

# Providing Perinatal Palliative Care with Compassion, Care and Confidence

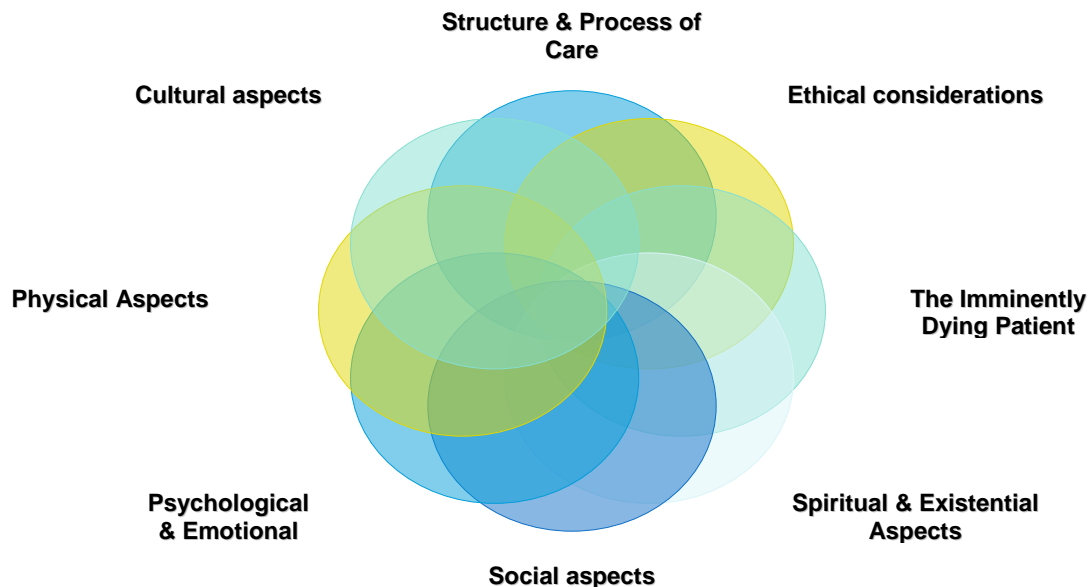
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## *Communicating with Compassion, Care and Confidence*

### GOALS

#### I. Identify the major domains of palliative care



- A. Realize how integral to all domains effective communication is – long before caring for the imminently dying patient
- B. Essential characteristics of effective communication with families.
  - a. VALUE system (Curtis, et al. NEJM, 2007)
    - Valuing & appreciating what families communicate
    - Acknowledging their emotions (reflection & summation)
    - Listening to families
    - Understanding who the patient is – a person
    - Eliciting questions from families effectively
  - b. Collaborative communication (Feudtner, *Pediatr Clin NA*, 2007)
    - Establishing a common goal or set of goals that guide our collaborative efforts.
    - Exhibiting mutual respect and compassion for each other.
    - Developing a sufficiently complete understanding of our differing perspectives.
    - Assuring maximum clarity and correctness of what we communicate to each other.
    - Managing intrapersonal and interpersonal processes that affect how we send, receive, and process information.

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**TABLE 1 Physician “Competencies” for Health Care Communication**

1. Develop a partnership with the patient
2. Establish or review the patient’s preferences for information
3. Establish or review the patient’s preferences for his or her role in decision making
4. Ascertain and respond to the patient’s ideas, concerns, and expectations
5. Identify choices (including those suggested by the patient) and evaluate research in relation to the individual patient
6. Present information and assist the patient to reflect on the impact of alternate decisions with regard to his or her lifestyle and values
7. Negotiate a decision with the patient
8. Agree on an action plan and complete arrangements for follow-up

**TABLE 2 Recommended Communication Behaviors for Procedural Interventions**

- Find a private setting for discussion and decision making
- Use language the family can understand
- Use visual aids (drawings, models, and radiographs)
- Pace the information, providing it in a logical sequence; be prepared to patiently repeat information and answer questions
- Recognize emotional distress
- Discuss indications, risks, benefits, and all reasonable alternatives (including not doing the procedure at all) and the associated risks and benefits
- Discuss specific tubes and drains immediately before surgery
- Personalize the information rather than giving it as a rote speech (eg, use the child’s name)
- Avoid last-minute surprises when feasible
- Ask parents and the child (when appropriate) to repeat what they understood in their own words, and clarify information and plans as needed

**TABLE 3 Strategies to Engage Children in the Outpatient Setting**

- Speak with the child; not at or to him or her
- Speak in a private setting
- Determine whom the child would like to be present (younger children will generally prefer parents to be present; children who have been abused by family members may need privacy to facilitate disclosure; most adolescents prefer privacy)
- Begin with a nonthreatening topic
- Listen actively
- Pay attention to body language and tone of voice
- Use drawings, games, or other creative communication tools
- Elicit fears and concerns by reference to self or a third party
- Ask the child what he or she would do with 3 wishes or a magic wand

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**TABLE 4 Prompts to Elicit Medically Relevant, Culturally Important Information**

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What concerns prompted you to bring your child (use the child's name) for health care?  
What behaviors and symptoms are of greatest concern to you?  
What do you think caused this problem?  
How do you think the illness affects your child?  
What have you tried to do to make the illness better? Have you tried any traditional remedies?  
Are there any specific dietary, religious, or cultural practices that need to be accommodated?

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**TABLE 5 Suggestions for "Breaking Bad News" With Skill and Empathy**

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Do not disclose bad news over the telephone  
Use trained translators as needed  
Avoid telling a lone parent without his or her spouse and/or a preferred support person present  
Enable the parents to touch the deceased child before or during the interview  
Hold or touch the child with obvious care  
Recognize that parents are primarily responsible for their child  
Show caring, compassion, and a sense of connection to the patient and the family  
Pace the discussion to the parents' emotional state; do not overwhelm them with information  
Do not use jargon  
Elicit parents' ideas of the cause of the problem; ensure they do not blame themselves or others  
Name the illness and write it down for the parents  
Ask the parents to use their own words to explain what you have just told them to confirm effective transmission of information  
Address the implications for the child's future  
Acknowledge their emotions and be prepared for tears and a need for time; it is helpful to bring a social worker and/or chaplain to the meeting  
Be willing to show your own emotion; aloofness or detachment is offensive  
Give parents time to be alone to absorb the information, react, and formulate additional questions  
Be able to recommend relevant community-based resources  
Provide contacts with other willing families with a similarly affected child  
Provide a follow-up plan and make an appointment for the next conversation

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**Levetown, AAP, 2008**

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**TABLE 6 Family Centered Communication and Support in the ICU**

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Early (within 24–48 hours of admission) and frequent communication
Indication that the health care team cares for the child as an individual
Practitioners trained in meeting facilitation and conflict management
The use of open-ended questions and reflective explanation
Hopeful but honest and clear communication; acknowledgment of uncertainty
Discussion of likely and hoped-for outcomes
Use of numeric terms when describing probabilities; use of drawings and models
Provide timeframes for improvement and future discussion
Participation of families in clinical bedside rounds, caregiving for their child and ability to stay with their child during invasive procedures
Listen to and involve the nurse, chaplain, and social worker in the information loop
Open visitation, including sibling and pet visitation
Consistent caregivers; if this is not possible, ensure consistency of the message
Prompt informing of parents of transitions, such as a change of location, condition, treatment plan, assignment of attending physician or residents
Shared decision making rather than autonomy; encourage the parents to involve their family, friends, and medical home pediatrician to help them to understand information and make decisions
Written, audiotaped, and computerized education for families (see <a href="http://www.icu-usa.com">www.icu-usa.com</a> )
Discussion and support of coping mechanisms, including religious and spiritual values
Initiation of palliative care at the time of admission

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**TABLE 7 Coping Strategies of Parents of Critically Ill and Injured Children<sup>16</sup>**

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Focus on the positive (hope)
Minimize the significance of the information
Preoccupation with medical details
Support from family, friends, and clergy
Religious faith
Hostility, depression, irritability

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**Levetown, AAP, 2008**

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## II. Determine feasible measures to improve care for dying newborns, infants and children - and their families

- a. Identify barriers to effective communication...time, environment, knowledge/skills, internal v external, confidence/competence?
- b. Evaluate the research and evidence base on effective communication:
  - i. Hsiao, et al. *Pall Support Care*, 2007:
    1. Relationship building skill
    2. Demonstration of effort & competence
    3. Process of information exchange
    4. Availability
    5. Appropriate level of child & parent involvement
    6. Coordination of care
  - ii. Williams, et al *Pediatrics* 2009;123:e87-95

**TABLE 3** Ways in Which HCWs Most and Least Effectively Support Parents Facing WLST in the NICU

Statement (Domain)	Median (Range)
<b>Most effective</b>	
HCWs officially recognize the child's existence (BC)	7.0 (5.0–7.0)
HCWs provide parents with a grief package (BC)	7.0 (4.0–7.0)
Parents are given specific keepsakes (eg, photo) (WP)	7.0 (4.0–7.0)
HCWs encourage parents to hold their child when he or she dies (WP)	7.0 (4.0–7.0)
The child is treated with dignity during WLST (WP)	7.0 (4.0–7.0)
WLST is done with compassion (WP)	7.0 (4.0–7.0)
Parents have adequate time with their child before WLST (WP)	6.5 (4.0–7.0)
Parents are encouraged to ask questions (C)	6.5 (5.0–7.0)
<b>Least effective</b>	
Government agencies are made aware of the child's death to ensure that inappropriate reminders do not occur (eg, follow-up vaccinations) (BC)	4.0 (1.0–7.0)
HCWs provide specific counseling in dealing with sibling grief (BC)	4.0 (2.0–7.0)
Autopsy results are sent to both parents and their family physician (BC)	4.0 (1.0–7.0)
Parents are offered a prompt discussion regarding autopsy results (BC)	4.0 (2.0–7.0)
HCWs respect when parents do not want to make a decision (SDM)	4.5 (1.0–6.0)

Most effectively: median score  $\geq 6.5$  of 7; least effectively: median  $\leq 4.5$  of 7. HCW indicates health care worker; BC, bereavement care; WP, WLST process; C, communication; SDM, shared decision-making.

**Conclusion (Williams):** "Respondents identified that parents' practical needs were met during the withdrawal process but were not consistently met in regard to the quality of in-hospital and follow-up bereavement care."

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- iii. Jones, et al. *Patient Educ Counsel* 2007;69:202
  - 1. Measure of nurse-parent communication in NICU
  - 2. Is it accommodative? Under-accommodative? Or, over-accommodative?
    - a. Interpretability
    - b. Discourse management
    - c. Interpersonal control
    - d. Emotional expression
    - e. Positive face
    - f. Negative face

“Parents regarded nurse communication as more effective when nurses made the interaction more equal (vs. emphasizing intergroup or interpersonal differences), where nurses adapt to the behavior or conversational needs of parents. The most frequently mentioned strategies for effective communication were discourse management and emotional expression, highlighting the importance for parents of communication that is both nurturing and shares the exchange of information. Parents valued communication that was two-way and involved informal chatting as well as more formal discussions. The importance of the relational aspects of communication cannot be underestimated. Such communication considers the emotional impact on parents of the communication.”

- iv. Lamiani, et al. *J Perinatol* 2009;29:1-7
  - 1. Enacted conversations in NICU (role play)
  - 2. Evaluated contribution of interdisciplinary team members (20 MD, 22 RN, 6 SW, 2 Chaplain).

“Reflecting their characteristic role as the bearer of difficult news, physicians generally talked the most in conversations, offering primarily biomedical information.”

“Nurses’ communication style bridged the medical and the psychosocial worlds as their communicative contributions differed neither from those of physicians in providing biomedical information, nor from those of social workers and chaplains in providing psychosocial information and engaging families in social talk. Nurses played an important part in providing parents information about treatment and procedures and offering psychosocial information and counseling, thus representing a knowledgeable resource for parents. Nurses’ communicative style...including formal information, emotional support as well as social talk, has been identified by parents as characterizing good interactions with nurses.”

“Compared to the other practitioners, social workers and chaplains asked more psychosocial questions, sought more family opinion and understanding, and more frequently expressed agreement and approval. This finding is especially meaningful because integration of psychosocial aspects of care and the opportunity for parents to express their opinion and understand information have been highly valued by parents. Wolfe reported that the inclusion of psychosocial professionals in pediatric oncology family meetings was associated with greater concordance in the timing of physicians’ and parents’ understanding that the child had no realistic chance for cure, and also with greater integration of palliative care.”

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## What about Hope?

*Table 2. Coding Framework and Quotes: Should Physicians Withhold Prognostic Information to Maintain Hope?*

Theme	Description	Quoted Example
Preparing for the future, emotionally and logistically	Families used information to start coming to terms with the patient's condition and start the logistical preparation for death.	"I think that people cope better from a standpoint of knowledge. If there's going to be bad news, they have to learn it sometimes, they might as well begin preparing themselves for it." "And we should know whether we're in it for a long haul or a short haul, because then we can manage our lives differently. We can schedule and we can support our family and call in different resources."
Supporting the patient and family	Prognostic information allows the family to choose to act differently (be present at bedside more, pray more or differently).	"Depending on what is going on with him, I can try to focus positive energy on those specific things. . . . I personally believe in the power of positive thought putting positive energy into the universe. . . . All knowledge is better than no knowledge, for me." "Oh [sigh] because I think I would rather hear the truth and see where I'm standing at, and, you know, and prepare myself emotionally for whatever's going to come. So I can be more supportive to my mother or my sisters."
Aversion to false hope	Families feel that fostering false hope is wrong.	"Well, if there's no hope, I think that to encourage the family's hope would be wrong, because then it comes as a real shock, if something does go wrong." "Doctors should just be honest. You know, it's hard enough, like, going through all this. And if we are steered in the wrong direction or given false hope, then it's just gonna set us up for more hardship, in the long run."
Physicians' obligation to discuss prognosis	Families view disclosing prognosis as a central duty of physicians.	"Also, I think it's a matter of respect and I wouldn't want a doctor assuming that I couldn't handle something or that I wouldn't understand something. That's demeaning to me. So, I think it's a matter of honor and respect." "Because it's their responsibility. That's the role they play in becoming a doctor." "I think their job is to tell us, based on medicine, the truth about what they think."
Outside sources of hope	Families find hope outside of what is offered by the physician.	"And hope? Doctors don't give hope. Do you know what I mean? I don't believe that that's what they're here to do. I think that they're here to do their job and do things the best that they can, but hope comes from somewhere else, I think." "My hope is not based on what doctors tell me, it's based on how I feel as a person, my spiritual beliefs, my . . . you know, how my family and I interact with each other and hold each other up and whatever."
Importance of how prognosis is discussed	Families feel that physicians should avoid expressing absolute certainty while delivering prognosis.	"I intensely resent when doctors say, 'Well, he's only got so long to live.' How do they know? Are they gonna kill him?" "I think it would always be good for the doctor to end with, 'But, you know, anything's still possible.'"

**Apatira, et al. *Ann Intern Med* 2008;149:861**

- c. Outline educational objectives to address effective communication among all staff, patients and families
  - i. What you can do:
  - ii. What you need help with:
  - iii. What others can do:
  - iv. What everyone in your unit needs help with:
  - v. What the hospital can help with:
  - vi. What parents say:
  - vii. What parents need:

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