduced fees
- Refer to professional supports
- Community Resources/Human Service Organizations
- Volunteers and Charitable Organizations
- Friends/Church/School
- PeFamily
Families Served

<table>
<thead>
<tr>
<th></th>
<th>2012</th>
<th>2013</th>
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<td>461</td>
<td>484</td>
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Average Length of stay
1.1 years

Primary Diagnostic Categories

- Neoplasms (ALL) 40.5%
- Congenital Anomalies 21.7%
  - Hypoplastic Left Heart Syndrome 7.6%
  - Perinatal Period Conditions 7.6%
- Disease of Circulatory System 4.5%
- Endocrine/Nutritional/Metabolic 4.1%
- Disease of Nervous System 3.6%
- All Others Combined 18%

Supports Provided

<table>
<thead>
<tr>
<th>Services Offered</th>
<th>Physician Visits</th>
<th>Nurse Practitioner Visits</th>
<th>Financial Support (i.e. copays, medical equipment travel, hospital food and parking)</th>
<th>Massage and Expressive Therapies</th>
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<tbody>
<tr>
<td>Utilization last 6 months of life</td>
<td>47%</td>
<td>69%</td>
<td>89%</td>
<td>39%</td>
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Utilization last 6 months of life
Objective 2

Identify strategies to analyze and overcome barriers in program implementation.

Culture Change

A universal reality is that, overwhelmingly, places where palliative care has not existed before will require major cultural adaptation.


Overcoming DENIAL

• Carefully and rapidly document level of unmet need in patients and families in institution

• Simple surveys of uncontrolled symptoms or emotional distress might be extremely useful
Overcoming PALLIPHOBIA

Making great efforts at reassurance to existing clinical team(s) that PPC
- Will work in integrated fashion with them
- Will not invalidate their patient care plans, but rather enhance them by focusing on aspects not addressed so far

PALLILALIA

• Usually 2-4 years after establishment of PC initiative
• Repetitive nonsense spoken about PPC, without anything being done to advance its development
• Dangerous stage: results in burnout among PPC professionals
• Leadership describe PPC as “very important” or “a major priority,” but there’s no significant allocation of personal, space, money, curriculum time, etc.

PALLILALIA

• Colleagues frequently talk about how useful PPC is, but refer only small minority of patients with terrible problems
• This attitude: PPC not viable financially and administratively
• Institutions at this stage frequently:
  - Appoint a committee to discuss PPC
  - Propose major study to see whether PPC works in their institution
  - or, suggest PPC applies for external grant, so funds can be obtained for a “pilot program” in a year or two…
Overcoming PALLILALIA

• Colleagues and institutions become used to beneficial presence of PPC, while having made no major commitment to support it

• Important to anticipate this developmental stage by gathering data of provided clinical services
  – Patients seen
  – Teaching conducted
  – Revenue captured
  – Research studies, etc.

• Aim mostly at leaders of hospital and medical schools (rather than just immediate supervisors or peers) when providing documentation of work

• Request, that information be compared to output and resources of other programs

• Ask for external review by regional or national leaders in the field
PALLIATIVE

- Fully integrated service
- Responsible stewardship of scarce resources
  - Demonstrate to organization
  - Preservation of team health
- BEWARE: gears can slip

Barriers: Background

- Palliative team inpatient activity visible, understood and appreciated within heart institute (CTICU, CV acute, NICU)
- Perhaps best known to those with highest acuity patients (cardiology- heart failure, transplant, complex congenital)
- Cardiology brainstormed improving outpatient care/ quality of life for chronic heart failure and terminally palliated CHD
- Cardiology contacted palliative care: discussion of common ground and goals and plan to proceed

Barriers: Valuing

- Leadership of heart institute
- Leadership of palliative care (anesthesia/ critical care)
- Hospital administration
- Pediatric cardiologists
- Patients and families
Barriers: logistics

Financial
- Determining eligibility
- Clinic authorization
- Reimbursement/billing
- Costs (space, staff)

Geographic
- Cardiology vs palliative care space

Personnel
- Inpatient palliative care team to cover

Time
- Coordinating palliative care and cardiology with pt convenience

Barriers: solutions

• Cardiology administration:
  – Utilizing ‘underutilized’ space (revenue)
  – Consolidating like patients (clinic efficiency)
  – Patient satisfaction

• Cardiology faculty/staff:
  – Offering new service to patients
  – Relieve cardiologists of stress of not being able to meet patient needs

Barriers: solutions

• Anesthesia/critical care administration:
  – Increased visibility for palliative care program
  – Pilot program to demonstrate potential PPC growth and secure funding
  – ‘free’ clinic space by locating in cardiology
  – Patients pre-authorized (reimbursement) rather than free PRN consults
  – Cost savings
Barriers: solutions

- Palliative care team:
  - Patients consolidated in place and time to help efficiency of small / stretched team
  - Continuity of care
  - Improved interaction and communication with primary care team

Steps to Implementation

- Design the Model Using
  - Parent Focus Group
  - Research Best Practices
  - Interviews with local providers
  - Input from community organizations
  - Environmental Inventory (all assets in the community to meet family needs)
  - Gap analysis

Provider Input

- Met with staff at the local Children’s Hospital to identify areas of frustration and need for themselves and their families
- Met with large pediatric offices
- Met with leaders of the regional AAP organization
Form Partnerships among Hospitals, Hospice, and Home Care

- Acknowledge Barriers to Hospice
  - Resistance on the part of parent/child to forego aggressive treatment
  - Reluctance from Dr.'s to give 6 month prognosis
  - Families fear the loss of Medical Home
  - Lack of specially-trained pediatric Hospice staff persons

- Acknowledge Barriers to Quality End-of-Life Care in the Hospital
  - May not be as comfortable as home environment
  - May not be able to have all the family/friends desired at time of death
  - May be intimidating or scary for child

- Acknowledge Barriers to End-of-Life Care in traditional Home Care
  - Lack of Palliative Care Training
  - Family comfort level with going to the Hospital
  - Primary Care Team trust of home care abilities
Strategies to Overcome Barriers

- **Education**
  - Train Home Care Nurse on End-of-Life Care for Pediatrics (standardized training)
  - Train Hospital Staff on home care abilities
  - Monthly Core Curriculum for the team

- **Collaboration and Communication**
  - IDG (Interdisciplinary Group q.2wks)
  - Physician/NP communication with Primary and/or Specialists

Strategies to Overcome Barriers

- **Sharing of Resources Builds Trust:**
  - Purchase Hospice Support Services
  - Purchase MD time from hospital
  - Joint On-Call System for end-of-life nursing needs (home care and CompassionNet)

- **Build Family Trust**
  - Determine One Physician Lead
  - Frequent communication across settings
  - Proactively determine pt/family needs as death approaches and share action plan

Objective 3

List the main outcome measures to document quality of care.
Outcome measures: PPC

- Logistical success
  - Met time demands of extra clinic with adequate personnel

- Cost/ revenue/ funding
  - Revenue per time in clinic
  - Intangible (cost savings to hospital)

- Improved efficiency (inpatient to outpatient)

Outcome measures: cardiology

- Efficiency
  - Free up time during the “regular” clinic, while still deeply addressing patient needs

- Improved cardiologist satisfaction/ decreased frustration
  - Superior care provided by delegating complex social/ spiritual/ psychological issues to TLC team

Outcome measures: patients

- Improved needs assessment
  - Improved communication with clarification of expectations, fears

- Improved meeting patient needs
  - Referrals/ interventions from TLC clinic

- Patient satisfaction
  - Choose to return to TLC rather than cardiology clinic
  - Increased understanding of pt illness, prognosis and options; decreased stress
  - Less frequent and shorter admissions
Metrics Monitored

- Site of Death
- Preferred Site of Death
- Family Satisfaction
- Goals of Care Discussions
- MOLST Completion
- Hospitalizations
- Cost Avoidance (a work in progress)

Site of Death

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<th>Hospital</th>
<th>Home</th>
<th>Preferred Site</th>
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<tr>
<td>56%</td>
<td>44%</td>
<td>88%</td>
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*Of those preferences recorded

Family Satisfaction

- Overall Rating of 98%
- Quote: “My case manager has done a wonderful job – giving us services I never thought I would be able to continue since I had to quit my job” (e.g. counseling)
Goals of Care Discussions and MOLST Completions

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<thead>
<tr>
<th>Goals of Care Discussion</th>
<th>MOLST or home DNR</th>
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<td>81%</td>
<td>69%</td>
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Cost Avoidance: Actuarial Data from Milliman & Roberts

- Study of Medicaid children who died without coordinated palliative all-inclusive care vs. children who died with such services at Essential Care in Buffalo, NY
- Children with life-limiting illness have annual medical costs about **100 times** that of a typical commercially insured population.

Cost Avoidance

- Palliative care model reduces 5 days off LOS
- $28 PCPM associated with avoiding outlier days
- $1,560 PCPM associated with avoiding terminal hospitalizations
Significant Findings

- 95% confidence level in the findings, provides high confidence and high usefulness
- Costs are predictable and findings are portable to smaller populations
- Uniform costs from month to month support case management approach
- High cost of care supports the significant impact of small percentage changes

In Progress: Quality of Care Data

- Pre and Post Nurse Practitioner Visit Data being collected and analyzed
- Pain
- Dyspnea
- Anxiety
- Goals of Care/MOLST

What to measure?

Discuss in your team:

- Principles of measurement in palliative care
- Review elements which are important to collect, measure, analyze, and report for a pediatric palliative care service
  - What matters to your stakeholders?
- Start with low-hanging fruit
- Data collection: start as early as possible
What to measure

• Additional resources:
  http://www.capc.org/research-and-references-for-palliative-care/additional-resources

• Consider CAPC-PCLC (Akron, OH or Minneapolis, MN)

What to measure

• Cross-cutting performance measures for all hospice and palliative care programs
  http://aahpm.org/quality/measuring-what-matters

• Standards of PPC (NHPCO)
  http://www.nhpco.org/quality/nhpcos-standards-pediatric-care

- How did you overcome barriers?
- Your outcome measures?
Summary

• There are many successful PPC models of care (inpatient, and/or outpatient, and/or in the community)
• Expect and address barriers of PPC implementation
• Identify and track outcome measures to document quality of care