Family Visitation Matters: Meeting the Needs of Child Visitors in the Adult ICU

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Goals and Objectives

• Discuss benefits of children visiting acute and critically ill patients

• Describe strategies to support children through a loved one’s critical illness or death

• Describe strategies and lessons learned in development of a Children of Adult Patients (CoAP) program

• Discuss case study examples/feedback and potential impact on patient and family experience
Why Support our Patients’ Children?
Why Support our Patients’ Children?

• Patient’s First

• Joint Commission
  - Views patient and family-centered care as an important component of safe, quality care
  - Applies to patients of all ages & in all health care settings

• Evidenced-Based Best Practice
Literature Review: Barriers

- Parents restrict child visitation based on fear
- Nurses/physicians restrict visitation based on concerns of possible negative consequences:
  - Infection control concerns
  - Emotional harm to children
  - Adverse effect on patient
- No evidence found in the literature to validate these concerns

(Clarke, 2000; Knutsson & Bergbom, 2007)
Literature Review: Family Visitation

AACN Practice Alert (2012)- Family Presence: Visitation in the Adult ICU

• Children (supervised) allowed to visit critically ill patients

• No restriction based on age

• Contact with children can be of significant importance to patients

• Prepare children for hospital environment, family member’s illness

• Nurses ensure a positive and developmentally appropriate experience for children

(American Association of Critical Care Nurses, 2012)
Literature Review: Patients

- Visits from children gave them “the inner strength to continue to fight illness”
- Helped to “instill hope, re-oriented them to the outside world and encouraged them to fight”
- Helped to restored a sense of normalcy; maintain identify

“Having them near was good… Afterwards I've realized this meant a lot to me…their presence made me feel safe”

(Engström & Söderberg, 2007; Hupcey, 2000)
Literature Review: Children

• Benefits to children:
  ✓ Increased understanding and participation in crisis
  ✓ Decrease in feelings of “helplessness, guilt, separation and abandonment”
  ✓ Reassurance
  ✓ Decrease in misconceptions
  ✓ Support during a time of uncertainty

(Clarke, 2000; Hanley & Piazza, 2012; Kean, 2010; Knuttson & Bergbom 2016)
Our Story....
Background

• Visitation policy change (2011)

• \(\uparrow\) number of child visits

• \(\uparrow\) request for Child Life services

• Growing concern: impact of visitation
CVICU Study: Family Interviews

- Qualitative, IRB approved
- 12 families (22 children)

Five Emergent themes:
1. Prepare children for visitation
2. Help parents to educateprepare children
3. Provide activitiesdistraction
4. Prepare environment
5. Responses to child visit
CVICU Study: Family Interviews

• Conclusion: Recurrent need for age appropriate resources/ preparation prior to visitation

• “Trying to prepare yourself and your child is hard.”

• “Have someone designated to explain things on her level. As parents, we don’t always know how to do that.”
Caregiver Survey

Of 266 respondents…

42% Do not believe needs of child visitors in ICU are being met

73% Do not have the resources in their unit to meet the emotional needs of child visitors
Caregiver Survey

80% Have not received training on meeting the needs of children visiting an ICU

83% Have not received training on providing bereavement support to children of dying patients
What needs frequently come up?

- Bereavement Support: 57%
- Terminal Diagnosis: 45%
- Preparation for visit: 68%
- Explaining tubes, drains, etc.: 67%
- Distraction/Play: 64%
- None: 6%
Children of Adult Patient’s Program (CoAP) Planning and Justification
Program Development

- Track need
- Job justification
  - Education to stakeholders
- Business proposal
CoAP Program

CLS Responsibilities:

- Needs assessment
- Consultation
- Clinician education
- Patient and family resource
- Collaborate with other services
  - Palliative Services
  - Bioethics
  - Spiritual Care
Program Development

CoAP Hours

- Resource: 18%
- Leadership: 32%
- Education of others: 9%
- Education of self: 9%
- Education of Patient Care: 24%
- Indirect Care: 8%
Vision/Goals

• Complement CC culture to provide family-centered care
• Improve end of life care for our patients/families
• Adequate CLSs & resources to meet the need of the adult ICUs
• Improved patient experience scores in the adult ICUs
• Support frontline caregivers to improve employee engagement
Lessons Learned

• Justification process
• Timeframe
• Hiring Process
• Adult versus Pediatrics
• Sustainability
What is CoAP?
Keeping Families Connected

- 40-year-old woman in cardiac failure
- 2-year-old daughter at home
- Patient anxious about how illness and hospitalization would impact daughter

Soon Mommy will be coming home with medicine to help her heart
Bereavement Support for Children

- 44-year-old woman in SICU at the end-of-life
- Two children, 7 and 9 years old both with developmental delays
Implementation and Outcomes
Key

- Yellow: Children of Adult Patient Programs in hospitals
- Green: Child Life Specialist who can consulted for CoAP cases
- Red: Hospice Centers with Child Life

United States

- Washington
- Oregon
- Idaho
- Montana
- Wyoming
- Colorado
- Utah
- Arizona
- New Mexico
- California
- Nevada
- Texas
- Louisiana
- Florida
- North Carolina
- Ohio
- Michigan
- Indiana
- Kentucky
- Tennessee
- Missouri
- Arkansas
- Mississippi
- Alabama
- South Carolina
- Georgia

Hospice Centers with Child Life

- Cleveland Clinic

Countries outside the United States:

- Mexico
- Canada
- United Kingdom
- India
- Nigeria
- Brazil
- Argentina
- Japan
- Australia
- South Africa
- Spain
- France
- Italy
- Germany
- China
- Russia
- Brazil

Map shows nodes representing locations in the United States with Child Life programs and hospice centers.
Resources and Educational Tools Developed

- ICU activity book
- Patient Education Sheets
  - “How to Talk to Children about a Parent’s Serious Illness”
  - Age-Specific Information on Coping
  - Preparation for a Visit to the ICU
  - Diagnosis-Specific Education
- Educational Module (in development)
- Nursing Grand Rounds
- Preparation iBook (in development)
The nurses use an IV pole to hang bags of extra water or medicine. The pole may have small machines called pumps attached to it. The pumps help us give the right amount of medicine.

Sometimes when people are in the ICU, they need extra help breathing. A ventilator gives small puffs of air to help patients breathe. A breathing tube is taped to the nose or mouth to keep it in the right place. Doctors will give him or her special medicine to help the patient sleep.Patients are not able to talk while they have a breathing tube.

The doctors and nurses use special tools and medicines to help people when they are very sick or hurt.

In the ICU patients are usually lying or sitting in a hospital bed. They might be sleeping. When people are very sick, they need a lot of rest. Sometimes the medicines, bandages, or special machines that patients need might make them look different.
Reasons to Consult Child Life

• Education for a new diagnosis
• Changes in quality of life
• Preparation for visiting ICU
• Navigation of challenging conversations
• Emotional support of patient and/or patient’s children
• End-of-life and grief issues through the use of supportive services, legacy building, and bereavement care
Child Life Services Provided To Children Vs. Patient/Caregiver

- Education and/or Emotional Support for Patient/Caregiver: 37%
- Education and/or Emotional Support for Children: 63%

Consult Types:
- Other: 7%
- New Diagnosis: 15%
- Preparation for Visit: 22%
- Change in Quality of Life: 26%
- End of Life: 30%

Cleveland Clinic
CoAP Program Outcomes

- September 2016-April 2017
  - # of Consults: 111
- # of total interventions (consults + follow-up interventions): 250
- # of children/teens impacted: 300+

Cleveland Clinic
Hours spent per Consult

- Less than 45 min: 22%
- 45 min- 2 hours: 51%
- 2-3 hours: 20%
- 3 hours +: 6%
Working with Children of Adult Patients

Preparation for Visiting the Hospital
Why Preparation is Important? Evidenced Based Practice

• 6 of 11 children interviewed who visited without preparation found equipment frightening.
  • “I had never seen anyone with a tube in their nose. It was really scary.” (Craft et al 1993).

• “Information/explanations about the technical equipment and what is done for the relative is important as it can make the child feel confident and secure,” (Knutsson and Bergbomb 2016).
Simple Guidelines to Remember

• Good preparation involves the 5 senses:
  • See
  • Smell
  • Hear
  • Feel
  • Touch (experience, do, etc.)
Explaining Equipment

- **Younger Children**
  - Keep explanations short and simple.
  - Focus on the general purpose of device or machine

- **May be able to give more detail**
  - Can talk about general purpose of device and why/how it’s helping

- **Older Children and Teens**

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Case Study #2

- 47-year-old man in CVICU post-traumatic accident connected to multiple devices
- Pt.’s 15-year-old son had not been to see patient yet
- Child Life Specialist for preparation and support during visit
Working with Children of Adult Patients

End-of-Life and Bereavement Interventions
Considerations for End-of-Life

• Use concrete wording; avoid euphemisms

“Children who are prepared for impending death by being allowed to ask questions, express feelings, and participate in caregiving cope more successfully,” (Sahler, 2000).

• Children should have the opportunity to say good-bye if they chose to do so
  • Preparation and support person
  • Positive, meaningful visits at the end of life (Christ and Christ, 2006)
• Children should not be forced to visit if they chose not to
Preparation for End-of-Life Visit

• Questions for Nurse:
  • How might this patient’s room look to a child?
  • What can I put away?
  • Closing doors/curtains to other patients’ rooms.
  • Could the caregiver or family put on soft music?
  • Special items from home?
  • Does the child have a support person?
Case Study #3

- 36-year-old man. In the Neuro ICU due to tumor.
- Patient at the end-of-life.
- Consult for patient’s 7-year-old daughter
- Patient’s wife unsure of how to explain and help patient’s daughter say good-bye to her dad
- Child Life helped provide preparation and legacy building
Simple Interventions for End-of-Life

- Thumbprints
- Memory bracelets or necklaces
- Handprints (Embossing)

Find free grief resources to provide to families:

- Cornerstone of Hope (Cleveland)
- Met Life: After a Loved One Dies

[Cleveland Clinic]
Program Feedback
Feedback from Healthcare Team

“Thank goodness child life was here.”

“what a difference (child life) made with how these children are coping”

“Very helpful”

“amazing resource when withdrawing support”

“child life intervention has been so beneficial to these children”

“This is such a needed resource—to have someone whose specifically can focus on patient’s children”

“wonderful with families and children”
Program Feedback

- Patient came to hospital after MI. Patient has 12-year-old daughter with autism. Patient’s wife concerned about how their daughter is coping with separation from patient.

- “My daughter, being autistic, is very literal in her understanding of things. Working with the pictures and diagrams of the heart to understand what was happening helped her to comprehend what is going on....meeting with a child life specialist positively impacted our family during hospitalization.”
  - Wife of patient; feedback given by email after patient’s hospitalization
Program Feedback

“(Patients’) children met with Child Life specialist. The interactions went well--the patient's daughter met with the clinician and then both children participated in a "mini TAH" training session. (Patient) has been surprised and pleased with how the children's comfort level with the device has increased. He has noted the most significant changes with his son. Both children are looking forward to discharge to home and they have been reassured to know that there are steps that can be taken if patient should need assistance…”

–ICU Social Worker
Conclusion

• Patient’s children are an important part of the family unit; meeting their psychosocial needs should be a priority

• ICUs across the country are expanding visitation policies to include children

• The healthcare team often lack the knowledge and resources needed

• Child Life Specialists are a beneficial part of the medical team and can help meet the unique needs of patients’ children

• A CoAP program and other resources can help provide support to children during their loved one’s critical illness or end of life
Thank You!!

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References


References


