EPA 3: Demonstrate Competence in Communicating a New Diagnosis of a Life-Altering Disease Using a Patient and Family Centered Approach

Supervision Scale for This EPA

1. Trusted to observe only
2. Trusted to execute with direct supervision and coaching
3. Trusted to execute with indirect supervision and discussion of information for most simple and some complex cases
4. Trusted to execute with indirect supervision but may require discussion of information for a few complex cases
5. Trusted to execute without supervision

Description of the Activity

Pediatric pulmonologists are often responsible for introducing a new diagnosis of a serious disorder. Scope of practice for this EPA includes the child and family that has recently been diagnosed with an acute or chronic life altering disease. An example for pediatric pulmonology would be the new diagnosis of cystic fibrosis made through newborn screening. The pediatric pulmonary subspecialist must have the knowledge and skills needed for the comprehensive initial discussion and the initiation of a long-term management plan.

The specific functions which define this EPA include:

1. Demonstrating knowledge of the disease, common course of illness, and management/treatment of the disease by delivering details about the disease in a clear and comprehensive manner
2. Establishing rapport and initiating a therapeutic alliance with newly diagnosed patients and their families by recognizing the importance of verbal and nonverbal cues and managing the emotional and human response to the difficult news
3. Engaging patients and families in shared decision making to develop a care plan that meets their medical and psychosocial needs
4. Demonstrating the self-confidence needed to deliver bad news and support the emotional response of the patient and family

Judicious Mapping to Domains of Competence

- Patient Care
- Medical Knowledge
- Practice-Based Learning and Improvement
- Interpersonal and Communication Skills
- Professionalism
- Systems-Based Practice
- Personal and Professional Development
Competencies Within Each Domain Critical to Entrustment Decisions

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Context for the EPA

**Rationale:** Pediatric pulmonologists must be able to provide all aspects of care following the diagnosis of a serious, life-altering disease. This includes an understanding of the diagnosis, implications for immediate intervention, and the development of a management and treatment plan. The physician must have the ability to empathetically convey information regarding the diagnosis to the patient and family and be able to do it in a way that allows best understanding and comprehension and subsequently involve them as a member of the team who is engaged in shared decision-making.

**Scope of Practice:** The care of the patient with a life-altering disease begins when the physician is made aware of the diagnosis and begins to prepare to meet with the patient and family. The therapeutic relationship begins with this first meeting of the patient and family and may continue for several meetings depending on the complexity of the diagnosis and the health literacy of the caregivers. For the scope of this document, this care will continue until the initial care plan has been created and implemented and the family begins the process of chronic disease management.

Curricular Components That Support the Functions of the EPA

1. Demonstrating knowledge of the basics of the diagnosis of the disease, common course of the disease, and management/treatment of the disease
   - Knows the current guidelines for care regarding the diagnosis, management, and treatment of newly diagnosed disease
   - Interprets the required diagnostic testing related to diagnosis and management
   - Recognizes the usual disease course and possible complications

2. Establishing rapport and initiating a therapeutic alliance with newly diagnosed patients and their families
   - Recognizes and acknowledges the importance of the interprofessional team in the care of the patient
   - Assesses the current knowledge of the disease, health literacy of the family, as well as previous health experiences
   - Solicits multidisciplinary team input into the care plan for the patient
   - Communicates with the primary care physician about current and future plans for the patient

3. Engaging the patient and family in shared decision making to develop a care plan that meets their medical and psychosocial needs
• Introduces the concept of interprofessional team care with explicit focus on the central role of the patient/family on the team
• Discusses and considers the home environment and readiness/ability of the family to provide care for the patient
• Distributes educational material to the family to assist in understanding disease, the care plan, and anticipated future issues

Demonstrating insight into the emotional and human response to difficult news and manages those responses

• Recognizes the importance of verbal and nonverbal bidirectional cues in communication and responds accordingly
• Gauges the families understanding with verbal and nonverbal cues (emotional intelligence) and adjusts communication to meet their needs
• Demonstrates empathy with the current and future concerns of the family
• Delivers only the information that the family can understand based on their current emotional state
• Invites questions and concerns from the patient and family
• Establishes a contact plan for the family for future concerns or questions

4. Demonstrating the self-confidence needed to deliver bad news and support the emotional response of the patient and family

• Demonstrates insight into one’s personal emotions regarding the diagnosis and process of giving bad news
• Anticipates anxiety that accompanies uncertainty and prepares information to address what is known about an illness, with a plan to continually update patients/families as new knowledge emerges
• Utilizes a communication plan that balances delivery of diagnosis with hope, information, and exploration of patient goals

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