Adolescents and Young Adults with Life-Threatening Illness

Special Considerations, Transitions in Care, and the Role of Pediatric Palliative Care

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KEYWORDS

- Pediatrics • Young adults • Adolescents • Palliative care • Transition of care
- Life-threatening illnesses

KEY POINTS

- Medical advancements have led to an increased prevalence of children with life-threatening illnesses who are also surviving longer.
- Adolescents and young adults (AYAs)with life-threatening illness experience unique vulnerabilities, complex health concerns, and, unfortunately, barriers to assessing health care.
- Many pediatric and adolescent patients with life-threatening illnesses age into adult care; thus, it is recommended that pediatric palliative care teams make timely transitions of care to appropriate young adult or adult services.
- Owing to the parent/family and patient attachment to pediatric providers, there may be feelings of reluctance and fear to leave behind health care providers who may have cared for years.
- Training can be 1 avenue for increasing providers' comfort in working with AYAs with life-threatening illnesses.

INTRODUCTION

Adolescents and young adults (AYAs) represent a distinctive group of young people who are either experiencing, or have recently experienced a period of accelerated growth and change that bridges the complex transition from childhood to adulthood.

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It is often an unsettling period characterized by rapid hormonal changes, physical maturation, and cognitive and emotional development. The patterns of behavior AYAs adopt during this time may have long-term consequences for their health and quality of life. When the challenges that accompany a life-threatening illness are added to this already tumultuous developmental stage, the problem of transitioning from pediatric medical homes to adult medical homes becomes even more crucial. AYAs with life-threatening illness experience unique vulnerabilities, complex health concerns, and, unfortunately, barriers to accessing health care. For them, the process of transitioning from a pediatric medical home to an adult medical home is increasingly complex. The transition of AYAs with life-threatening illnesses is fraught with difficulties, and in some cases these difficulties lead to increased mortality during the transition period.[1–4] This mortality is linked to a poor transition process. At the time of transition, patients struggle to form a relationship with members of their new medical home. Meanwhile, care plans and routine surveillance are disrupted by the lack of bridging communication from 1 medical home to the next.

In order to understand the scope of the nuances and challenges that come with caring for AYAs with life-threatening illness, it is important to begin with the parameters that define this group and the transition of health care. The Centers for Disease Control and Prevention (CDC) and the World Health Organization define adolescents as young people between the ages of 10 and 19 years. The CDC takes a step further and defines young adults as ages 20 to 24 years. Yet, professionals within oncology state that this age group actually includes individuals up to 39 years of age.[5,6] With these ambiguities in the parameters that delineate this group of patients, the challenges that come with caring for them become clearer, especially with regard to transitioning their health care. Taking these definitions together, caring for AYAs with life-threatening illness consists of caring for a patient population that spans nearly 3 decades.

Transition of health care, has been defined as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.”[7] When caring for a patient population that spans 3 decades, the problem of transitioning their care can seem insurmountable. AYAs with life-threatening illness have unique developmental and psychosocial considerations. Often caught between pediatrics and adult medicine, they have specific needs for support, communication, and involvement with their care that is rooted in their developmental, cognitive, and psychosocial needs.[8]

Currently the medical community does not have either a defined method, or a systematic way to care for this patient population. Learning the developmental considerations and psychosocial needs and understanding the tools to transition to adult medical homes may help create such a system. Other considerations to help transition in this care period include introducing team members who are skilled in caring for children and young adults with life-limiting illness. The palliative care team may be especially useful in ensuring smooth transitions.

DEVELOPMENTAL CONSIDERATIONS

According to the American Academy of Pediatrics (AAP), palliative care for children, adolescents, and young adults should be patient centered and family engaged, offering a respectful partnership that is concerned about quality, access, and equity.[9] Specifically, the AAP recommends that the pediatric palliative care (PPC) team be committed to offering care across the age spectrum and life span. As many pediatric and adolescent patients with life-threatening conditions age into adult care, the AAP recommends that the PPC team make timely transitions of care to appropriate young