

Developmental Considerations in the Context of Pediatric Transplantation

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ANNALS OF TRANSPLANTATION, Vol. 10, No. 1, 2005, pp. 13–16

Abstract:

This paper describes important psychological and psychosocial considerations in pediatric transplantation that can be valuable for all pediatric health care providers in the transplant setting. A developmental perspective is necessary in the consideration of these implications throughout the transplant process. Each age range (infancy, toddler and preschool, school age, and adolescence) is discussed with its normal associated developmental milestones as well as the impact transplantation can have on these milestones. Appropriate evaluation and referrals are also explained in the context of the pediatric transplant setting.

Key words: Pediatric Transplant; Development; Psychological Issues

Introduction

Transplantation in children of all ages offers the chance for an improved quality of life and extended survival. A child's ability to engage in age- and developmentally-appropriate activities is considered an important anecdotal and clinical indicator of transplantation success. Nevertheless, children who undergo transplantation face many medical and surgical events that challenge and threaten development throughout infancy, childhood, and adolescence. The purpose of this article, therefore, is to provide a developmental context for those who work with pediatric patients before and after transplantation. It is imperative that this developmental context be considered when conducting pre-transplant evaluations and providing necessary services (medical, nursing, behavioral) to children and their families.

The major developmental phases of childhood and their associated normal developmental milestones are summarized in Tab. 1. As expected, there is some variability in the attainment of these milestones. Nevertheless, they should be used as a guide when evaluating a child's understanding of illness and transplantation, the medical regimen, and self-care activities throughout the transplant process and recovery, as well as psychological adaptation to physical limitations imposed by illness, extended hospitalization, medications, and surgery.

Infancy

Growth, physical exploration, caregiver attachment, and stranger anxiety are prominent developmental milestones during infancy. Infants with significant medical problems can experience considerable interference in the attainment of these milestones, particularly if often physically ill, confined to a hospital crib, and required to undergo numerous invasive

medical procedures. In addition, the development of the parent-infant bond that characterizes this age period can be seriously disrupted due to repeated hospitalizations and infection precautions. This is a particularly stressful time for parents who are simultaneously mourning the loss of their idealized child and attempting to cope with the trauma associated with their child's life-threatening illness and need for transplantation.

There have been no systematic studies examining the cognitive, motor, or emotional development of infants with end-stage organ disease or of those who have undergone transplantation during this developmental period. Despite the lack of research, those who work clinically with children between the ages of 1 and 42 months should consider tracking their developmental progress using the Bayley Scales of Infant Development -II [1]. These scales provide valuable clinical information about the child's mental and motor development [2] and can be used to assess developmental progress in infants undergoing transplantation.

Toddler to Preschool

At the toddler and preschool ages, children are expected to meet several important developmental milestones in areas such as motor, language, cognitive, and social development. These milestones signify a normative age at which children should acquire certain skills and abilities [3]. The transplantation

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Phase	Age	Developmental Tasks
Infancy	0 to 18 months	Physical growth Physical exploration of environment Attachment to caregivers Stranger anxiety
Toddler	18 months to 3 years	Physical growth Language development Physical coordination Autonomy Cause and effect
Preschool	3 to 5 years	Initiative and mastery Perspective taking Oral awareness Visual motor integration, coordination
School age	6 to 11 years	Competence and mastery Social skills Social comparison Self-esteem Begin independence
Adolescence	12 to 18 years	Abstract thought Independence Identity issues Body image Sexuality

process can adversely affect a child's progress of critical developmental milestones during this time period. For example, children who are attached to an external feeding tube or other medical devices may display inhibited gross and fine motor skills acquisition due to their inability to navigate the environment [4]. In addition, bed-ridden preschool-aged children may not learn appropriate toilet training procedures and may develop enuresis or encopresis. Due to long hospitalizations and infection precautions, children might be restricted from attending preschool programs or day care [5], which may result in limited peer interactions. At the toddler and preschool ages, communicating with peers is critical, so such children may be at a disadvantage in developing language abilities and social skills. Thus, health professionals should carefully assess the achievement of such developmental milestones and refer for appropriate interventions (e.g., occupational, physical, and speech therapy) when necessary.

It is also essential to appropriately explain the transplant process to toddler- and preschool-aged children due to their developing cognitive abilities. Young children (under 11 years) are not expected to appreciate the long-term implications of their chronic illness and transplantation because they lack the ability to think abstractly [5]. They may have difficulty understanding the necessity for common medical procedures and can develop subsequent fears or phobias [4]. Children actively seek out stimuli in their environment and may misinterpret overheard comments and conversations between physicians and

their parents. Thus, it is important to discuss transplant – related medical procedures with children in a manner that is developmentally appropriate and sensitive. Health professionals should make an effort to use simple language when describing any medical procedures to the child.

Adherence is another important concern for pediatric transplant professionals due to the potentially serious outcomes of missed medications [6]. For toddler- and preschool-aged children with disruptive behavior disorders, adherence can be particularly problematic. The hallmark of these disorders is a pattern of noncompliance and disobedience that can likely be directed toward parents and health care professionals in the case of the transplanted child. For young children with disruptive behaviors, parent-training interventions have been established as an efficacious treatment choice [7] and such interventions have been successfully used in children with chronic illness and disruptive behavior [8]. As such, it is critical to assess adherence and, when necessary, to teach parents effective behavior management strategies to maximize adherence to the strict medical regimens that precede and follow transplantation.

School Age

Early school-aged children engage in significant cognitive and social processes that are essential for normal development. Academically, they learn basic skills and consolidate ascertained information. School-aged children who undergo transplantation typically

experience significant disruptions in their schooling. They often have a history of intermittent extended school absences due to illness, medical treatment needs, or hospitalization. School-aged children who have undergone transplantation often exhibit significant deficits in academic achievement and may be at a disadvantage when compared to their peers who have not been absent for a considerable time from school. Re-entry into the school system following transplantation is likely to occur on multiple occasions, which can often lead to school refusal, appearance concerns, and separation anxiety [6]. Additionally, children may exhibit cognitive deficits associated with end-stage disease, transplantation, and immunosuppressive agents.

Socially, school-aged children exhibit increasing interests in developing relationships with peers. The social development of these children can also be compromised due to frequent interruptions in school attendance. Prior to transplantation, children are often too ill to engage in many social activities. During the post-transplant recovery period, their social contact is usually limited due to compromised immune functioning. Following the immediate recovery period, children continue to experience restrictions in social interactions due to prior disruption of peer interactions, continued post-transplant treatment constraints, and personal and parental fear of illness with increased peer exposure. The school age is a critical time in which children attempt to improve their competencies in forming and establishing social relationships with their peers. Transplantation may decrease necessary opportunities to engage in such interactions and can lead to diminished abilities in social skills and social relatedness.

Adherence following transplantation is a potential problem in school-aged children as well. Disruptive behaviors and issues related to self-esteem and social comparison can contribute to poor adherence. For example, children may feel uncomfortable taking their cocktail of medications in front of peers at school, and they may not fully appreciate the consequences of delaying or not taking immunosuppressant medication. Thus, an assessment of adherence behaviors is an essential aspect of the pre-transplant evaluation for the school-aged child [9]. Additionally, teachers, school psychologists, guidance counselors, and school nurses are fundamental liaisons to the transplant team as they can help to identify barriers to adherence, teach self-management strategies, prompt adherence behaviors, and alert the team of adherence-related problems before becoming precarious or fatal.

Adolescence

Prominent developmental phases in adolescence include abstract thinking, identity issues, body image, sexuality, and emerging independence. Transplantation can disrupt the normal stages of adolescent development. Due to the impact of certain illnesses, parents may have to be more involved in the adolescent's life than is typical. Adolescents who received a transplant may also feel alienated from

their peers, be concerned about acceptance, and have difficulty adjusting to the stringent medical regimen. Often, these disruptions can lead to anxiety, depression, anger, and other adjustment related problems. For instance, in one study, 14 of 15 adolescents who received heart transplants had at least one clinically elevated personality scale that included internalizing rather than externalizing symptoms [10].

In contrast to younger children, adolescents understand more complex aspects of transplantation. Their ability to use abstract thought enables them to think about hypothetical situations and imagine hypothetical alternatives to realities [11]. As a result, adolescents may have recurrent thoughts about their own prognosis, possible death, and the anonymity of the donor and donor's family. These thoughts may lead to further anxiety and depression. Thus, it is important to assess for these symptoms in a pre-transplant evaluation. Cognitive-behavioral and/or supportive psychotherapy may be warranted in reducing overall distress and adjustment difficulties that may be present for adolescent transplant recipients. Interventions aimed at managing anger, stress, and improving coping skills may also be helpful in improving the adolescent's adjustment.

As noted previously, adherence to medical treatment is a concern for all pediatric transplant populations and is particularly salient for adolescent transplant recipients. With increased independence, adolescents often take responsibility for their own medication regimen. However, their suspicion of adults, need to feel independent, and anxiety about the effects of medications on appearance may lead to noncompliance. In addition, adolescents spend more time with their peers who can have an influence on delinquent behaviors such as the use of alcohol or drugs [11]. These issues are even more serious for adolescent transplant recipients because the use of alcohol and drugs may be considered a contraindication for transplantation and can have serious health implications for post-transplantation and recovery. Thus, an assessment of adherence in adolescents should focus on attitudes toward medication and authority figures, use of alcohol and drugs, knowledge of medication, and side-effect profiles. As with the school-age population, liaisons (e.g., teachers, school psychologists, guidance counselors, and school nurses) are essential to the transplant team, especially when integrating the adolescent into academic and social networks.

Conclusions

Although pediatric transplantation can offer many children an improved quality of life and extended survival, success is often dependent on a child's ability to engage in age-appropriate developmental milestones. Because transplantation can affect the normal achievement of developmental milestones throughout childhood, it is imperative that its success be considered within a developmental context. Each age range offers unique developmental considerations,

and pediatric providers in the transplant setting should strive to be aware and knowledgeable of these issues. Appropriate referral to child psychologists and developmental specialists should be considered to effectively monitor all aspects of physical, cognitive, and emotional development throughout the transplant process.

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