FAMILY-CENTERED BEREAVEMENT CARE: FROM THE ICU TO THE IPU AND BEYOND

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BEREAVEMENT SUPPORT AND PALLIATIVE CARE

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PALLIATIVE CARE & BEREAVEMENT SUPPORT

- Unlike hospice programs, hospital-based palliative care teams have no specific requirement to provide grief support services.

- However, need for services recognized by national organizations:
  - NHPCO
  - NASW (Standards of Social Work Practice in Palliative & End of Life Care)
  - Joint Commission Standards for palliative care certification
PALLIATIVE CARE & BEREAVEMENT SUPPORT

• Lack of access to services places family members at higher risk for
  • Physical health problems
  • Depression
  • Anxiety
  • Intense anger
  • Hopelessness
  • Lower overall quality of life

• Complicated grief
  • 10% of people may develop complicated grief
  • **10-20% of people may develop MDD during grieving process**
    (Waller, et al, 2015)
TEMPLE UNIVERSITY HOSPITAL (TUH) PALLIATIVE CARE

- TUH: a 721-bed non-profit acute care hospital in North Philadelphia, PA (99 ICU beds)
- Palliative Care Team
  - 3 Physicians (2 part-time)
  - 1 Nurse Practitioner
  - 3 Social Workers (1 part-time)
  - 1 Chaplain
  - (Residents, Fellows, medical students, social work intern)
- All except one physician contracted through the VNA of Greater Philadelphia
- Team started in 2009 through TUH/VNA partnership
OUR COMMUNITY

- Our primary population service area includes more than 750,000 residents
- 83% of the population in Temple’s service area is African American, Latino, or another minority
- 64% have a household income of under $20,000
- Highest volume of patients covered by Medicaid in Pennsylvania among full-service hospitals
- Poverty, trauma, and family estrangement are prevalent
COMMON OBSTACLES TO PROVIDING GRIEF ASSESSMENT & SUPPORT

• Limited time
• Lack of funding
• Low client interest
• Lack of organizational support
• Limited contact with caregivers or difficulty contacting them after a death
• Lack of generalizable, standardized bereavement risk assessment tool
• Lack of evidence for most effective treatment methodologies for complicated grief
PALLIATIVE CARE & THE ICU

- Nearly a quarter of TUH palliative care patients are seen in ICUs
- Nearly that percentage will die in the hospital: almost 25% of patient’s families will not benefit from hospice bereavement support
- Scant supportive resources available in the community
- Population at high risk for complicated grief
- **Families who experience time in the ICU as traumatic are at higher risk for complicated grief** (Tyrie & Mosenthal, 2012)
- No pediatric care at TUH, but children often visit loved ones in the ICU
“Delivery of services that revolve around the incorporation of the family in the development and implementation of interventions: a family-professional partnership.”

(Kenner, Press & Ryan, 2015)
PALLIATIVE CARE & BEREAVEMENT SUPPORT

• Support services developed over life of program

• Assessment process
  • Universal complicated grief risk assessment of all patients and families receiving an initial psychosocial-spiritual assessment
  • Document known risk factors such as
    • Family conflict
    • Low levels of social support
    • Low acceptance of impending death
    • Other deaths recently experienced
PALLIATIVE CARE & BEREAVEMENT SUPPORT

Services we provide:

• Brief counseling for anticipatory/complicated grief
• Educational materials re: coping with grief
• Support and education for children and families visiting ICUs
• Referrals to outside counseling resources
• Twice-annual 5-week grief support group

We partner with the VNA to provide:

• A follow-up phone call made by a trained volunteer to each family following the death of a patient
• A condolence card signed by the palliative care team members but mailed by volunteer
• Phone follow-up with family members flagged by volunteer
• Referrals to the VNA Bereavement Coordinator for those at very high risk for complicated grief
PALLIATIVE CARE & BEREAVEMENT SUPPORT

• Some psychotherapeutic methods utilized, but we clearly define a support group rather than a psychotherapeutic one

• Interventions utilized in grief support group
  • Sharing our stories (ground rules discussed)
  • Psycho-education: “normal” grief and coping skills
  • Cognitive-Behavioral interventions
    • Identifying thoughts and feelings
    • Self-assessment of coping skills and self-care
    • Self-care homework
  • The Grief Bubble (modified)
THE GRIEF BUBBLE

helping kids explore and understand grief...

Kerry DeBay
PALLIATIVE CARE & BEREAVEMENT SUPPORT

What has worked for us

• Follow-up phone assessment by trained volunteer
• Twice-annual 5-week group
• ICU staff education on working more effectively with children and families

What has not worked for us (but might work for you!)

• Monthly group
• 5-week children’s group concurrent with adult group

We face ongoing challenges with family transportation, work schedules, and childcare responsibilities...
FAMILY-CENTERED SUPPORT IN THE ICU

KATHERINE EADDY, MSW, LSW, CCLLS
HELPING CHILDREN SAY GOODBYE AND/OR VISIT LOVED ONES IN ICUS

• **Evidence-based research supports**: Developmentally appropriate therapeutic play, information, reassurance, and psychological preparation. These interventions allow children to play and rehearse coping strategies.

• Child Life Specialists are professionals that aim to “empower children with knowledge and equip them with coping strategies, so that they may face potential stressors with understanding and confidence.” (American Academy of Pediatrics, 2000)

• Child Life Services are gaining an increased presence in adult hospitals; however, it is scarce to find Child Life programs in adult settings. (Sutter & Reid, 2012)
PEDIATRIC LITERATURE CLEARLY SUPPORTS

• Preparing children for stressful situations to improve coping and mastery of difficult situations, and providing a sense of normalcy to unfamiliar settings.
• Developmentally appropriate play modalities.
• Creative or expressive arts- music/art therapies.
• Medical Play Interventions.
  (Child Life Services, 2006)
• Children do have the capacity to understand stressful health care situations, when prepared to do so, depending on both their developmental and chronological age.
• Evidence-based literature supports that children do not have adverse effects after visiting a loved one in the Intensive Care Unit. Conversely, negative behavioral and emotional responses have been shown to decrease after visitation.

(Child Life Focus, Volume 30. No 2. Spring, 2012)
REASSURANCE THROUGH PLAY

• Creative and Medical Play is used by CCLs to teach children what is happening to their loved one in the ICU environment and about unfamiliar medical equipment.
• Decrease Anxiety/ Magical Thinking of Death/ Concrete Language/ Developmentally Appropriate Terms and Explanations.
• Allowing Supportive and Therapeutic play, and to guide children in their processing of serious/ critical illness and often imminent death in ICU settings.
• Loved One’s absence
• Potentially altered relationships with other family members.
• Child-centered play or Child-directed play is “most effective in promoting self-healing and is particularly useful with children under stress.”

(Brown, 2007)
STRESSORS FOR CHILDREN AND TEENAGERS

• “25% of children experience anxious moods, sleep problems, poor concentration, and difficulties in school when there is an illness in the family.”
  
  (Sutter & Reid, 2012)

• When a parent is ill, adolescent girls are at increased risk of short and long term emotional and psychological problems.

• Children and teenagers’ anxiety can be decreased when the TRUTH about a parent’s treatment and prognosis is discussed.

• “Family-Centered Care implies that a diagnosis of an individual important to that child affects their entire family unit.”

  (Institute for Patient and Family-Centered Care, 2010)
INTERDISCIPLINARY PLAN TO SUPPORT CHILDREN DURING AN ICU VISIT

• Listen to adult family members’ questions, fears, and concerns.
• Answer questions, validate concerns, and correct misinformation.
• Care more about what “they” feel than what you “think”.
• Is the child typically developing?
• Any challenges - mental, physical or emotional in the past?
• Does the child have an info-seeking or info-limiting coping style?
• How much does the child know already?
• Are there certain things the family doesn’t want the child to know about their loved one and why?
• Does the child have any prior experience with end of life care?
• Assess the level of involvement for the child and family.
• Meet the children and family in a private, contained room.
• Gather Information of each child’s understanding and perspective of the ICU, and loved one’s illness/situation.
• Provide individual support depending on each child’s age, developmental level, and personality.
• Provide simple, honest verbal information regarding patient’s condition and prognosis.
• Provide verbal description of what will be seen, heard, smelled, and felt in the ICU.
• Provide information about what the child can do once at bed side with their loved one. (Hold patient’s hand, kiss, hug. If possible, sit and/or stand close to the bed).
• Prepare and alert ICU staff and patient (if appropriate) for visit, and let them know children are coming for a specific time frame.
INTERDISCIPLINARY VISITATION PLAN CONTINUED

- Ensure patient “appears” without linens and or dressings/tape that is soiled or blood stained.
- Elevate the head of the bed (if appropriate) and place bed in the lowest position possible.
- Make the patient room less institutional by encouraging the child to create drawings, write notes, and bring photos and sentimental items from home.
- Discuss potential reactions of the child (crying, clinging, etc.) and alert patients and family members.
- Make the family members aware that the child may not want to enter the room, and/or have an extended visit with patient.
- Accompany child and adults into the patient room and allow the child to lead the way.
- Stay near the child to support any potential fears or questions.
INTERDISCIPLINARY VISITATION PLAN CONTINUED

• Reassure the child that the patient is being well-cared for by many health care professionals.

• Allow the child to know it is safe to show any kind of emotion (fear, sadness, anger, etc.) and that they will be supported with their feelings.

• Encourage adult family members to discuss the ICU visit with the child to debrief and assist with any post-visit stress.

• Provide psycho-education to family members of symptoms indicative of poor child coping (headaches, GI complaints, vague pains, poor academic performance, regressive behaviors, changes in mood, fearfulness, enuresis, sleeping, and/or eating habits).

• Adults openly modeling their grief gives permission for children and teenagers to do so.

• **Companioning with Grief Model** (Alan Wolfelt, 1990)
SUPPORTING CHILDREN TO SAY GOODBYE

• Provide art supplies for creative expression to facilitate memory making, legacy building, and storytelling.
• Encourage children to draw pictures and write notes and to tell you about their loved one.
• Reassure children that they will be cared for if their loved one is a primary caregiver, and tell them who will care for them (if possible).
• Support the family in reinforcing once they leave the hospital who the child will go home with or live with if known.
• Ask the child and family “what helps you feel better when you are sad?”
• Encourage family members to participate in “helping each other feel better.”
• Fostering continuing Bonds for the child and loved one.
FACTORS INFLUENCING THE GRIEF OF CHILDREN IN BEREAVEMENT

- The nature of the person’s death - sudden, traumatic, suicide, unexpected, or expected - chronic and/or life-limiting illness/diagnosis.
- Relationship with the person who died.
- Availability of family and friend support systems.
- Child’s unique personality and resiliency.
- Cultural, Ethnic, and Religious backgrounds.
- Prior experiences with death and loss, other crisis, and stressors in the life of their family. (Complicated Grief)
- Social expectations based on gender.
- Rituals, funeral/memorial experiences, or lack there of.
- “Bearing Witness & Holding Space” are integral tenants of compassionate care for those at the end of life.
FAMILY-CENTERED
BEREAVEMENT SUPPORT

KELLY KAMPF, MSW, LCSW
HOSPICE OF PHILADELPHIA
BEREAVEMENT SERVICES: ON ADMISSION

- Social worker completes bereavement risk assessment with initial psychosocial assessment
- Members of care team can request pre-bereavement counseling
  - Unresolved existing grief
  - Anticipatory grief
  - Overwhelming issues of presenting grief
HOSPICE OF PHILADELPHIA
BEREAVEMENT SERVICES: AFTER DEATH

• 13 months support: monthly letters/psycho-educational materials
• Workshop once/month: “Journey Through Grief” (open to the community)
• Support group (open to community)
• Supportive phone calls at 1, 2, 3, 6, and 13 months
• Individualized counseling (8 free sessions)
• Invitations to memorial service (quarterly)
• Referrals to community resources (grief counselors, support groups, resources for children)
• Specialized Children’s Bereavement Resource packet
The philosophy of the Hospice of Philadelphia is to offer as many bereavement services as possible to members of the community whose loved one did not die on hospice.
FAMILY-CENTERED BEREAVEMENT SUPPORT: ANTICIPATORY GRIEF

- **High risk families** (patient aged <35, patient with young children, rapid decline, disfiguring illness, multiple losses, etc.) identified for early support

- **Early intervention** can help people cope more effectively, which leads to more adaptive forms of grief expression

- Those who receive support prior to death of loved one tend to cope better when assessed at 13 months post-death (Worden, 1992)

- A major task of the grieving process is to actively confront feelings and thoughts while receiving education and support (Parry, 2001)
FAMILY-CENTERED BEREAVEMENT SUPPORT: COMPLICATED GRIEF

• Grief often classified as “complicated” if it is extended, repressed, or manifests in maladaptive behaviors

• For children, complicated grief more likely to lead to later symptoms of depression and difficulty forming close relationships in adulthood
FAMILY-CENTERED BEREAVEMENT SUPPORT

• When children are present, they are always included in the family mourning plan
• Counselor meets initially with adults/parents
  • Discuss their fears
  • Assess how they are coping with grief
  • Get more information on the family coping style
• Counselor meets with family unit – adults may help to normalize grief experience for children
• Counselor meets with children separately
  • May utilize art, writing, books, playing games
  • Utilize age-appropriate honesty with simple explanations
HELPFUL BOOKS FOR INTERVENTION WITH ADULTS AND CHILDREN

• **For adults**
  • *The Grief Recovery Handbook* by John James & Russell Friedman
  • *The Journey Through Grief* by Alan D. Wolfelt
  • *Preparing the Children* by Kathy Nussbaum

• **For children**
  • *Healing Activities for Children in Grief* by Gay McWhorter
  • *Creative Interventions for Bereaved Children* by Liana Lowenstein
FAMILY-CENTERED BEREAVEMENT CARE

QUESTIONS?

DISCUSSION?
FAMILY-CENTERED BEREAVEMENT CARE

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REFERENCES: EMILY BROWNING


