Talking with Children about Death

We have a natural instinct to shield children from harm, both physical and emotional. It is likely this protective instinct that makes it so emotionally distressing to break bad news to children. We want children to feel confident that they live in a safe and stable world. The reality of everyone’s life is that the major changes that come with loss are unavoidable. Sometimes this occurs in childhood or adolescence exposing children and teens to the hardships and challenges of bereavement. When bereavement enters a child’s life they need guidance to understand the experience and grow through it.

Children are exposed to serious illness and death more often than one would think. Approximately 25% of patients with cancer in the United States have an underage child at home. 3.5% to 5% of children under the age of 18 will experience the death of a parent. Disruption of daily routine creates anxiety, confusion and fear of the future with experts reporting 25% of children experiencing the serious illness or death of a loved one having a lowered mood, sleep problems, poor concentration, difficulties at school and developmental regression.

Favorable outcomes and a positive growth experience will more likely follow an open and honest approach to communication. Avoidance of euphemisms such as “gone to sleep” or “gone on a journey” is usually best. Of course, the developmental stage of the child needs to be kept in mind since the capacity to conceive the permanency and consequences of death evolves with maturity.

Children and teens may react in manners that adults may initially find off-putting, unusual or even abnormal. The desire to return to a sense of normalcy can be perceived as ambivalence or denial. Children and teens will often grieve in stages and in their own time. Maintaining a sense of a place in the family will be important. Experts encourage including children in family responsibilities such as roles in funerals if desired by the child. Giving permission to grieve is essential. More listening than talking is the general rule when providing guidance to bereaved children and teens. They will say what is on their mind but patience is required. Listening with an open mind and heart will allow understanding and opportunity to guide and correct misconceptions. Older children and teens may feel a sense of personal responsibility for tragedy. Close listening will help discover these often hidden thoughts. Comments regarding self-harm need to be taken very seriously. Children and teens can have fantasies or thoughts of being reunited with a deceased loved one. Professional counseling may be needed. Keep in mind that children are looking at the adults in their lives as models for acceptable and expected behavior in new experiences.

REFERENCES
A Note from the Editor

Pediatric Palliative Care Experts

Can you believe it is August already? Time for the last bits of summer vacation, children returning to school and even a solar eclipse. LMHPCO’s Leadership Conference 2017 was a great success by every measure! It was exciting to hear Edo Banach, JD, CEO, NHPCO speak about his vision for hospice and palliative care within the shifting landscape of healthcare.

We were very fortunate to have two pediatric palliative care physicians sharing their expertise with us. In addition to their presentations at the conference, Dr. Richard Boyte (Forest General Hospital) and Dr. Cori Morrison (LSUHSC – Children’s Hospital) generously agreed to write an article for this month’s Journal. If you weren’t able to hear the presentations, take a few minutes to read their informative articles.

The November deadline is looming for the new Condition of Participation related to Emergency Preparedness. Be sure to take advantage of the wealth of information available on LMHPCO’s website and through Emergency Prep Specialist, Crystal Birmingham.

I’ve become a big fan of TED Talks. Here’s an interesting one that is relative to the August Journal. When Amy Green’s young son was diagnosed with a rare brain tumor, she made up a bedtime story for his siblings to teach them about cancer. What resulted was a video game, “That Dragon, Cancer,” which takes players on a journey they can’t win. In this beautiful talk about coping with loss, Green brings joy and play to tragedy. “We made a game that’s hard to play,” she says, “because the hardest moments of our lives change us more than any goal we could ever accomplish.”

https://www.ted.com/talks/amy_green_a_video_game_to_cope_with_grief

- Susan

Advance Care Planning/LaPOST Updates

Since 2010, the Louisiana Health Care Quality Forum has championed advance care planning and the Louisiana Physician Orders for Scope of Treatment (LaPOST) document with a commitment to educate health care professionals, patients and caregivers. The LaPOST website features an array of tools that are available for health care training purposes as well as information for health care consumers.

- One of the newest resources is an 11-minute video entitled, Having the Conversation. This informational program is designed to help patients, family members and caregivers discuss and document health care wishes at the end of life.
- The LaPOST initiative will host a free informational webinar for health care professionals about advance care planning and the LaPOST document. LaPOST Coalition Chair Susan Nelson, MD, will lead the session. The webinar will be offered on three different dates: Wednesday, Aug. 16 at noon; Thursday, Sept. 21 at 8 a.m. and Tuesday, Sept. 26 at 8 a.m. Health care professionals may register for the webinar by clicking here. The webinar is certified for one hour of CEU credit for social workers and Nursing Facility Administrators. Registration is limited to 150 participants per session. If you have any questions, please contact Cynthia Michael, LaPOST Project Director, at cmichael@lhcqf.org.
- You can order padded LaPOST documents (100 copies per pad) from the website free of charge and pay only shipping/handling fees. Click here for more information or to place an order.
Pediatric patients, encompassing all individuals under the age of 18, are dose-prescribing challenges for the palliative care clinician. When it comes to medications, children are not mini-adults. Often, labeled dosing recommendations do not include pediatrics and palliative care literature specific to this population is scarce. In these cases, the experience of the palliative care practitioner, specific medication properties, and patient characteristics guide the practical use of medications.

Pediatric patients have immature organ systems that affect drug disposition. The function of the kidney and liver must be considered when adjusting doses. Complete maturation of renal function is not reached until an infant is 6-8 months old. When organs are immature, medications are broken down and eliminated more slowly. To account for this, longer intervals can be used when dosing.

Pediatric patients also have different proportions of fat, body water and muscle compared to adults. In most cases, simple weight-based dosing is appropriate, but for others, recognition of water-soluble and fat-soluble medication properties must be considered. For example, the younger the patient, the higher percentage of body water and needed dose of a water soluble drug to avoid dilution. Dosing is determined on a milligram (of drug) per kilogram (of body weight) basis or by using body surface area (BSA) calculated from the patient’s height and weight. When pediatric dosing is available on a commercial product, you’ll see age group categories to help differentiate the stage of development:

- Pre-term – < 37 weeks gestation
- Neonate – newborn to one month
- Infant – one to 12 months
- Toddler – 12 to 36 months
- Child – 3 to <12 years
- Adolescent – 12 to <18 years

Regardless of recommendations, a pediatric dose should never exceed the maximum adult dose. Remember to use proper dosing devices when measuring liquid doses. Kitchen teaspoons and tablespoons do NOT measure accurately. Utilize calibrated measuring cups, droppers and oral syringes provided or ask for additional supplies. Also, remember that compliance is influenced by the taste and appearance of the medication and its ease of administration. Work with your pharmacist to prepare the most palatable formulation. Being prepared with the age, height and weight are key for preventing medication errors and will provide the pharmacist needed information to determine dosing appropriateness.

References:
Death is a challenging topic to discuss at anytime but especially when it applies to children. It becomes difficult for anyone to imagine a child not flourishing into adulthood. As a result, the support provided to a child or young adult and their family through end-of-life care poses additional barriers. The core issues underlying these barriers may stem from the patient, parent/guardian and healthcare providers.

The pediatric community also faces commonalities with adult palliative care providers as it relates to acceptance of palliative care support, timing of the team’s involvement in the care of the patient and understanding the totality of what the team can offer. Palliative care is often thought of as only hospice support therefore assisting with the dying process. These issues hinder the growth of a palliative care service and underscore the continual need for education.

Some of the additional barriers as mentioned above comprise dynamics of the relationship between the patient and their parents, the relationship the parents have with each other and the relationship between the patient, family and healthcare providers. Examples of these barriers include:

- Balancing patient autonomy of teenagers in treatment decisions and end-of-life care with parent/guardian medical authority.
- Recognizing that parents who have decision-making capacity for their child may be in conflict with each other regarding treatment plans.
- Acceptance shown by parents in acknowledging the idea that there will be unrealized dreams that they desired for their child.
- Navigating through the changes in expectations and goals of care during a chronic or life-threatening illness.

Steps toward overcoming these challenges often begin with healthcare providers understanding the depth of services provided by the palliative care team. It involves the realization that the psychosocial and spiritual well-being of the patient and their family are vital components of their medical care.

There needs to be an understanding that end-of-life care is only a fraction of the resources palliative care encompasses. The supportive resources are best utilized when implemented at the beginning of a diagnosis (National Consensus Project for Quality Palliative Care, 2013). This allows time to foster a trusting relationship with the patient and their family.

During the journey in palliative care, quality of life is at the forefront. The team continues to be a source of support throughout all treatment trajectories for those with a life-threatening or chronic illness (AAP, Committee on Bioethics and Committee on Hospital Care, 2000). There are opportunities to aid in bridging communication amongst a multidisciplinary team. There is also focus on offering provider support as all team members can experience compassion fatigue.

As providers, we must begin to examine our own personal judgments as it relates to palliative and end-of-life care issues, recognize the importance of defining patient and caregiver’s expectations and enhance communication about “Quality of Death” when that time arises. These steps will hopefully begin to pave the way for all children who are in need of palliative care services to receive this invaluable resource.
Conference Recap

Pelican Club dinner
Conference Recap

LMHPCO Act of Kindness Award recipients Dr Jack & Nancy Dunn

LMHPCO Act of Kindness Award recipient Carla Hughes

Heart of Hospice recipients with their guests

Correctional scholarship recipients from Elayn Hunt Correctional

Color Guard
Dear Members,

We would like to ask each of you to do something you may never have done before. Something that we believe will be a huge benefit to your agency, as well as our industry. We are asking you to write an opinion-editorial about hospice and the service we provide in your local newspaper.

After many years of working for the association as lobbyist, we are still amazed at how LITTLE most people know about hospice and many of the misconceptions that still exist. To be better advocates for the industry, we must take a more public stance in telling our story.

Here is what I would like you to include:
1 - a story about a patient or a quote from their family about the love hospice brings into the final days of our patients lives  
2 - what unique services hospice provides  
3 - what hospice is NOT (giving up, pill mill, etc.)

http://www.mspress.org/  
http://www.lapress.com

The above link will be helpful in locating your personal newspaper or feel free to contact us directly if you need further instruction.

MISSISSIPPI  
John Morgan Hughes  601.672.4988
Elizabeth Harper  225.287.4020

LOUISIANA  
John Morgan Hughes  601.672.4988
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Now let’s go tell OUR hospice story!
The Louisiana-Mississippi Hospice and Palliative Care Organization is a 501(c)3 non-profit organization governed by a board of directors representing all member hospice programs. It is funded by membership dues, grants, tax-deductible donations and revenues generated by educational activities. LMHPCO exists to ensure the continued development of hospice and palliative care services in Louisiana and Mississippi. LMHPCO provides public awareness, education, research, and technical assistance regarding end-of-life care, as well as advocacy for terminally ill and bereaved persons, striving to continually improve the quality of end-of-life care in Louisiana and Mississippi.

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