EPA 2: Provide Continuity of Care for Adolescent and Young Adult Patients with Chronic Medical Problems and Complex Health Conditions

Supervision Scale for This EPA

1. Trusted to observe only
2. Trusted to provide and coordinate care with direct supervision and coaching
3. Trusted to provide and coordinate care with indirect supervision for most simple and some complex cases
4. Trusted to provide and coordinate care with indirect supervision but may require discussion of case details and care coordination for a few complex cases
5. Trusted to provide and coordinate care without supervision

Description of the Activity

Although a relatively healthy group, many adolescents and young adults have chronic and/or complex medical, mental health, or developmental issues that persist from childhood or present during adolescence (such as eating disorders; abnormalities in growth and development; reproductive, gynecologic, and sexual health issues; substance abuse; musculoskeletal problems; behavioral and mental health issues; obesity; and other special health care needs). The assessment and long-term management of many of these conditions lend themselves to interdisciplinary care models that include care of the teen or young adult along with the family. Specialists need to incorporate into care models patient-centered approaches that respect confidentiality and facilitate communication with adolescents and young adults.

The specific functions which define this EPA include:

1. Developing knowledge of chronic physical and mental health conditions specific to adolescents and young adults, their etiologies, and the guidelines and standards of care for evaluation and management of these conditions
2. Monitoring and providing appropriate follow up for adolescents and young adults with chronic health conditions and their families, as appropriate, and addressing factors that impact quality of life (e.g., mental health, physical functioning, and support)
3. Developing skills in working in interdisciplinary team settings, recognizing the roles and expertise of each discipline and being able to facilitate communication and coordination within treatment teams and across different specialty teams
4. Demonstrating patient-centered, culturally competent approaches in the delivery of health care to adolescents and young adults with special health care needs or chronic conditions, respecting patient autonomy, shared decision making, and confidentiality, and involving families, as appropriate

Judicious Mapping to Domains of Competence

_X_ Patient Care
_X_ Medical Knowledge
___ Practice-Based Learning and Improvement
Entrustable Professional Activities
EPA 2 for Adolescent Medicine

- Interpersonal and Communication Skills
- Professionalism
- Systems-Based Practice
- Personal and Professional Development

Competencies Within Each Domain Critical to Entrustment Decisions

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<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>PC 2:</td>
<td>Organizing prioritizing responsibilities</td>
</tr>
<tr>
<td>PC 4:</td>
<td>Interviewing patients</td>
</tr>
<tr>
<td>PC 7:</td>
<td>Developing management plans</td>
</tr>
<tr>
<td>MK 2:</td>
<td>Practicing EBM</td>
</tr>
<tr>
<td>ICS 1:</td>
<td>Communicating with patients/families</td>
</tr>
<tr>
<td>ICS 3:</td>
<td>Communicating with health professionals</td>
</tr>
<tr>
<td>SBP 2:</td>
<td>Coordinating care</td>
</tr>
<tr>
<td>SBP 3:</td>
<td>Incorporating cost awareness into care</td>
</tr>
</tbody>
</table>

Context for the EPA

Rationale: Adolescent Medicine specialists must be able to coordinate the care of complex and chronic medical conditions of childhood that persist into the adolescent years and identify and then manage those conditions that present in adolescence. Understanding when confidentiality can be maintained while still providing a culturally sensitive and unified care approach with family is critical. Additionally, knowing when confidentiality must be broken for the safety of the adolescent is important. Navigating care with an interprofessional and/or multidisciplinary team is essential in the care of these adolescents/young adults.

Scope of Practice: The scope of practice will vary by clinical context. Specialists in Adolescent Medicine should be comfortable managing, coordinating the interprofessional and multidisciplinary teams, and/or being an identified specialist for most, if not all, of the following: eating disorders, obesity, and reproductive health, including menstrual disorders, genitourinary problems, chronic pain and/or fatigue, substance abuse disorders, HIV, organ-specific chronic disease states, and disorders of cognition, learning, attention, mood, and education. Comorbidity is common. The Adolescent Medicine specialist may be the key member of a team assessing pubertal development, fertility (and impacts of therapy on fertility), bone health, contraception and STDs, indications for genetic testing, and patient-centered, literacy level appropriate education.

Curricular Components That Support the Functions of the EPA

1. Developing knowledge of chronic physical and mental health conditions specific to adolescents and young adults, their etiologies, and the guidelines and standards of care for evaluation and management of these conditions

   - While not all training sites serve populations with each of the following conditions, trainees should demonstrate key knowledge of the pathophysiology of each condition and the evidence-based evaluation, care coordination, and personalized management of:
• Eating Disorders, per DSM 5, including anorexia nervosa, bulimia, binge eating disorder, Avoidant/Restrictive Food Intake Disorder [ARFID]
• Obesity
• Menstrual disorders (amenorrhea, oligomenorrhea, abnormal uterine bleeding, dysmenorrhea, polycystic ovary syndrome [PCOS], primary ovarian insufficiency [POI]), and other gynecologic conditions such as endometriosis and ovarian cysts
• Chronic pain and/or fatigue, including abdominal pain, fibromyalgia, and back pain
• Substance abuse disorder
• Disorders of cognition, learning, attention, and education (ADHD, learning disabilities)
• Depression and other mood disorders
• Anxiety disorders
• Acne, atopic dermatitis, and other chronic dermatologic disorders
• Transgender health and disorders of sexual development
• Bone health

• Describe the complex care coordination and monitoring for adolescents with:

  • Chronic immunologic or infectious disorders such as HIV/AIDS
  • Chronic pulmonary disorders such as cystic fibrosis and asthma
  • Cancer and morbidities in long-term survivorship
  • Chromosomal disorders such as Down, Turner, Klinefelter Syndromes and/or neurocutaneous disorders and/or intellectual disabilities
  • Chronic gastrointestinal diseases such as inflammatory bowel disease, irritable bowel syndrome, celiac disease, and liver diseases
  • Rheumatologic disease (JRI, lupus, scleroderma)
  • Hematologic disease (chronic anemia, thrombocytopenia, thrombophilias, hemoglobinopathies, bleeding disorders)
  • Endocrinopathies (type 1 and type 2 diabetes, thyroid disease, pan-hypopituitarism, adrenal insufficiency)
  • Cardiovascular diseases (congenital heart disease, hypertension, hyperlipidemia, dysrhythmias, Marfan syndrome, syncope)
  • Neurologic disorders including migraine headache and neuromuscular disorders
  • Chronic Renal insufficiency

2. Monitoring disease activity and adherence and providing appropriate follow up for adolescents and young adults with chronic health conditions and their families, as appropriate, and addressing factors that impact quality of life (e.g., mental health, physical functioning, and support)

  • Decides how frequently adolescents/young adults with chronic health conditions need follow up (based on activity of disease process, adherence to treatment plan, and need for support) with each member of their care team and for which issues (specialty care versus primary care; physical health versus mental health). Be a part of the process to facilitate appropriate follow-up care
  • Interprets laboratory values such as lipid testing, mononucleosis testing, HIV testing, Pap testing
  • Routinely assesses level of functioning in all spheres of a patient’s life (self-care, family interactions, social engagement, school attendance and performance, work)
• Understands the viewpoint of the patient and caregiver/guardian/family regarding the patient’s health status and quality of life and their “feeling connected” to supportive health professionals and family/peers

3. Developing skills in working in interdisciplinary team settings, recognizing the roles and expertise of each discipline and being able to facilitate communication and coordination within treatment teams and across different specialty teams

• Identifies treatment team members including the medical, mental health, school, sports, and home communities
• Demonstrates understanding of HIPAA and Family Educational Rights and Privacy Act (FERPA) rules and hospital policies regarding secure and appropriate communications between treatment team members
• Initiates and maintains close communication with the treatment team to direct high-quality care for adolescents/young adults with chronic illness
• Communicates with team members in a timely and professional manner
• Documents care coordination adequately to support complexity of medical decision making and maintains a comprehensive medical record
• Ensures patient-centered and, as appropriate, family-centered, approaches to agree on treatment goals and plans and to enhance adherence and follow-up

4. Demonstrating patient-centered, culturally competent approaches in the delivery of health care to adolescents and young adults with special health care needs or chronic conditions, respecting patient autonomy, shared decision making, and confidentiality, and involving families, as appropriate

• Understands that culture is a blend of multiple factors, including gender, race, ethnicity, language, religion, sexual orientation, class, socioeconomic status (SES), and education, and that cultural practices, beliefs, and norms can promote or interfere with healing
• Practices culturally sensitive medical care and identifies implicit bias that may shape responses of team members, patients and families
• Reviews the state-specific limits of confidentiality with all patients and caregivers/guardians/families as is appropriate for a given patient’s cognitive ability
• Assesses the use of patient portals and the confidential and nonconfidential documents and lab/procedure reports that are available to adolescents (13 to <18 years versus 18 years and above) and to parents. Makes plans to address confidentiality issues that require advocacy

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The Adolescent EPAs were developed by consensus with adolescent provider representatives from the AAP, SAHM, CoPS, and the ABP.

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