Implementing Palliative Care Across the Life Span

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Objectives

- Identify the essential elements to unify diverse Palliative Care (PC) programs.
- List potential barriers to a comprehensive PC program.
- List the triggers utilized for both adult and neonatal PC recipients.
- Examine methods in which to grow an existing PC program.

Palliative Care Service Line

Mission

Palliative Care Services is dedicated to improve the quality of life for patients and families with serious life altering disease or illness.

Vision

Through the commitment to working together as a multidisciplinary team, the Palliative Care Program will be the program of choice to ease or alleviate the suffering of patients and families with serious/life altering illness.

Palliative Care Service Line

Target Population

- Adults of all ages:
  - Suffering from serious/life altering illness
  - Life-threatening disease
  - Multiple comorbid health problems

- Neonates:
  - Who are extremely premature (less than 25 weeks)
  - Who have life-altering conditions
  - At the limits of viability (23 weeks)
  - In which curative treatment may fail
  - With an uncertain prognosis

Triggers

Adult Triggers:

- Life-limiting/altering diagnosis
- Advanced Care Planning
- Distressing symptom management
- Recipient of hospice services prior to admission
- Facing imminent death
- Enhanced communication and understanding
- Care coordination
- Thinking about withdrawal of life-supporting interventions
- Terminal illness
- Decreased quality of life

Neonatal Triggers

- Short Gut
- Stage IV Head Bleed
- Genetic (chromosomal) issues
- Neonatal withdrawal syndrome
- Multiple birth defects
- Ventilator dependence greater than 2 months
- Extreme prematurity (less than 25 weeks)

Evidence-Based Care Incorporated

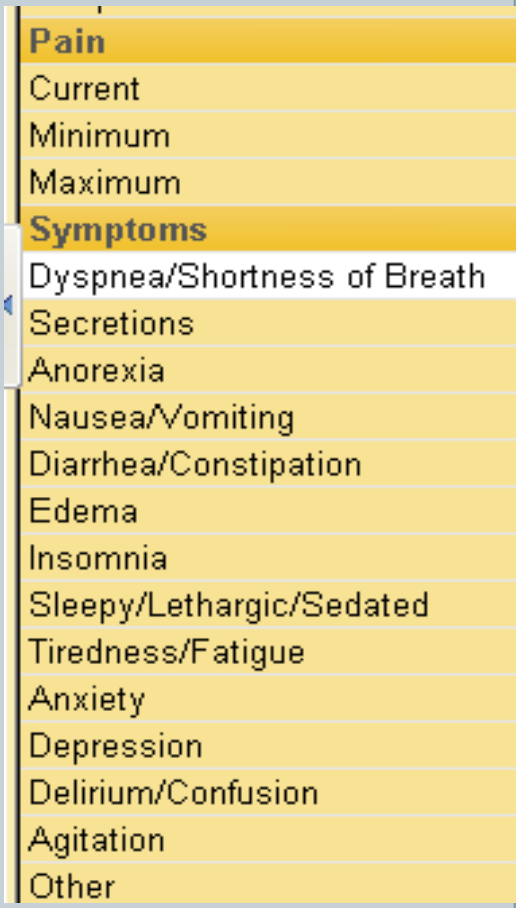
1. Clinical Practice Guidelines for Quality Palliative Care: The National Consensus Project
2. National Association of Neonatal Nurses Palliative Care for Newborns and Infants – Position Statement
3. Guidelines established through the Cystic Fibrosis Foundation

Domain 1: The Structure and Process of Care Integrated

- Created and Utilized Electronic Medical Record (EMR) note templates
  - Notes are comprehensive and serve as a tool for the interdisciplinary team
  - Goals of care are addressed and established
- Appropriately trained volunteers utilized
- Center to Advance Palliative Care Training
- Unit Memorial Services for staff
- PC involved in numerous hospital-wide councils
- Palliative Care Pearls, End-of-Life Nursing Education Consortium, National Cystic Fibrosis (CF) Conference

Domain 2:
Physical Aspects of Care

- Order Sets in EMR (PC Admission, End-of-Life, Withhold/Withdrawal, Neonatal ICU Comfort Care, CF Admission)
- Evidence-Based Care
- PC Flowsheet for nursing documentation
- Weekly rounds for
  - Palliative Care Unit
  - Neonatal ICU
  - Patient-led CF
  - Adult ICUs
- Dedicated Respiratory Therapy CF team



Domain 3: Psychological and Psychiatric Aspects of Care

- Memory forming activities
  - Hand molds for surviving family members
  - Memory box for parents who have lost a baby including pictures and infant mementos
- Referrals to Mother's Milk Bank
- *Hard Choices for Loving People* and *Life Transitions* available in English and Spanish
- Transition program for CF patients
- Psychiatric services
- Celebration of Life memorials
  - Support after losing a loved one by the Pastoral Care Department
  - Quarterly hospital memorial services
  - Annual "Walk to Remember"

Domain 4: Social Aspects of Care

- PC referrals can be initiated by anyone identifying a need
- *wee*Care is offered at any point at which the infant's life may be limited, including in utero
- Medical Management establishes care with the patient/family early in the hospitalization
- Child Life Specialists
- Family Meetings
  - Establish goals of care
  - Multidisciplinary
- Community involvement (March of Dimes, St. NICULas, CF Climb, 65 Roses and Cocktails for a Cure, Great Strides CF Walk, Tarrant County Food Bank, Heart Walk, Relay for Life)

Domain 5:
Spiritual, Religious and Existential Aspects of Care

AR=addiction / recovery
A=Anger
AT=awaiting test results
BC=beliefs challenged
CL=change / loss
CC=chronic condition
C=control / loss of
DA=decisions about care
D=disbelief
DC=discouragement
DV=disrupted view of God
DD=death / dying
FA=fearful / anxious
F=forgiveness
G=gratitude
GR=grief
GI=guilt
H=hopefulness
IS=sense of isolation
J=joy / happiness
L=loneliness
LH=loss of hope

- Patients are assessed for cultural needs and religious preferences
- Chaplains available 24 hours a day and represented on all PC Teams
- EMR Chaplain-specific flow sheet

AP=advocated for patient
AN=anointing
A=assisted with advance directives
CS=celebrated with subject
CI=clarified, confirmed or reviewed ir
BA=provided baptism
BL=provided blessing
PC=provided communion
CP=consulted with physician and/o
CC=contacted clergy
CF=contacted faith community
EFP=encouraged focus on present
ESC=encouraged self-care
EF=explored faith concerns
EM=explored meaning
EO=explored options
FC=facilitated conversation
FD=facilitated decision-making
FI=facilitated identification of emotio
FS=facilitated story telling
FR=faith ritual completed
GF=gathered family

Domain 6: Cultural Aspects of Care

- Chaplains contact preferred religious figures
- Transition program for CF patients
- Diversity Action Team
- Patient information and education available in English and Spanish
- In-house Spanish interpreter
- Language Line
- Hired Hands (sign language services)
- Point to Talk communication boards
- Vision assistance devices
- Hearing assistance devices

Domain 7:
Care of the Patient at the End of Life

- Provide management of distressing symptoms
- Butterfly to communicate imminent death of a patient
- Leaf to communicate perinatal death
- Chaplain support available 24 hours for the imminently dying & their families
- Bereavement support given to family for 13 months following loved one's death
- Care plan in Care Connect for the dying patient
- *Life Transitions* education manual available in English and Spanish
- Partnership with multiple hospice agencies

Domain 8: Ethical and Legal Aspects of Care

- Withholding and Withdrawing template
- Adherence to ethical principles
- Ethics and legal departments available 24 hours
- Order sets for withholding/withdrawing and end-of-life include PC Consult
- Advanced care planning
- PC Unit multidisciplinary rounds weekly with corresponding EMR note template
- CF multidisciplinary rounds weekly with corresponding EMR note template
- NICU multidisciplinary rounds
- Family care planning for CF patients

Growing an Existing Program

- Educate!
- Reach out to other departments
- “Think outside the box”
- Meet with physician groups
- Collaborate with the ICUs
  - Earlier referrals
  - Routine family meetings
  - Withdrawal of life-support
- Establish a Steering Committee
- Identify your Champions
- BE DILIGENT and BE PATIENT

What are our future endeavors?

- Outpatient Services
- Proactive in the development of research
- Process for automated PC involvement in patients presenting with out-of-hospital cardiac arrest and undergoing hypothermia protocol
- Integrate system-wide, comprehensive, PC Services
- Supporting new & existing programs across the nation and globally

References

- Clinical Practice Guidelines for Quality Palliative Care: The National Consensus Project
- NANN Position Statement
- CFF
- ELNEC
- CAPC

Questions?