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Parents' Quality of Life and Family Functioning in Pediatric Organ Transplantation[1,2]

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Review

Solid organ transplantation is an important treatment option for pediatric patients in end-stage organ failure. The impact of pediatric organ transplantation on parents' quality of life and family functioning has been found to be substantial, but findings on this topic have not previously been consolidated. Thirty-one studies were selected for analysis after a database search on this topic. We present future research questions and suggestions to improve clinical practice based on the integration of this knowledge.

SOLID ORGAN TRANSPLANTATION is an important treatment option for pediatric patients in end-stage organ failure. In 2011, 1,793 pediatric (< 18 years) transplants were performed in the United States (US), representing 6% of all transplants; in recent years, this percentage has remained stable (OPTN, 2012). According to LaRosa, Baluarte, and Meyers (2011), the 5-year survival rates for pediatric recipients are 77–86% (liver), 95–96% (kidney), 72–77% (heart), 39–51% (lungs), and 46–76% (intestines). Survival rates have improved in recent years such that long-term post-transplant survival is expected.

Transplant recipients have a severe chronic condition that requires medical management. In addition to their fundamental caretaking role, pediatric recipients' parents and family members provide daily care (with an emphasis on health management and hospital visits), address concerns about rejection and the adverse effects of immunosuppressive agents (Green, Meaux, Huett, & Ainley, 2009; Stubblefield & Murray, 2000), and manage financial burdens (Crowley-Matoka, Siegler, & Cronin, 2004; Spurkland, Bjorbae, & Hagemo, 2001). Thus, a child's transplant has a substantial influence on the family's daily life. Pediatric recipients' parents' quality of life (QOL) and family functioning should therefore be considered as an index for evaluating this influence.

Previous research on liver/kidney transplantation from living donors has mixed results. For example, some studies have reported that donors' psychological QOL improves (Schulz et al., 2001), their overall QOL is equivalent to that of the general population (Isotani et al., 2002), or their physical QOL generally deteriorates (Parikh, Ladner, Abecassis, & Butt, 2010). In pediatric living-donor liver or kidney transplantation, the donor is usually a parent. In this situation, the parent is also a patient, and QOL is thus affected on two levels. Therefore, support that is tailored to pediatric living-donor transplantation is needed.

The current review focused on pediatric organ transplant recipients' parents (including living-donors or non-donors) and their families. The objective of this study was to systematically review the research literature describing parent's QOL and family functioning after pediatric organ transplant and to identify areas for improvement in clinical practice and future research.

Methods

Search and Selection Strategy for Articles

The search for relevant articles was conducted across the following four electronic databases between August 11 and 16, 2012: Ovid SP (Medline), PubMed (Medline), Cumulative Index to Nursing and Allied Health Literature (CINAHL) with

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Table 1 Databases and search terms.

Database	Search terms
Ovid SP (Medline)	(Organ Transplantation OR Liver Transplantation OR Kidney Transplantation OR Heart Transplantation OR Lung Transplantation OR Intestinal Transplantation) AND (Pediatrics/OR Child/or Child Psychology/OR Adolescent/or Adolescent Psychology/) AND (Parents/OR Caregivers/OR Living Donors/) AND (Quality of Life/OR Mental Disorders/OR Family Health/OR Health Status/OR Postoperative Complications/)
PubMed (Medline)	(Organ Transplantation OR Liver Transplantation OR Kidney Transplantation OR Heart Transplantation OR Lung Transplantation OR Intestine Transplantation) AND (Pediatric OR Child* or Child Psychology OR Adolescent* or Adolescent Psychology) AND (Parent* OR Caregivers OR Living Donors) AND (Quality of Life OR Mental Disorders OR Family Health OR Health Status OR Postoperative Complications)
CINAHL Plus with Full Text	(Organ Transplantation OR Liver Transplantation OR Kidney Transplantation OR Heart Transplantation OR Lung Transplantation OR Intestinal Transplantation) AND (Pediatric OR Child or Child Psychology OR Adolescent or Adolescent Psychology) AND (Parent* OR Caregivers OR Living Donors) AND (Quality of Life OR Mental Disorders OR Family Health OR Health Status OR Postoperative Complications)
Ichushi Web	(Organ Transplantation OR Liver Transplantation OR Kidney Transplantation OR Heart Transplantation OR Lung Transplantation OR Intestinal Transplantation) AND Pediatric AND (Parents OR Parent OR Guardian OR Living Donor) AND (Quality of Life OR Family function OR Stress Disorder OR Postoperative Complication)

Full Text, and Ichushi Web (a Japanese database). Advanced search techniques were employed in the former three database searches. In each database, thesaurus terms were used to search relevant articles (Table 1). To be included in the review, the article had to include an evaluation of family functioning and/or QOL in parents of pediatric transplant recipients. In this study, "child" is defined as a person <20 years old. Studies as listed below were excluded.

- Not about pediatric transplantation
- Not covering the post-transplant or donation period
- Not including data about QOL and/or family functioning as evaluated by the parents
- Not analyzing transplantation separately from other diseases
- Not specifying pediatric recipient's status in cases where a parent was the donor
- Not analyzing the recipient's data separately from the adult's parent's
- Written in a language other than English or Japanese
- Review articles

Among the scales measuring pediatric recipients' QOL and family functioning (using parents as proxy raters), the Infant Toddler Quality of Life (ITQOL; Landgraf, 1994) and the Child Health Questionnaire-Parent Form 50 (CHQ-PF50; Landgraf & Ware, 1996) were identified as measuring the parents' psychological and social status or family functioning. The former has items measuring "parent impact-emotional," "parent impact-time," and "family cohesion"; the latter includes items from those categories and additional items measuring "family activities." Therefore, these independent subscales were included in the current review. Articles were excluded during the first review based on information in the title and abstract; the full text was scanned during the second review (Figure 1). After the articles were extracted from each database and duplicate articles were excluded, new articles were selected from the reference lists of relevant articles. A final list of relevant articles was then compiled. All study designs (quantitative, qualitative, or mixed methods) were included.

Quality of Extracted Articles

This review aimed to collect knowledge on several organ types; to do so, a few methodological concessions were necessary in order to assemble the breadth of data required. This review included some quantitative studies in which the reliability and validity of the scales had not been specified, because data on family functioning and the physical, psychological, and social status of recipients' parents were recorded. Similarly, it included qualitative studies when data on family functioning and the psychological and social status of parents were recorded.

Classification of Results

Two reviewers classified data from each article as either "QOL" (including physical, psychological, and social status) and/or "family functioning." They then confirmed and evaluated the resulting classifications. For qualitative studies, estimated categories were indicated with < <>>, and those data were classified with the data from the quantitative studies by discussion. The extracted data were then classified by consensus into QOL and family-functioning categories by