Sociocultural Issues in Pediatric Transplantation: A Conceptual Model

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Objective To demonstrate the value of viewing the pediatric transplant experience through a sociocultural lens and to offer an organized framework for identifying influential sociocultural variables in pediatric transplantation. Methods A conceptual model is presented which organizes sociocultural factors that may influence the transplant process. A review of the pediatric and adult transplant literature is conducted. Results The need for a model addressing sociocultural issues and benefits of using the proposed model is evident. Guided by the proposed model, pediatric psychologists will be prepared to more readily attend to sociocultural influences associated with the transplant experience when conducting research or providing clinical services to patients and families. Conclusions Further development and evaluation of the proposed model are necessary to investigate its practical utility and validate the influence of the identified variables on assessment and treatment of pediatric transplant patients as well as patient health outcomes.

Key words pediatric transplant, transplant, culture, diversity.

Thousands of families across the United States become acquainted with the transplant process each year. According to the Organ Procurement Transplant Network (OPTN), the national organ transplant waiting list as of January 2004 consists of over 2,200 pediatric patients (i.e., <18 years of age). Hundreds of additional children are awaiting life-saving bone marrow and stem cell transplants (M. Matlack, NMDP, personal communication, June 16, 2003). Since 1988, over 24,000 pediatric transplants have been performed in the United States. (M. Matlack, NMDP, personal communication, June 16, 2003) (OPTN, 2004). In addition to the listed patients, thousands of physically ill children and their families undergo evaluation for transplant each year but due to unforeseen circumstances (e.g., medical reasons and personal choice) are not placed on the waiting list. Consequently, the transplant statistics available offer a gross underestimation of the number of pediatric patients whose lives are directly affected by some phase of the transplant process.

The number of pediatric patients for whom organ, bone marrow, and stem cell transplantation is a viable and accepted treatment option is steadily rising (M. Matlack, NMDP, personal communication, June 16, 2003) (OPTN, 2004). Today, a wider range of diseases are being treated through stem cell or bone marrow transplants and, despite the organ shortage, more children are being transplanted compared with previous years as a result of innovative medical procedures such as split or partial organ transplantation. Furthermore, with improvements in surgical technique and immunosuppressant drug therapy, post-transplant graft and patient survival rates are steadily improving (OPTN, 2004). Consequently, transplant candidates and recipients are requiring a broader range of and extended preoperative, perioperative, and post-operative medical as well as psychological services.

Although transplantation offers children the opportunity for increased quality and quantity of life, a number of individual and family-related psychological and social problems also surface during the process (Rodrigue et al., 1997; House & Thompson, 1988; Uzark, 1992; Rodrigue, Greene, & Boggs, 1994; Rodrigue, MacNaughton, & Hoffmann, 1996; Serrano-Ikkos, Lask, & Whitehead,
Addressing the psychosocial as well as the medical needs of the child (and the child's family) throughout the transplant process is essential to enhance the child's immediate and long-term health outcomes. Psychological services may be considered necessary during any (or all) aspects of the transplant process, and in many settings, pediatric psychologists are the professionals providing these services to children and families. The level of involvement by pediatric psychologists will likely vary across settings and may range from collaborating with the health care team during the initial discussion of treatment options (one of which may be transplantation) to providing supportive counseling to patients and families in the months and years following transplant surgery. Table I presents various aspects of the transplant process that may require psychological assistance. The availability of resources within a particular setting will largely determine when and at what level (e.g., individual, group, family, or system interventions) psychological services are offered.

Professionals in pediatric psychology currently occupy a wide range of positions within numerous settings (e.g., children's hospitals, developmental clinics, pediatric and medical group practices, and educational systems) that provide psychological services to pediatric transplant patients and their families (Roberts, 1986; Society of Pediatric Psychology, 2003). As a result of medical advances occurring within the field of transplantation, the likelihood of encountering individual patients whose lives have been affected by the transplant experience is likely to continue to increase for pediatric psychologists.

Table I. Aspects of the Transplant Process that May Require Psychological Assistance

<table>
<thead>
<tr>
<th>Coping with the diagnosis of chronic, life-threatening illness</th>
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<tr>
<td>Frequent hospitalization</td>
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<td>Treatment decision-making</td>
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<td>Assessment of candidacy for transplant</td>
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<td>Challenges of parenting a child with a chronic illness</td>
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<td>Procedure-related anxiety</td>
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<td>Pain management</td>
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<td>Emotional adjustment of patient, siblings, and parents</td>
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<td>Lifestyle changes</td>
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<td>Adherence difficulties</td>
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<td>School reentry</td>
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<td>Trauma reactions</td>
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<td>Anticipatory grief</td>
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<td>Death</td>
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Sources: Parsons, Goodwin, Bickerton, and Lask (1996); Rodrigue (1994); Walker, Harris, Baker, Kelly, and Houghton (1999).

This is particularly true of pediatric psychologists employed within primary care, medical center, educational, and community settings. Despite the reality that pediatric psychologists are providing services to pediatric transplant patients and their families, a dearth of information is available to guide them in their work with this unique patient population. Moreover, as professionals in pediatric psychology continue to provide psychological services to greater numbers of transplant patients and commit to offer appropriate, culturally sensitive care to this diverse population, identification of the sociocultural factors that influence the transplant process is imperative.

The backgrounds and lifestyles of pediatric transplant patients and their families are incredibly diverse; yet issues of culture and diversity in this area of healthcare are relatively unexplored. Attending to issues of diversity, as we will describe them (e.g., differences in ethnicity, race, socioeconomic status, disability such as visual or hearing impairment, and spirituality or religious affiliation), is not simply the recognition of individual differences. Rather, attending to culture involves understanding the systematic effect of individual differences on the transplant process and integrating awareness of important diversity-related issues at each phase of the process. Doing so will inevitably improve the quality of assessments, facilitate communication with patients, guide treatment decision-making, and augment patient care.

Pediatric psychologists by training are particularly well suited to identify and address the influence of culture when offering services to children and their families. Issues of diversity take precedence in the training and practice of pediatric psychology (Spirito et al., 2003), and recently, there has been greater recognition of the importance of diversity in psychological research and practice in pediatric psychology (Clay, Mordhorst, & Lehn, 2002). An examination of the transplant literature suggests that individuals involved in the process are a relatively homogeneous group, as evidenced by infrequent mention of patient diversity. The lack of attention given to diversity issues in pediatric transplantation is troublesome, particularly because of the breadth of sociocultural factors that influence the transplant experience. Through our personal interactions with transplant recipients we have encountered numerous situations in which sociocultural issues affected patients' transplant experience. For example, a father expressed concern about his son receiving a donated heart from a female donor, seemingly because a woman's heart was perceived as a more delicate and lacking in strength than a man's heart. Another young person we encountered
risked being ostracized from his cultural community because of his decision to receive a medical treatment that was not culturally sanctioned (replacement of his heart, which is the seat of the human soul, with that which belongs to another). Others have shared their frustrations communicating with medical professionals whose English was difficult to comprehend or who failed to consider problems that culturally incongruent lifestyle changes, such as dietary changes, may create within a family system.

The purpose of this article is to demonstrate the value of viewing the pediatric transplant experience through a sociocultural lens and to offer an organized framework for identifying influential sociocultural variables in pediatric transplantation. Specifically, the proposed model is designed to help pediatric psychologists delineate sociocultural issues influencing assessment, treatment, and health outcomes associated with patients and their families. We begin by highlighting the need for a heuristic for organizing the sociocultural influences of health attitudes, beliefs, behaviors and expectations, medical decision-making, and patient medical and psychosocial health outcomes within the pediatric transplant population. This discourse will be followed by a description of the conceptual model and examples of how this model can be integrated into practice by clinicians and researchers. Subsequently, we will examine how the current pediatric and transplant literature addresses (or fails to address) sociocultural issues represented in the proposed model. We will conclude by discussing how the model may be used as well as the need to expand its usefulness through empirical testing of the model.

Why Do We Need a Sociocultural Model?
The need for establishing a framework that identifies, organizes, and embeds sociocultural variables into our conceptualization of the transplant experience has never been greater. The relationship between sociocultural factors and disease onset, course of illness, treatment acceptability, health beliefs, adherence, and health outcomes among pediatric patients remains ambiguous (Clay, 2000). Often psychosocial and treatment complications are discussed or examined without consideration of sociocultural underpinnings influencing patient behaviors. There is a tremendous need to examine pathways that lead to favorable as well as adverse physical and psychosocial health outcomes (i.e., patient and family sociocultural factors? assessment or treatment provisions? physical and psychosocial health outcomes). For example, it is unclear whether organ rejection and graft loss due to nonadherence is culturally mediated by illiteracy, parents suspicion with the medical community, insufficient access to health care, or other mediating factors. It is also unclear whether interventions designed to decrease risk of nonadherence are culturally incongruent for some families (Prieto, Miller, Gayowski, & Marino, 1997; Girvan & Wong, 1999). Recognition of culturally driven assumptions, biases, or expectations will aid in the development of culturally appropriate recommendations, more sensitive interventions, and better patient–healthcare team relationships. New barriers to care may also be uncovered by attending to culturally grounded assumptions, biases, and expectations. Additionally, expanding the outcomes investigated beyond graft survival to other health or medical and psychosocial outcomes will offer a more holistic picture of the transplant patient’s experience. For example, we know little about the quality of life of pediatric transplant patients (Nixon & Morris, 2000) and even less about variations in perceived quality of life by ethnicity, sex, socioeconomic status (SES), or age. Only when risk and protective factors are viewed within the patient’s cultural context will cultural determinants of patient decisions and behaviors become clearer. Carefully examining these factors is necessary to overcome the barriers to successful health outcomes with transplant patients.

We contend that a higher level of patient and family care will be achieved through the development and empirical validation of a conceptual framework that draws attention to embedded sociocultural factors involved in the transplant process. Through the pioneering work of Aley (2002); Goodwin, Bickerton, Parsons, and Lask (2000); Kazak (1989) and Kazak, Simms, and Rourke (2002); Rodrigue (1994); and Streisand and Tercyak (2000), the need to attend to developmental and systemic issues in pediatric psychology has been well established. Still, few contemporary models of care incorporate cultural issues (Prieto et al., 1997) and general models are not easily applied to the unique features of the transplant experience. Standards for culturally and linguistically appropriate healthcare have been developed to ensure that every consumer seeking care receives effective services that are culturally and linguistically appropriate (U.S. Department of Health and Human Services, Office of Minority Health, 2000). Recently, the Journal of Pediatric Psychology (2002) published a special issue on ethnic minority and low-income children and families emphasizing the importance of attending to cultural issues in pediatric psychology. Specifically, the significant influence of culture in transplantation has
also recently been highlighted in the journal. In their study on predictors of medication adherence among renal pediatric patients, Tucker et al. (2001) found that predictors of adherence differed among Caucasian and African American patients.

Now the time has come for a systematic integration of sociocultural aspects of care into our models of care. A descriptive cultural model will offer a more comprehensive representation of the variables influencing aspects of the transplant process. Such a model will serve to encourage researchers and practitioners to consider a broader range of cultural variables (beyond age, sex, and ethnicity) in research and practice. This model will also draw much needed attention to the existence of diversity among individuals within ethnic groups as well as assist in understanding diversity that exists between ethnic groups.

**Potential Benefits**

The transplant experience unfolds within a sociocultural context. Our primary aim in proposing the Sociocultural Transplant Experience Model (STEM) (Figure 1) is to offer health care professionals an ecologically and culturally informed heuristic that will further advance systematic investigation and professional practice of those involved with the pediatric transplant experience. Specifically, the proposed model will encourage professionals to: (1) acknowledge the pervasive presence of culture in the pediatric transplant experience; (2) identify specific cultural underpinnings associated with problematic treatment issues (e.g., treatment acceptability, health beliefs, and adherence) and adverse health outcomes; (3) highlight the existence of cultural and family strengths as protective factors associated with the transplant experience (e.g., dependence on extended relatives, influence of spiritual or religious coping, and availability of community resources); and finally, (4) offer culturally appropriate accommodations to established treatment protocols and work toward establishing culturally congruent recommendations and interventions that meet the needs of this diverse population.

![Figure 1. Sociocultural Transplant Experience Model.](image)

*Residential factors include rural or urban location, neighborhood risks (e.g., access to drugs or alcohol, and violence), distance needed to travel to receive care, and geographic isolation.
relevant literature with our own years of clinical experience working with transplant patients and their families. The variables included in the model are by no means exhaustive. Our goal was to create a model with enough detail to provide clinical utility and direction for future research, while remaining sufficiently flexible enough to apply the model to a variety of circumstances that may be encountered during the transplant process.

As illustrated in Figure 1, several sociocultural factors have been identified and embedded within a framework that depicts the natural flow of the transplant process, including its eventual outcomes. The transplant process is depicted as having four key phases: assessment and candidacy, preoperative and waiting, transplantation and hospitalization, and post-transplantation and posthospitalization. It should be noted that each phase involves a qualitatively different experience for children and families primarily because their needs change as the process progresses. Although each phase is independently influenced by sociocultural factors, the impact of cultural issues is best conceived as cumulative. In other words, cultural issues that arise during the assessment phase will likely affect each of the following phases. Consequently, sociocultural factors that interfere during any phase are likely to influence children's medical and psychosocial outcomes. Essentially, the STEM provides a map of sociocultural considerations that should be made to ensure the highest quality of care to children and families.

The first phase within the model is assessment and candidacy. During this phase, the child and the family undergo extensive physical and psychological evaluation. Findings from this evaluation will be used to make decisions about the child's candidacy for transplantation. The strength of the healthcare team–patient–family relationship is critical for this first phase and continues to be important in those phases that follow. Consequently, awareness by the healthcare team of cultural factors that may interfere with identifying a family's strengths, establishing trust, and maintaining rapport with the family is essential. During this phase, the team's awareness of their own cultural assumptions and biases is important, as these assumptions are likely to influence the quality of care provided to culturally different patients and their families. Cultural assumptions about an older child's level of autonomy in decision-making, for example, may create an adversarial relationship with some parents. Conversely, awareness of a family's values, strengths, and cultural beliefs could help establish a strong team–patient–family relationship. For instance, validating the presence of family loyalty when a large number of family members wish to be typed to determine whether they will be able to donate rather than rejecting or ignoring their offers would serve to strengthen the working relationship with the family.

In addition to forming a good working relationship with the family, sociocultural influences on access to and barriers to care should also be considered during this phase of the process. The quality of care received may be compromised by an inability to access transportation, work-related obstacles, or inadequate insurance coverage. Sociocultural factors such as gender may also diminish a family's access to efficient care. For example, a single mother may be less aggressive about negotiating the multiple steps necessary for activation of her child's name on the waiting list than a two-parent family headed by an assertive male. Such differences can have a substantial effect on patients' long-term outcomes.

The selection of assessment tools that contain both appropriate norms and are in the individual patient's native language is critical to obtain useful and accurate information. When appropriate, accommodations should be made for visual and hearing-impaired members of the family who are involved in the care of the patient (and this may mean the inclusion of extended family such as grandparents). Additionally, when assessing potential living donors, including parents and/or caregivers, consideration should be given to sociocultural factors that may influence motivation, decision-making, or expectations of parents. As an example, ignoring cultural views of power, authority, and caregiving that exist within the family system may lead to the team making requests that are culturally offensive (e.g., asking the eldest son to undergo medical risk to donate an organ to his youngest sibling). Was the team aware of these views, the issue could be addressed in a more culturally sensitive manner.

In the second phase of care, the preoperative or waiting period, care providers and researchers must address cultural issues impacting organ allocation and waiting time. The team–patient–family relationship continues to be important to the quality of services provided. Identifying and optimizing family strengths, including family unity or strong spiritual practice, are vital to assist families to cope effectively during this period, as they prepare for the hospitalization of their child and transplantation. Learning about the influence of culture or religion on the questions raised by the family concerning organ allocation policies may be important. For example, cultures that regard men highly and women as somewhat inferior to men may raise concerns should a male child receive an organ from a female donor. Questions about disparities in waiting time based on ethnicity may also arise as a concern.
As the team members become more acquainted with the family, they may begin to observe the coping styles exhibited by one or more family members. Knowledge of cultural differences in coping will help caregivers encourage, rather than impede, a family's natural and culturally congruent ways of coping. For instance, a family with many close extended family members may request a large space that is private, where they can be assured that confidentiality is ensured. A family's cultural-based fears, concerns, and questions about the trust-worthiness of the medical team may need to be validated (not shamed or denied) and addressed throughout this period. Such knowledge is also needed to avoid interpreting unfamiliar emotional responses (e.g., wailing), although culturally appropriate, from being viewed as disruptive or unhealthy.

During the third phase of care, transplantation and hospitalization, awareness of how cultural assumptions held by team members toward different cultural groups may influence the quality of care is critical. Assumptions and biases influence the style, quality, and strength of the team–patient–family relationship. For example, families may have a qualitatively different experience when the health care team is culturally similar to them. Health care providers may allocate more time or attention to a family with whom they perceive themselves as being more alike to them than families who have markedly different beliefs about the health care system, organ donation or transplantation, unconventional relationships, and parenting.

Patients and families will also face new challenges during the phase of transplantation and hospitalization that may require additional resources to cope effectively. As in the second phase of care, cultural awareness and sensitivity to culturally approved styles of coping as well as emotional expression are important. For instance, during the child's transplant surgery, a family may turn toward their faith as a means of coping. Thus, it would be important to recognize the incongruity in directing a non-Christian family to the hospital chapel. Instead it should be a priority for an individual to identify a more fitting sacred space for the family where they can have their spiritual needs met. A family may also find comfort in having their own religious leader or members of their congregation to join them throughout the wait during the child's surgery and post-surgical recovery. Of course, hospital visitation policies that prohibit contact from non-family members may need to be reexamined through a cultural lens when issues such as these present themselves.

In the final phase of the transplant process, clinicians and researchers should consider how a patient's cultural values and worldview influence their beliefs about adherence, health behaviors, and health-related outcomes. Awareness of potential barriers to adherence that may be culturally mediated (Washington, 1999; Chisholm, 2002) and knowledge of culturally appropriate resources for the family are important to ensure adherence to the long-term post-operative health regimen. For example, a family believing that medications should be administered or medical guidance sought only when the child appears to be in poor health (a cultural-based belief) may be at risk of missed appointments and medication nonadherence. Providing education and training regarding medication administration to the family member(s) responsible for the child's care at home is critical in avoiding adherence problems.

Furthermore, to the extent possible, treatments should be made to fit the patient and family's lifestyle and values. Culturally congruent treatments are more likely to be accepted and followed by the patient and family. A family whose lifestyle is taken into account when making follow-up appointments, developing a medication routine, or making dietary recommendations will likely be more apt to follow-through than those individuals who believe the team makes no attempt to understand how this child's care must fit into an already established lifestyle.

The transplant process impacts many dimensions of a child's physical health and the psychological health of each member of the family. The primary objectives of the transplant team are to improve the child's physical health through transplantation, while also fostering psychosocial wellness and providing support to the entire family throughout the process. This is not always the way the process unfolds, however, and a multitude of positive and negative outcomes are possible. Within the STEM, several health or medical and psychosocial outcome variables of interest to researchers or clinicians are listed. Because transplantation is seldom a linear process (e.g., a patient may be transplanted, the organ rejected, the patient subsequently re-listed, and re-transplanted), ongoing assessment of health and psychosocial outcomes are likely. Not all pediatric patients will encounter all phases of the transplant process, and where this is the case the model may be revised to include only those phases relevant to a particular patient. It should also be noted that physical and psychological health changes occur as children move through the process. For example, some children may experience medical complications and declining quality of life early in the process (e.g., while waiting for an organ), only to improve after they are transplanted. Similarly, some will experience
organ rejection during their hospital stay, whereas others may encounter rejection or organ failure many years after their transplant. Although fluctuations in health and psychosocial functioning occur throughout the transplant process, the STEM is more specifically designed to help clinicians and researchers identify the sociocultural variables that may actively influence eventual outcomes for specific children.

In sum, the STEM provides a snapshot of the cultural issues that should be considered when participating in or studying the transplant process. However, the process is not static as this model would suggest. It is a complex and dynamic process, and cultural issues may arise at any point in time. The expectation is that, with this model, professionals will be better able to identify when an issue is influenced by culture and when culture does not play a significant role.

Of course, the list of cultural factors included in the STEM is in no way exhaustive. Many of the factors included in the proposed model were extracted from extant literature highlighting the role of culture in transplant. In the next two sections, we will present empirical support for our inclusion of the sociocultural factors presented and the need for a conceptual model of cultural issues influencing transplantation.

**Examination of Culture in Transplant**

A host of disease processes diagnosed in children and adolescents may be treated through transplantation. These include congenital heart lesions, cardiomyopathy, end-stage kidney disease, cystic fibrosis, biliary atresia, acute viral hepatitis, leukemia, aplastic anemia, and sickle cell anemia. Unlike prevalence rates of certain diseases, transplantation as a treatment does not discriminate. Transplantation occurs in children and adolescents of all ages, races, sexes, religious backgrounds, physical abilities, educational levels, sexual orientations, and social classes.

Despite the diversity of experiences that patients and families carry into the transplant process, attention to diversity issues by national transplant organizations as well as transplant researchers is rather limited. For example, organizations such as OPTN, National Marrow Donor Program, and Minority Organ Tissue Transplant Education Program are three primary publishers of statistical data on transplantation in the United States. Although patient demographic data (e.g., age, sex, and ethnicity) are available, other cultural information that may have a more indirect relationship with patient health outcomes is not being collected (e.g., religion and SES). Predictably, these variables (i.e., age, sex, and ethnicity) that will be referred to herein as privileged sociocultural variables have been the most widely reported and studied in the pediatric transplant literature.

Researchers are only beginning to unravel the sociocultural threads that line various aspects of the transplant experience. Socioculturally conscious research is prevalent in the adult transplant literature, and efforts are being made to extend, developmentally modify, and expand this line of investigation with chronically ill pediatric populations, including pediatric transplant recipients. For example, the importance of cultural factors in treatment design and implementation has been highlighted (Clay, 2000; Clay et al., 2002). Additionally, the influence of age, gender, and ethnicity on children’s progression through the transplant process and on post-transplant health risks has been examined. Other variables, however, such as SES, religion, and spirituality, have received less attention.

**Age, Gender, and Ethnicity**

Researchers have reported greater risk of nonadherence (Serrano-Ikkos, Lask, Whitehead, & Eisler, 1998; Tucker et al., 2001; Tucker et al., 2002) and late acute rejection episodes (Tejani et al., 1998; Gupta et al., 2001) among older patients (over 6 years of age) and ethnic minority patients. A higher rate of nonadherence also has been found among children who live without both biological parents (Lurie et al., 2000; Serrano-Ikkos et al., 1998). Ethnicity and gender differences associated with medication nonadherence (Meyers, Thomson, & Weiland, 1996), access to the renal transplant waitlist (e.g., likelihood of being listed) (Ayanian, Cleary, Weissman, & Epstein, 1999; Epstein et al., 2000; Furth et al., 2000; Garg, Furth, Fivush, & Powe, 2000), and parental perceptions of the transplant experience (Suddaby, Flattery, & Luna, 1997) have been reported in the pediatric literature.

**Socioeconomic Status**

With transplant being among the most expensive medical therapies, those with limited economic means seemingly may be at increased risk of encountering complications during the process. Additionally, evidence in the broader medical literature suggests that SES is often associated with the quality of the physician–patient relationship (Epstein, Taylor, & Seage, 1985; Johnson, Kurtz, Tomlinson, & Howe, 1986; van Ryn & Burke, 2000). Discrimination and cultural biases also have been shown to impact patients’ health behaviors (LaVeist, Nickerson, & Bowie, 2000). Preliminary data support the well-accepted clinical notion that SES is an important variable to consider (Clay et al., 2002), and evidence is
available to suggest that income disparities are indeed influential in the transplant process (Gaylin et al., 1993; Rovelli et al., 1989; Meyers, Weiland, & Thompson, 1995; Garg, Diener-West, & Powe, 2001). Despite these findings, studies examining the impact of family socioeconomic status and social class on process and outcomes in transplant are severely lacking.

**Religion and Spiritual Beliefs**

Although interest in the role of spiritual belief and religious faith in health and medicine is prevalent (Moss, 2002; Powell, Shahabi, & Thoresen, 2003), the appeal has not yet permeated the field of transplantation. Preliminary evidence, however, points to the significance of assessing spiritual beliefs that may be incongruent with the transplant process, (Goodwin et al., 2000; Sears & Wallace, 2001), faith-based attributions that may influence a patient’s sense of responsibility for their own health care (e.g., God externally controls the outcome) (Siegal, Hanson, Viswanathan, Margolis, & Butt, 1989), faith-based coping strategies (Tix & Frazier, 1998), and religious underpinnings that may influence patients’ decisions to refuse transplantation (Gordon, 2001).

More extensive empirical examination of the influence of sociocultural factors on various aspects of the transplant process, including assessment, treatment issues, and patient health outcomes, is needed. To date, the primary focus in the extant literature has been on the examination of the direct effect of sociocultural variables (e.g., ethnicity) on treatment issues (e.g., nonadherence). It cannot be assumed, however, that these variables are directly linked to poor health outcomes (e.g., graft loss) because current studies do not control for the presence of potentially confounding sociocultural factors (e.g., SES, racism, and religion). In light of the relatedness of sociocultural factors, multiple relationships rather than individual variables alone should be examined. Furthermore, it is important to recognize that a number of sociocultural variables have yet to be cited in the transplant literature including language, geography, sexual orientation, and disability. Perhaps these variables are unrelated to treatment and outcomes, but we cannot assume this to be true in the absence of rigorous scientific examination.

**Why is Culture Important?**

Two significant trends have given rise to the need for increased attention to culture in transplantation. The first is the diversification among the transplant patient population, and the second is the growing awareness in psychology and medicine of associations between culture and health.

**Patient Diversity**

During the next decade, more than one half of the U.S. population will be composed of racial and ethnic minority citizens (Sue, Bingham, Porche-Burke, & Vasquez, 1999). Consequently, the likelihood of encountering patients and families with cultural backgrounds and experiences that differ from one’s own will increase. Specifically, psychologists will be more likely to encounter patients and families holding culture-based beliefs that are in some way related to the success of the child’s transplant. Patients and their families may hold cultural-based beliefs about health, healthy behaviors, religion, the sanctity or desecration of the body, life after death, and the power of the dead to take over the body of the living. Accordingly, population diversification in the United States necessitates a reexamination of what health care providers define as quality care. When patients’ values or beliefs are in conflict with the treatment or those of the health care team, the quality of care will likely suffer (Clay et al., 2002). Quality care should include services that are both medically and culturally indicated by care providers who are both technically and culturally competent.

**The Culture–Health Link**

As evidenced by the prevalence of health disparities in the U.S., sociocultural factors influence patient health status. Disparities exist in rates of disease, life expectancy, and utilization and access to preventative or remedial health care by ethnic minority citizens when compared with non-ethnic minorities (Clay et al., 2002). Disparities associated with transplantation include differences among specific groups in incidence, prevalence, and mortality associated with several adverse health conditions that may necessitate the need for transplant. Several diseases associated with end-stage organ failure affect some ethnic and racial groups more frequently than others. Table II highlights prevalence rates of groups across several diagnostic categories commonly associated with transplantation. Although gender and ethnic group differences are highlighted, it is possible that unstudied differences such as those characterized by age, education, income, social class, disability, geographic location, or sexual orientation may be present as well.
Conclusion

The STEM offers promise and possibility for improving the sensitivity and quality of care provided to pediatric transplant patients and families. Conceptually, it offers greater awareness of the sociocultural issues that can influence the entire transplant process. Additionally, it will enable readers to analyze current research findings related to cultural issues and transplantation more judiciously.

Empirical examination and validation of the variables outlined here is a vital next step in this process. Although the identified variables have yet to be empirically supported as predictors of treatment complications and patient health outcomes, from a practical standpoint, the model may be useful in facilitating the generation of questions that may assist clinicians in exploring the cultural context within which patients and families reside. Table III presents some preliminary examples of cultural inquiry extracted from the model that may promote providers cultural consciousness when caring for pediatric transplant patients and their families.

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References


