Cognitive Functioning as a Contraindication to Organ Transplant Surgery: Dilemmas Encountered in Medical Decision Making

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A case is presented to illustrate some of the difficulties encountered when providing psychological consultation to evaluate the readiness of patients for pediatric heart-lung transplantation. The outcome of complex medical decision making can often hinge on information provided by the psychological consultant who is attempting to simultaneously serve the needs of the patient as well as the transplant team. Ethical dilemmas frequently arise when medical decision making is driven by limited health care resources and cost constraints. The utility of cognitive functioning as a variable in pediatric transplant decision making is discussed. Recommendations are made for further work in this area on both conceptual and empirical grounds to guide the integration of psychological information into transplant decision making as health care delivery continues to evolve in the future.

KEY WORDS: cognitive functioning; heart–lung transplantation; medical decision making.

INTRODUCTION

Heart–lung transplantation is the final treatment option for severe irreversible respiratory failure with associated end-stage cardiac disease. Heart–lung transplantation is considered in pediatric patients with irreversible pulmonary vascular disease who are not candidates for heart repair and single lung transplants. The survival rates and quality of life that result from transplantation make this an acceptable modality for patients whose

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disease is at an end state where there are no alternative treatments (Baum & Bernstsin, 1993). This procedure offers new hope to children and adolescents who would otherwise be at risk for premature death, however, it is a surgical procedure that results in significant personal and family disruption (Neill, Clark, & Clark, 1992). Although heart–lung transplantation may dramatically improve quality of life, the life-long complex medical regimen including postoperative medications, the constant threat of rejection, and the possibility of unknown long-term side effects results in many difficulties for the transplant recipient, the family, and members of the medical team.

The initial phase of transplantation consists of extensive involvement with members of the transplant team to ensure that an informed decision can be made about whether a child or adolescent is appropriate to place on the waiting list. Factors that may influence this decision include the medical vulnerabilities of the child, his/her level of cognitive functioning, the availability of social support, and the potential for families to successfully manage the postoperative medical regimen (Bright, Craven, Kelly, & Toronto Lung Transplant Group, 1990; Nussbaum & Goldstein, 1992). These factors determine whether or not the child will have difficulty functioning postoperatively and the likelihood of adherence to the complex postsurgical medical regimen. Families are often asked to participate in a preoperative assessment as a part of the application process to be placed on the waiting list (Bright et al., 1990). Preoperative assessments typically provide information regarding the child’s cognitive functioning, past and present psychiatric conditions, treatment responses, previous compliance with medical recommendations, coping style, social support, and attitudes toward surgery (Freeman, Davis, Libb, & Craven, 1992). This information can subsequently be used to create interventions that can assist the child and his/her family with becoming adherent to the extensive postsurgical regimen. Research suggests that the risk of noncompliance may be used as an exclusionary variable when determining whether or not the child is an appropriate candidate for heart–lung transplantation (Nussbaum & Goldstein, 1992).

Preoperative assessments have been widely used by transplant teams to identify if the transplant applicant is in need of professional or social support or is at risk for nonadherence. Selection of transplant candidates should consist of an interdisciplinary collaboration between team members to ensure that ethical, psychosocial, and biomedical factors are taken into consideration. Applicants should be informed about the potential uses of the assessment data in determining whether or not they are a suitable candidate. Due to the complexity of the selection process of candidates for transplantation, the integration of information from psychological consult-