

The Adolescent Transplant Recipient

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KEYWORDS

• Adolescent • Transplant • Adherence

Adolescents constitute a significant proportion of pediatric transplant patients, whether they have survived a transplant in early childhood (like most heart and liver recipients) or are transplanted in older childhood or adolescence, such as many renal transplant recipients. Their needs can be significantly different from either children or adults, as they are undergoing a major transformation that involves making educational and vocational decisions and commitments, establishing a new and more equal relationship with their parents, discovering their sexual identity, taking increasing responsibility for their health and creating the moral, philosophic, and ethical perspective that they will carry through their lives. Research addressing adolescence and transplantation should be an important focus in the future. Adolescent issues identified as research foci at a 2003 pediatric transplant consensus conference include adolescent graft survival, growth and the pubertal hormonal axis, quality of life, adherence, and alterations in drug metabolism.¹ This article discusses adolescent issues in transplantation.

THE ADOLESCENT INTERVIEW

Talking with adolescents does not have to be difficult nor particularly time consuming. To lay the groundwork, a discussion of confidentiality and its limits will make it clear what can be kept private and what cannot. This varies between jurisdictions, but

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confidentiality should not be promised for situations of suicide or homicide risk. Abuse must be reported (again, at varying ages) in most places. When discussing confidentiality, bring up any differences between what you will tell parents, what you will share with the team and what must be charted.

The HEADS acronym has been used to remind the clinician what to discuss. This originally stood for Home, Education, Activities, Drugs and Sex. Over the years other letters have been added: A for affect, D for depression, or S for suicidality; D for diet; S for safety.² The authors would also add A for adherence. Questions should be asked in a nonjudgmental fashion and some need to be fairly specific (“What were your grades on your last report card?” as opposed to “How is school?”). Questions about sexuality should use nongendered language (“Are you romantically interested in anyone?” as opposed to “Do you have a boyfriend?”). Younger adolescents tend to be concrete thinkers (see later discussion) and language should be nonambiguous.

ADOLESCENT DEVELOPMENT

Young people with solid organ transplants are young people first and foremost. Knowledge and expertise in addressing their developmental needs are important for all professionals involved in their care. There is a myth that teens see themselves as immortal and invulnerable but early adolescence is a time when many teens think about death and its permanency. As cognitive ability, knowledge of the world, physical prowess, and communication skills increase, adolescents desire and require increasing autonomy. Children learn what limits they should set for themselves by trying things out (and making mistakes) and by observing the limits that have been placed on them.

Cognitive Development

Although some adults with normal intelligence do not acquire significant abstract thinking skills, most teenagers move from concrete to sophisticated abstract thinking. Concrete thinkers do not see a spectrum of possibilities; things are black or white. As their reality shifts, they see today’s truth as the only one, often surprising health care professionals as they espouse opposite views on sequential visits. This makes it difficult for providers to predict future behavior from current statements. Concrete thinkers have difficulty in deducing rules from their experiences, as each experience seems unique. They can be adherent as long as their situation remains constant, but when decisions have to be made, adherence is more challenging. For example, an adolescent may take his morning medication without reminder, but if he sleeps in, he might not take it as he has missed the appointed time. Difficulties can also arise when literal interpretations of health care advice are incorrect.³

Adolescent brain development is an active process, finishing in the third decade of life.⁴ There is no literature on brain development in transplant recipients or in others with growth or pubertal delay. Executive functions, the last to fully develop, include organization, planning, self-regulation, selective attention, and inhibition. We expect young people to plan ahead for clinic appointments, arrange to be away from school to attend these appointments, focus on the dialog with their provider, and to restrain the impulse to miss medication. These are difficult tasks without significant executive function. This is not to say that we should have low expectations; rather we should develop strategies to aid them in developing these skills while their increasing brain maturity makes the tasks easier.

Cognitive function in pediatric transplant recipients has been examined in the pre- and posttransplant periods. Pretransplant, cognitive function was equally affected in young children awaiting heart or heart-lung transplants, those unlisted with congenital

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