

Editorial

Family roles and routines after pediatric liver transplantation: Implications for quality of life and beyond

Quality of life after pediatric liver transplantation

The quality of life (QoL) of pediatric liver transplant (LT) recipients has been repeatedly shown to be impaired relative to healthy populations and other chronic illness groups (1–6). Recent studies have demonstrated that impairments in QoL persist 10–20 yr after transplant (7, 8). Despite growing recognition that pediatric LT recipients have lower QoL and require monitoring and support, little attention has been given to the impact childhood liver transplantation has on parents and families.

Nearly a decade ago, a call was issued to include assessment of family functioning in the study of functional outcomes for pediatric LT recipients (4). Unfortunately, this research continues to be limited to few studies. Overall, families of pediatric LT recipients are not dysfunctional (9), yet aspects of family functioning may have important implications for adjusting to life after transplant.

The role of family in child health

The role of family in child health has been long recognized (10). Disruption of family functioning has been associated with emotional and behavioral difficulties, lower QoL, and medication non-adherence, which can ultimately lead to poor child health (11, 12). Among pediatric transplant recipients, low QoL has been linked with family conflict, disruption of family activities, and lack of family cohesion (6, 9, 13, 14). In addition, increased stress related to parenting a child with a chronic health condition has been shown to be associated with lower child QoL (9, 14).

In this issue of *Pediatric Transplantation*, Denny et al. (15) examined the relationship between family functioning and QoL among

pediatric LT recipients. Family functioning in this study focuses on family routines following transplant. The authors used the Family Accommodations Questionnaire (FAQ) to measure the degree to which families modify or adjust routines to accommodate their children following LT. The FAQ assesses areas such as work, support services, family home, domestic workload, childcare tasks, assistance from others, child peer groups, marital roles, and parent information. Denny and colleagues sought to examine the association between the FAQ and child QoL, as measured by parent-proxy reports on the pediatric quality of life (PedsQL) Transplant Module. The PedsQL Transplant Module (5) measures domains related to solid organ transplant, such as perceived barriers to regimen adherence, medication side effects, social relationships, physical discomfort, health-related worry and anxiety, communication, and perceived body image. The authors hypothesized that families of pediatric LT recipients would make more adjustments to family routines compared with families without a child living with a LT. They also hypothesized that more adjustments to family routines would be related to lower child QoL.

Why assess family routines in context of chronic illness?

Family routines and rituals shape daily life and provide a context for child development. Family and developmental researchers have described the transactional model to illustrate the mutual effects between parent and child, wherein child outcomes are the result of a series of transactions between the child and his/her environment (16). These dynamic, complex interactions form the routines of daily family life. Reorganization and

reprioritization of family routines and rituals may increase the risk of family conflict and instability.

Studies investigating the impact of family routines on child health are not conclusive. Predictable family routines and roles have been shown to be associated with increased parental efficacy and child well-being (16). Predictability may be associated with increased medication adherence, particularly with respect to complex regimens (17). While predictability may represent an organized family system, adaptability and flexibility in family routines are also important, particularly among families living with a child with a chronic health condition as they may find themselves reallocating time, energy, and resources to meet the needs of the child. For example, in a recent study of families of children following renal transplantation, poor family flexibility and efficacy were associated with medication non-adherence (18). Thus, the degree to which families adapt to changes in routines may vary based on the dynamics within the family system.

Denny et al. (15) found that compared with a community sample, parents of pediatric LT recipients made significantly more adjustments to family routines to accommodate their children, particularly in the area of child care as it relates to the need for “constant monitoring.” This finding is not surprising. Undoubtedly, caring for a child with a serious medical condition requires accommodations with respect to work, child care, social activities, family rituals, and routines. One might argue that accommodations and adjustments to family routines do not uniformly reflect poor family functioning. Rather, adjustments to daily family life may reflect higher level problem-solving, adaptability, and coping. However, Denny and colleagues found that more adjustments to family routines were associated with lower child transplant-related QoL, as measured by parent-proxy report.

Unfortunately, there are methodological limitations that impact these findings. The study authors selected the FAQ as a measure of family functioning, although this measure has not yet been validated. There are empirically supported measures of family functioning that are available to assess various domains of interest (19). The authors attempted to reconcile this limitation by providing the internal consistencies of the FAQ for this study sample. Although the FAQ requires additional study, the information gathered is still valuable and warrants further attention.

To investigate the impact of adjustments to family routines on QoL, Denny et al. (15) included parent reports of child QoL using a transplant-specific module. The PedsQL Transplant Module is a relatively new measure (5), which provides a richness of information related to adjustment following solid organ transplant. While Denny and colleagues provided scores and internal consistencies for the PedsQL Transplant Module, they did not describe which aspects of transplant-related QoL were most related to adjustments in family routines. Fiese et al. have written extensively about family routines in pediatric asthma, demonstrating that practice-based family routines around medication use were related to adherence, while perceived burden associated with management routines was negatively related to QoL (20). Specifically, “routine burden” reflected the degree to which parents perceived asthma management to be a chore or hassle. Thus, it is possible that impact on QoL varies based on the particular family routine or ritual. Insight into areas of QoL most impacted by changes in family routine may lead to specific prevention and intervention strategies.

In the study described by Denny et al. (15), based on parent-proxy report, the subscale measuring anxiety and health-related worry was the most impacted area of child QoL. It may be that parental concern about their child’s anxiety or ability to cope with life after transplant may influence the parent perceptions of the need for monitoring and support of their child, as reflected by adjustments to child care. Denny et al. did not report on the health status of the children in this study, thus it is not possible to determine whether adjustments to family roles and QoL were related to the medical stability of the child.

The omission of a generic QoL measure precluded an examination of how family adjustments relate to QoL in a healthy population. Parents who perceive their children to have lower QoL may also perceive greater disruptions in their family. It could be that better QoL leads to fewer adjustments within the family. Perceptions of the child’s health status may drive perceptions of family adjustment rather than family adjustment of routines negatively impacting QoL. This remains an empirical question, particularly as QoL was not measured in the control group. Further prospective investigation of the aspects of QoL related to family roles and routines may guide clinical research and intervention.

Similarly, this study only included parent-proxy report of child QoL. In a large cross-sectional

study of pediatric LT recipients compared with other chronic disease populations, Limbers et al. demonstrated that parent-proxy report of child health-related QoL is not equivalent to child self-report (21). Likewise, using a different measure of QoL, Taylor et al. found that proxy assessment alone was insufficient (22). Utilizing only parent-proxy report of child QoL may reflect parent functioning rather than child functioning, as a parent who is experiencing stress and anxiety may be unable to objectively rate their child's functioning. Thus, it is critically important to include assessment of both patient and parent perspectives of QoL.

As researchers begin to answer the call to include measures of family functioning in their assessment of functional outcomes following liver transplantation, I would encourage the inclusion of multiple family members. Because of design limitations, Denny et al. (15) were unable to examine the impact of family structure on QoL or role adjustments. Similarly, it is important to consider the influence of income and family structure when assessing family functioning in the context of chronic illness, as these variables may present additional challenges in managing the daily responsibilities involved in caring for a child with a chronic illness.

Implications for clinical practice and research

Limitations notwithstanding, the study by Denny et al. (15) in the current issue of *Pediatric Transplantation* provides important insights into the relationship between family roles and QoL following pediatric liver transplantation. In the era of patient- and family-centered care, consideration should be given to how families are managing the demands of caring for a child with a chronic health condition. Interestingly, in a study across chronic illness groups, there were no significant differences in overall family functioning between families with and without a child living with a chronic condition (11). Yet, "unhealthy functioning" in the areas of role functioning and the division of responsibility for health management tasks was more common among families with chronic health conditions. This suggests that families may benefit from strategies to improve communication, time management, and conflict resolution to help negotiate roles and responsibilities—particularly before being faced with an acute stress crisis.

Assisting families with incorporating health-related tasks into their preexisting routines may reduce parental burden, which could ultimately improve family cohesion, QoL, and adherence

to recommended treatments (12, 23). By evaluating family functioning, clinicians and researchers may be able to determine whether the family is equipped with the skills and resources to incorporate health management tasks into daily routines. Families that exhibit deficits in communication and the division of responsibility for family tasks may have difficulty coping during periods of stress. Embedding health management tasks, such as medication administration, laboratory visits, doctor appointments, into family routines may reduce burden and or stress related to unexpected accommodations or adjustments.

By routinely assessing family coping and resources, clinicians and researchers may be able to identify families that could benefit from additional support. Denny et al. (15) found that the extent to which parents adjust routines to accommodate their child after transplant was related to lower child QoL. While it is important to assist families in realigning their routines to reduce the risk of conflict and burden (16), it is also important to avoid viewing adjustments to roles and routines as universally negative. Thus, I join Denny and colleagues in the continued call for increased focus on families of pediatric transplant recipients. With increased attention on promoting patient- and family-centered care, perhaps it is time to focus on families by encouraging flexibility in providing practices to meet the unique needs of each child and family (24). Parents' QoL and overall functioning should be monitored, not to place blame, but to identify families in need of additional services to assist with managing their child's chronic health condition.

Conclusions

In this editorial, the intention is to concur with and to contribute to the important discussion of the impact of family functioning on QoL among pediatric transplant recipients. Family functioning is a multidimensional, dynamic construct that has not been well studied in this population. Likewise, QoL is a complex, multidimensional construct that is influenced by a wide range of factors. It is critically important to obtain parent and patient-reported measures of QoL, as well as perceived family functioning, to guide the development of meaningful patient- and family-centered interventions.

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