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END-OF-LIFE NURSING EDUCATION CONSORTIUM
Advancing Palliative Care

Goals of Care Discussions for Caregivers of COVID-19 Patients – Support for Pediatric Patients

Opportunities for Nurses to Provide Best Practices at the Bedside

Objectives

- Review the current findings related to pediatric patients impacted by the COVID-19 pandemic

- Discuss the role of the bedside nurse in goals of care discussions during the COVID-19 pandemic in caring for pediatric patients

- Discuss communication strategies to provide optimal emotional support for families and to promote best practices

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Case Study

- J.H. is an 11-year-old female admitted to the pediatric intensive care unit (PICU) for fever, cough, rash, abdominal pain, diarrhea, found to have acute kidney injury (AKI) and she tested positive for COVID-19. Her parents are distraught about the findings and they are also worried about her past medical history of congenital heart disease as an infant. The PICU team has plans to update the family about her status and the family is ready for the video call.

- *Where does the bedside nurse begin with providing support for this family?*

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COVID-19 Pandemic: Pediatric Patients What Do We Know So Far?

- As of September 2020, pediatric reported COVID-19 cases total 624,890 and roughly 10% of COVID-19 cases in the U.S. are among children, up from 2.2% in April.

- Hospitalization among children is low (8.0 per 100,000 population) compared to adults (164.5 per 100,000 population) however the numbers continue to increase.

(AAP, 2020; CDC, 2020)

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COVID-19 Pandemic: Current Guidelines

- Some children with COVID-19 develop multisystem inflammatory syndrome in children (MIS-C), a rare but serious inflammatory condition linked to COVID-19, characterized by fever, inflammation, and multisystem organ dysfunction

- Clinicians who suspect MIS-C should use a multidisciplinary approach involving many pediatric specialists, including cardiology, infectious disease, immunology, hematology, rheumatology, pediatric hospital medicine, and critical care, to guide treatment

- **Additional AAP information:** https://services.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/multisystem-inflammatory-syndrome-in-children-mis-c-interim-guidance/

(AAP, 2020)

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COVID-19 Pandemic: What is Different for Families of Pediatric Patients?

- COVID-19 illness has caused anxiety related to separation from normal activities

- Limited contact with support systems and extended family

- Concern of spreading illness to family members

- Hospitalized children may experience separation from family members who are unable to visit

CDC, 2020

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COVID-19 Pandemic: Settings for Goals of Care Discussions

- Given current hospital visitation restrictions, nurses can advocate for creating adequate settings for family meetings to take place

- Possible options for communication with family:

  ➢ Video call with parents/family (e.g. FaceTime, Google Duo, WebEx, Zoom, and other options, utilized as permitted by institutional protocols)

  ➢ Private family meeting room with proper PPE and appropriate visitor screening

  ➢ Phone call (least favored due to lack of visual contact)

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COVID-19 Pandemic:
Key Questions to Consider

- What is the meaning of illness to the family?

- What is the family's prior experience with sickness/death? (family member, pet(s)?)

- How does the family typically communicate difficult news?

- Are there other team members who should be included in the video/meeting/phone call with the family?

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Tips for the Discussion

- Discuss the facts while paying attention to the family's emotional signals

- If giving updates by phone, utilize pauses throughout the conversation to allow for questions.

- It is okay to show/express emotion when speaking with families via video or by telephone.

- Seek to partner with Child Life Specialists and Clinical Social Workers.

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COVID-19 Pandemic: What/How to Communicate

- Turn off phones and pagers
- Determine how much child/family want to know
- Assess family's preferred style of communicating
- Utilize a language interpreter, when needed
- Establish an appropriate atmosphere (if meeting in person have tissues available)
- Utilize developmentally appropriate language

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COVID-19 Pandemic: What/How to Communicate

- Specific to the video call experience: ensure the least amount of background noise possible

- If possible, find a private space for the video call

- Use empathetic language

- Allow each family member present for the video call to introduce themselves

- Prepare the family for 'difficult news' and ask for permission to speak in front of siblings of the patient (who may be present during the video call)

SPIKES Protocol

Six steps for delivering bad news when preparing for and participating in a family meeting.

- *Setting up* the discussion.
- *Perception:* assessing the patient's perception of the situation.
- *Invitation:* obtaining the patient's invitation for information about his/her diagnosis, prognosis, details about their illness, or treatment options.
- *Knowledge:* providing education to the patient.
- *Emotions:* addressing the patient's emotions with empathic responses.
- *Summary:* providing the opportunity for the patient and family to summarize their understanding of the discussion, decisions made, feelings about the meeting, and any questions or concerns.

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Child/Family Expectations of Healthcare Provider

- Be honest

- Non-abandonment

- Elicit values and goals

- Help explore realistic options

- Take time to listen

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The Ask-Tell-Ask Strategy

- Ensures that the interaction remains a conversation

- Nurse will *__ask__* open-ended questions to determine the needs of the patient.

- After the patient responds, the nurse can address the response by *__telling__* information that answers the question to clarify the patient's understanding of the response or identify additional concerns of the patient.

- Following the exchange, the nurse can *__ask__* another question to clarify the patient's understanding of the response or identify additional concerns of the patient.

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Acronym NURSE: Communication Tool

- Evidence-based communication tool that assists the nurse to utilize verbal expressions of empathy:

  <u>N</u>ame

  <u>U</u>nderstand

  <u>R</u>espect

  <u>S</u>upport

  <u>E</u>xplore

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Acronym NURSE: Communication Tool

**Name** the emotion - assures the patient of the nurse's recognition of his/her emotion.

> **Example:** "You seem really sad since the doctor talked with you this morning"

**Understand**: using words that communicate understanding normalizes the patient's emotion and a non-judgmental attitude is demonstrated.

> **Example:** "I can't imagine how you have been feeling, but it wouldn't surprise me if you were feeling sad right now" helps the patient to know the nurse understands he/she is having a difficult time.

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Acronym NURSE: Communication Tool

Respect: Communicating respect acknowledges the patient's ability to overcome some of the challenges of his/her life-limiting illness.

> **Example:** "I am so impressed that you have been able to continue participate in physical therapy even though you said that you don't like it" recognizes the challenges that the patient is encountering and coping with.

Support: Using words that communicate support communicates the nurse's presence at that time and in the future, assuring the patient of non-abandonment.

> **Example:** "I know that you have been struggling with anxiety at night, we will continue to work with you to control this problem."

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Acronym NURSE: Communication Tool

Explore: the nurse can communicate empathy through words that explore his/her experience. Demonstrating an interest in the story of their experience allows the nurse to explore the patient's concerns.

Example: "You said you were worried about your family through all of this, can you tell me more about that?" This acknowledges the patients' concerns and provides opportunity for them to clarify their experience

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Helpful Tips for Talking with Children

- Child life specialist
- Appropriate language for developmental age
- Begin with non-threatening topic
- Listen actively/observe non-verbal
- Ask child what he/she knows
- Give valid choices
- Respect opinions
- Allow time to plan

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Listen With Parents' Ears

What HCP Says	What the Parent Hears
Her creatinine is better.	She will get well.
She is stable today.	She is getting better.
We have an experimental treatment.	This new therapy will cure my child.
Do you want us to do CPR?	You think CPR will help.
Do you want us to "do everything" for your child?	Doing everything means you think my child will survive and get well.

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"Doing Everything"

- Means providing comprehensive care
  - ➢ Pain management
  - ➢ Symptom management
  - ➢ Addressing physical/spiritual needs

Durall et al., 2012

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Communicating With Patient/Family

- Never say:

  ➢ "There is nothing more we can do."

- Instead say:

  ➢ "If the medical and nursing teams can not cure your child, then we can help to provide care to make him/her as comfortable as possible until death."

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Conclusion

- The bedside nurse has a key role in ensuring an adequate setting for goals of care discussions during the COVID-19 pandemic while caring for pediatric patients.

- The nurse should seek to partner with Child Life Specialists and Clinical Social Workers.

- The nurse can implement evidence-based communication strategies to provide optimal emotional support for patient/families and to promote best practices.

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References

American Academy of Pediatrics. (2020). Children and COVID-19: State-level data report. Retrieved from: https://services.aap.org/en/pages/2019-novelcoronavirus-covid-19-infections/children-and-covid-19-state-level-data-report/

Berkey, F.J., Wiedemer, J.P, & Vithalani, N.D. (2018). Delivering bad or life-altering news. *American Family Physician*, 98(2), 99-104.

Center for Disease Control and Prevention. (2020). Coronavirus disease 2019 (COVID-19). Retrieved from: https://www.cdc.gov/coronavirus/2019-ncov/faq.html#COVID-19-and-Children

Cruz, A. & Zeichner, S. (2020). COVID-19 in children: initial characterization of the pediatric disease. *Pediatrics.* doi: 10.1542/peds.2020-0834

Dahlin, C., Coyne, P. & Ferrell, B. (Eds.). (2016). *Advanced Practice Palliative Nursing*. New York: Oxford University Press.

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References

Jenco, M. (2020). AAP: Limit visitors to hospitalized children during COVID-19 pandemic. Retrieved from:
https://www.aappublications.org/news/2020/07/01/covid19hospitalvisitors07

Shapiro, J., Lynne, R., Galowitz, P., Gallagher, T.H., Bell, S. (2018). Disclosure coaching: An ask-tell-ask model to support clinicians in disclosure conversations. Journal of Patient Safety. DOI: 10.1097/PTS.0000000000000491

Wittenberg, E., Ferrell, B., Goldsmith, J., Smith, T., Glajchen, M., & Handzo, T. (Eds.). (2015) Textbook of Palliative Care Communication. Oxford, UK: Oxford University Press. Retrieved 12 Aug. 2020, from
https://oxfordmedicine.com/view/10.1093/med/9780190201708.001.0001/med-9780190201708.

Wittenberg, E., Goldsmith, J.V., Ragan, S.L., & Parnell, T.A. (2020). Communication in palliative care: The COMFORT model (second edition). Oxford University Press, DOI: 10.1093/med/9780190061326.001.0001

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