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LITERATURE REVIEW

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A systematic review of parent and family functioning in pediatric solid organ transplant populations

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Abstract

The process of pediatric solid organ transplantation (SOT) places new and increased stressors on patients and family members. Measures of family functioning may predict psychological and health outcomes for pediatric patients and their families, and provide opportunity for targeted intervention. This systematic review investigated parent and family functioning and factors associated with poorer functioning in the pediatric SOT population. Thirty-seven studies were identified and reviewed. Studies featured a range of organ populations (eg, heart, liver, kidney, lung, intestine) at various stages in the transplant process. Findings highlighted that parents of pediatric SOT populations commonly report increased stress and mental health symptoms, including posttraumatic stress disorder. Pediatric SOT is also associated with increased family stress and burden throughout the transplant process. Measures of parent and family functioning were associated with several important health-related factors, such as medication adherence, readiness for discharge, and number of hospitalizations. Overall, findings suggest that family stress and burden persists post-transplant, and parent and family functioning is associated with health-related factors in SOT, highlighting family-level functioning as an important target for future intervention.

1 | INTRODUCTION

Rates of pediatric SOT have increased in prevalence over the last decade with 5-year survival rates exceeding 75% across pediatric heart and liver transplant populations and >90% in pediatric kidney transplant populations.[1,2] While SOT offers many children and adolescents increased quantity and quality of life,[3–5] patients and families are faced with many stressors and burdens. During the pretransplant phase, patients and families may experience long waits due to the scarcity of donor organs available,[2] financial challenges, stress on siblings and caregivers as roles and responsibilities shift, and complex medical regimens, all while the child remains seriously ill.[6,7] Following transplantation, SOT recipients must continue to take daily medications, attend frequent follow-up appointments, and undergo various procedures, such as biopsies and cardiac catherizations. As Gold and colleagues[8] described, parents state that they must "adapt to the new disease called organ transplant," which is accompanied by risks of rejection, graft loss, need for re-transplantation, and mortality. Beyond the stressors of the transplant course itself, children pre- and post-SOT may have complex developmental and emotional needs, which can result in even greater strain on the family system.[3,6]

Thus, it is necessary to consider the impact of SOT on both the family system and the child. Bronfenbrenner's social ecological framework places a child at the center of concentric circles representing various aspects of a child's social ecology, such as parents/family, school, healthcare team/system, community, and socioeconomic class.[9] Per this framework, parent and family functioning is considered to be critically important with regard to the relationship between a child's development and their disease course.

Abbreviations: PAT, Psychosocial Assessment Tool; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-analyses; PTSD, posttraumatic stress disorder; SES, socioeconomic status; SOT, solid organ transplantation.

A large systematic and meta-analytic review of parents of children with a variety of chronic illnesses supported this notion. Cousino and Hazen[10] found that parents of children with chronic illnesses experienced greater general parenting stress than parents of healthy children. Although SOT populations were not included in this review, increased parenting stress was found to be associated with poorer child psychological outcomes across disease groups. As a result, parent and family stress has been highlighted as a modifiable intervention target in families of children with chronic illnesses given associations with patient psychological functioning and health-related outcomes.[10]

Similar relationships have been demonstrated in pediatric SOT populations. For example, greater parent and family stress is associated with poorer adherence to post-transplant immunosuppressant medications.[11–13] This is consistent with studies that have found that parents and adolescents who report healthier family functioning also report fewer medication barriers, such as forgetting medications, scheduling issues, and voluntary resistance of medication administration.[14,15] As a result, pediatric SOT recipients from healthier functioning family systems experience fewer hospitalizations[16] and better quality of life.[3]

While investigators have begun to examine parent and family functioning in pediatric SOT populations, far less has been performed when compared to other pediatric illness groups.[6] The findings to date have not been systematically reviewed and synthesized, which may be attributed to focus on single organ groups and small samples limiting quantitative analysis, among other reasons. Other reviews of this kind have been completed across pediatric chronic illness groups, including oncology,[17] diabetes,[18] and chronic pain,[19] among others. While similarities are expected among pediatric SOT populations and these other illness groups given the chronicity of SOT, differences in life expectancy, treatment regimen demands, and unknown timing of organ availability, among others, are likely to impact SOT families in unique ways.

To address this gap in the literature and guide the development of evidence-based interventions, this study aimed to review and summarize the literature regarding family functioning among pediatric SOT patients and their families. Guided in part by the social ecological framework,[9] the current study aimed to answer the following questions: (i) What is the impact of pediatric SOT on parent psychological functioning? (ii) What is the impact of pediatric SOT on family functioning? and (iii) What variables are associated with poorer parent and family functioning in the pediatric SOT population? It is our objective that answers to these questions will help to identify modifiable family-based intervention targets in pediatric SOT populations.

2 | METHODS

2.1 | Search strategy

Literature searches were conducted on the following databases: PsychInfo, PubMed, MEDLINE, and Cumulative Index to Nursing and Allied Health Literature, and the Cochrane Systematic Review and Controlled Trials Database. In an effort to provide an extensive review of the literature while also limiting the review to studies most relevant to current medical practice, the search included articles published in peer-reviewed journals from 1980 to 2016. Databases were searched using the following word stems: (i) "child$$," "youth," "adolescen$$," "teen$$," "infant," "pediatric," "paediatric," (ii) "organ," "transplant," "solid organ transplant," (iii) "parent," "mother," "father," "caregiver," "family," "system," and (iv) "depression," "anxiety," "trauma," "stress," "distress," "marital," "functioning," "coping," and "adaptation." The reference sections of articles meeting the predefined inclusion criteria were examined for additional studies reporting on parent and family functioning in pediatric SOT populations. Manual searches of the Journal of Pediatric Psychology and Pediatric Transplantation were also conducted.

2.2 | Inclusion criteria

In accordance with Cochrane Collaboration guidelines,[20] the following inclusion criteria were defined prior to initiating the literature search: (i) publication date between 1980 and 2016; (ii) publication in a peer-reviewed journal; (iii) published in the English language; (iv) included a study sample of pediatric (0-21 years) SOT populations, including heart, lung, kidney, liver, intestinal, and multivisceral transplant populations, either pre- or post-organ transplantation; and (v) included an objective measure of parent report of psychological, family, or marital functioning. Initially, the authors aimed to complete a meta-analytic review; however, search results yielded an insufficient number of studies with comparison group data and/or data needed for the computation of raw effect statistics for between-groups comparisons. Studies specific to sibling functioning only were not included in this review.

2.3 | Data extraction and study coding

Each included study was coded for patient and family outcomes and evaluated for potential bias by the first two authors (MC and KR). Data extracted from each study included transplant sample characteristics (organ population, pre-/post-transplant, age), parent and family characteristics, use of a comparison group, assessment measures, and overall findings. Sample size, control group comparisons, use of established measurements, multimodal and multi-informant assessment, and data attrition, including missing, lost, or excluded data, were all considered when assessing studies for risk of bias. Bias analysis revealed that in all of the studies, a minimum of at least one parent-completed questionnaires was used. Although few authors included psychometric data in their manuscripts, all of the studies included use of at least one commonly used, valid and reliable measure of either psychological, family, or marital functioning.

3 | RESULTS

3.1 | Study characteristics

Following the PRISMA guidelines, our search yielded 617 studies, after excluding duplicate studies (n=61). See Figure 1 for the PRISMA flow diagram. Of the studies excluded, the majority did not include a pediatric SOT population or did not utilize a quantitative measure of

parent and/or family functioning. The 37 studies meeting inclusion criteria were further reviewed, and data were extracted according to our predetermined questions of interest. Within these 37 studies, year of publication ranged from 1988 to 2015, with approximately half of the studies published more than 10 years ago (n=18), and 11 studies published within the last 5 years. Many studies (n=12) included SOT patients across multiple organ groups. Eleven of the included studies examined only kidney transplant populations, followed by nine studies looking at only liver transplant populations. Five studies included heart transplant patients only. The overwhelming majority of included studies examined only pediatric patients post-transplant (n=27), as compared to only pretransplant patients (n=6) or both pre- and post-transplant patients (n=4). Included studies examined pediatric patients within the United States (n=27), as well as other countries: Japan (n=3), Germany (n=1), Canada (n=1), United Kingdom (n=1), Norway (n=1), Switzerland (n=1), Argentina (n=1), and Australia (n=1).

3.2 | What is the impact of pediatric SOT on parent psychological functioning?

3.2.1 | Parent psychological functioning

Results are summarized in Table 1. Findings specific to parent psychological functioning were found to be inconclusive across the literature. For example, in a study of 86 mothers and 58 fathers of children prekidney transplant, scores on a commonly used adult depression measure were predominately in the minimal to mild range, with <6% of mothers endorsing severe symptoms.[21] Consistent with this finding, in a sample of mothers of 14 children ages 3-8 who underwent a kidney transplant in the past 3 years, mean scores on a parent-completed global mental health rating scale were in the average range.[22] Others have reported similar findings when assessing depression and anxiety in parents post-heart, kidney, and liver transplant.[23]

However, contrary to these findings, in a sample of 61 parents (41 mothers and 20 fathers) of children pre- or 2 months post-liver and/or intestinal transplantation, 51% of parents reported clinically significant psychological symptoms on a global distress rating scale. There were no differences observed with regard to time at assessment (ie, pre- or post-transplantation).[24] Similar findings were reported by Diseth and colleagues[25] in a post-kidney transplant population, noting that mothers' reports of mental health problems were greater than healthy controls and similar to mothers of children with leukemia. Simons and colleagues found that mothers of pre-SOT patients reported greater global distress than normative populations with those mothers of listed patients reporting greater distress than those who were not listed.[26] Although Douglas and colleagues reported mean scores within the average range for mothers of kidney transplant recipients, over 50% of fathers reported clinically significant mental

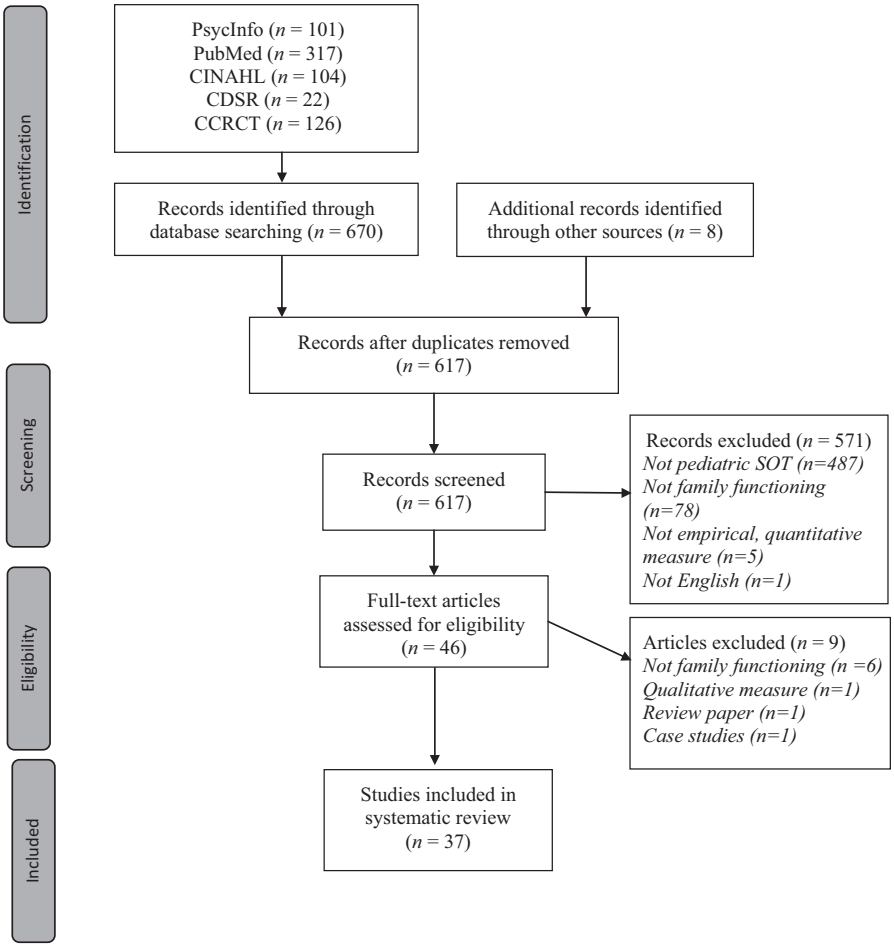

FIGURE 1 PRISMA flow diagram

TABLE 1 Parent and family functioning in pediatric SOT

Study	Transplant type	Parent sample	Compare group	Measures	Results
Heart					
DeMaso et al. (2004)[47]	Post-transplant 3.7-20.8 y	N=23 parents		GARF	Lower family functioning at time of transplant was related to lower child psychological functioning post-transplant
Farley et al. (2007)[28]	Post-transplant mean age=12	Mothers (N=46), fathers (N=6)	None	PIP, PDS	56% of parents indicated moderate PTSD symptoms, 39% of parents indicated moderately severe to severe post-traumatic stress symptoms; 10 parents met for clinical significant PTSD. Frequency and difficulty of parenting stress related to caring for an ill child was significantly associated with symptoms of post-traumatic stress
Suddaby et al. (1997)[35]	Pretransplant 2 wk to 13 y	N=26 mothers and fathers	None	FILE, FCOPES	Parents reported moderate levels of stress. No difference in scores between mothers and fathers. No relationship between parental perceptions of child's health status and stress levels
Uzark & Crowley (1989)[31]	Post-transplant 6 mos to 16 y	N=10 parents	None	CICI, FFFS	A majority of parents had concerns regarding the uncertainty of their child's future and reported having little control over their child's condition. Most commonly reported stresses were related to the uncertainty of the child's future health and well-being, role strain, social isolation, and financial burdens
Uzark et al. (1992)[32]	Post-transplant 8-18 y	N=49 families	Normative comparison	FILE, FIRM, CHIP, CICI:PQ	Families of pediatric transplant patients reported significantly greater family stress. SES was not significantly correlated with family stress. Child behavior problems were significantly associated with greater family stress
Kidney					
Anthony et al. (2010)[29]	Post-transplant 2-18 y	N=21 parents	Parent proxy of healthy children	PedsQL FIM	Parents of all age groups had low scores on emotional function and worry. Parents of younger children had lower family and emotional functioning. Despite good general health and QOL, parents reported high negative impact of transplant on family, mostly in psychological functioning
Diseth et al. (2011)[25]	Post-transplant (kidney); median age=13	Mothers (N=32)	Healthy controls and children with leukemia	General Health Questionnaire (GHQ), Quality of Life Scale (QOLS)	Mothers of transplant children reported significantly greater mental health problems as compared to mothers of the healthy controls, but comparable to mothers of children with ALL. Mothers who were parental donors to their children reported significantly more mental health problems and lower QOL compared to mothers who were not parental donors
Douglas et al. (1998)[22]	Post-transplant, 2-8 years old	N=14 mothers and fathers	None	GHQ, PSI, CHIP, FCOPES	Mean maternal GHQ score was within average range; mean paternal GHQ score was above average range. Half of fathers reported clinically significant mental health symptoms
Fedewa & Oberst (1996)[33]	Post-transplant 4-17 y	N=20 mothers and fathers	None	CBS, ACS, POMS-S	Caregivers reported the greatest demand in the areas of increased housework, running extra errands, giving emotional support, and providing transportation. The younger the patient, the more perceived caregiver demands. Length of illness and SES were unrelated to measures of parent functioning
Foulkes et al. (1993)[12]	Post-transplant 6-21 y	N=32 mothers and fathers	None	FACES, FILE	Parent and family functioning and support related to health variables, such as medication adherence

(Continues)

TABLE 1 (Continued)

Study	Transplant type	Parent sample	Compare group	Measures	Results
Fukunishi & Kudo (1995)[41]	Post-transplant, 6-15 y	N=53 mothers	Matched healthy controls	FES	There were no significant differences in family cohesion, expressiveness, or conflict in transplant families compared to control families. Transplant families had significant lower scores in the area of independence and achievement orientation
Gerson et al. (2004)[13]	Post-transplant, 2-20 y	N=12 caregivers	Non e	PSI/SF, FES	Mean parental distress scores were higher in the possibly non-adherent group compared to the probably adherent group. Better child behavior was associated with better medical adherence. Higher family achievement orientation was associated with poorer medical adherence
Guilfoyle et al. (2011)[14]	Post- transplant, 7-18 years old	N=45 caregivers	None	FACES, PCFES	Family efficacy and flexibility may minimize perceptions of adherence barriers and promote better adherence. Younger patient age was correlated with less family efficacy. Lower SES was associated with poorer functioning
Soliday et al. (2000)[42]	Post-transplant mean age=14.21	N=14 mothers and fathers	Children with kidney disease and healthy controls	FES, PSI-SF	Family environment variables significantly predicted child behavior and parent stress for both parents of ill and healthy children. No differences in family functioning
Soliday et al. (2001)[16]	Post- transplant, mean age=14.21	N=14 mothers and fathers	Children with kidney disease	FES, CMI	Higher family conflict predicted higher externalizing behavior problems in the child. Family environment and cohesion had a significant effect on medical indicators. SES and child gender were not associated with functioning
Zelikovsky et al. (2007)[21]	Pre transplant, 6-18 y	N=144 mothers and fathers	Non e	PIP, BDI-II, BC	Mothers experienced more stress than fathers related to their child's condition. There was a negative relationship between length of time since diagnosis and depression. For mothers, the degree of illness-specific stress predicted higher depression. Scores on BDI were majority minimal to mild range
Liver					
Alonso et al. (2008)[43]	Post-transplant 2-18 y	N=102 families	Healthy control	FAD	Compared to healthy control, no increase in family dysfunction in SOT. Lower education, full-time employment, and younger patient age had a significant impact on FAD subscale scores
DeBolt et al. (1995)[38]	Post-transplant, 5-18 y	N=41 mothers and fathers	Normative sample of parents to chronically ill children	IFS	Parents of post-transplant children did not have increased personal strain compared to children with other chronic illnesses. Length of illness, age at transplant, years post-transplant, # of hospitalizations, and SES had no association with functioning
Denny et al. (2012)[49]	Post-transplant 3-16 y	N=30 caregivers	Non-transplant children	FAQ, PedsQL 3.0 transplant module parent report	Impaired family functioning was associated with decreased QOL. There was a significant difference in adjustments made to family routines and more alterations to accommodate children in transplant families compared to control. Transplant families made more adjustments in all areas except for seeking information related to caring for children

(Continues)

TABLE 1 (Continued)

Study	Transplant type	Parent sample	Compare group	Measures	Results
Kaller et al. (2014)[40]	Post-transplant, 1-18 years old	N=170 caregivers	Normative sample of families w/ disabled or chronically ill child	IFS (German)	Age of patient at survey, more severe clinical course, restrictions following transplant, and financial losses follow transplant were significant predictors of the total score in the IFS. Higher strain in families was associated with more emotional and behavioral disturbances in children
LoBiondo-Wood et al. (2000)[34]	Pretransplant 0-12 y	N=29 mothers	None	FILE, NSSQ, CHIP, PPUS, POMS, FAD	Many relationships detected; correlations detected between increased family strains, fewer coping skills, and unhealthy family adaptation
Posfay-Barbe et al. (2013)[52]	Pre/post-transplant Age range NR	N=35 mothers and fathers	None	Pir-Gas, GAF	Higher maternal functioning was significantly associated with a higher child developmental quotient. Child functioning is related to parental functioning
Sanchez et al. (2010)[44]	Post-transplant 5-18 y	N=54 mothers and fathers	Normative sample, chronically ill patients w/ JIA	CHQPF50	Parents of LT patients scored similar to the normal population and parents of JIA patients in family activities and cohesion scales Family functioning appeared normal
Splinter et al. (2015)[39]	Pre/post-transplant 2-18 y	N=35 parents/ caregivers	Healthy controls	Parent free response	There were no statistically significant differences in scores between families with and without LT. Parents reported positive impacts of LT in their free responses
Stone et al. (1997)[45]	Post-transplant	N=20	None	GARF	90% of parents reported being able to pursue their own interests. According to the GARF scale, 70% of families were functioning within the normal range
Multi-organ					
Devine et al. (2011)[48] (heart/lung/kidney/ liver)	Post-transplant, 11-20 y	N=80 mothers and fathers	None	FES	Greater family conflict was associated with poorer child health-related quality of life
Ingerski et al. (2010)[27] (heart/lung/kidney/ liver)	Pretransplant, 6-15 y	N=64 mothers and fathers	Chronically ill children (sickle cell, HIV)	IES-R, PTSRI	Parents of transplant recipients had greater symptoms of PTSD which persisted post-transplant
Kikuchi et al. (2015)[46] (heart/kidney/liver)	Post-transplant, 1-19 y	N=82 mothers and fathers	None	HRQOL, PBNS, Family APGAR, SSS	Parent mental component score (MCS) was significantly correlated with family functioning and all the subscales of family social support. Parent role/social component score (RCS) was significantly correlated with family functioning and non-family social support
Lerret & Weiss (2011)[37] (heart/ kidney/liver)	Post-transplant, 3 mos to 18 y	N=37 mothers and fathers	None	PDCDS, PedsQL FIM	Family functioning, as measured by the PedsQL, improved after transplantation. There was an association between parent readiness for hospital discharge and family functioning improvements after 3 wk post-discharge
Lerret et al. (2015)[51] (heart/kidney/liver/ lung/multivisceral)	Post-transplant, 3 wk to 17.5 y	N=51 mothers and fathers	None	PDCDS, PedsQL FIM, FaMM	Parents who were more ready to leave the hospital reported less difficulty coping, less impact on the family 3 wk following discharge, and easier family management of child's condition. Higher readiness for hospital discharge is related to improved family management ability

(Continues)

TABLE 1 (Continued)

Study	Transplant type	Parent sample	Compare group	Measures	Results
Mavis et al. (2015)[50] (kidney/liver)	Post-transplant, 5-18 y	N=47 mothers and fathers	None	PedsQL FIM,	Child functioning was negatively associated with greater family impact
Rodrigue et al. (1997)[30] (kidney/liver/heart/ bone marrow)	Pre/post-transplant, Age range NR	N=27 Mothers	None	PSI, CHIP, FES, IFS, FIRM	Stress levels were higher in mothers pretransplant and immediately post-transplant. The impact on family functioning of transplantation appears to be long-lasting. SES appears to be associated with these stress, coping, and family functioning variables
Rodrigue et al. (1996)[36] (kidney/liver/heart/ bone marrow)	Pretransplant Age range NR	N=18 fathers	Normative samples for each measure	PSI, FES, IFS	Father PSI scores were significantly lower than previously reported mother scores of PSI, and lower than the normative sample for PSI, FES. Fathers had higher scores than the norms on financial stress, disruption of family activities, and increased perceived family burden
Simons & Blount (2007)[15] (heart/ kidney/liver/lung)	Post-transplant, 11-21 y	N=78 mothers and fathers	None	PMBS/ AMBS, MAM, FRI	Greater family cohesion and expressiveness, as well as less family conflict, was associated with fewer perceived medication barriers and less disease frustration. SES was not associated with functioning
Simons et al. (2007)[26] (heart/kidney/liver/ lung/bone marrow)	Pretransplant, 0-18 y	N=34 mothers N=22 fathers	Adult non-patients	BSI, CSI-S, MSPSS	Mothers reported significantly greater distress than non-patient norms Fathers' distress was elevated compared to norms, but was not significant
Tarbell & Kosmach (1998)[24] (liver/ intestine)	Pre/post-transplant, Age range NR	N=61 mothers and fathers	US general population	BSI, PSI; SF-36 HS; FES, CHIP	A majority (51%) of the parents reported clinically significant psychological distress symptoms. Fathers reported higher levels of distress. Scores on BSI/GSI did not differ pre vs post-transplant. PSI did not differ from normative population. SES and type of transplant were unrelated to functioning. Greater family conflict, and younger children were associated with poorer parent psychological functioning and greater parent stress
Young et al. (2003)[23] (heart/kidney/liver)	Post-transplant 0-19 y	N=170 caregivers	None	PDS, BDI, STAI; HCOS; IFS; SSS	Depression and anxiety scores were not clinically significant. Half of parents reported at least moderately severe PTSD symptoms, with 27.1% meeting DSM-IV criteria for PTSD diagnosis. Parent perception of worse health of their child related to more severe reported PTSD symptoms

GARF, Global Assessment of Relational Functioning (GARF); PIP, Pediatric Inventory for Parents; PDS, Post-traumatic Diagnostic Scale; FILE, Family Inventory of Life Events and Changes; FCOPES, Family Crisis Oriented Personal Scales; CICI, Chronicity Impact and Coping Instrument, FFFS, Feetham Family Function Survey; FIRM, Family Inventory of Resources for Management; CHIP, Coping Health Inventory for Parents; CICI:PQ, Chronic Illness Coping Inventory: Parent Questionnaires; PSI, Parenting Stress Index; PSI/SF, Parenting Stress Index-Short Form; CBS, Caregiving Burden Scale; ACS, Appraisal of Caregiving Scale; POMS, Profile of Mood States; POMS-S, short form of Profile of Mood States; FACES, Family Adaptability and Cohesion Evaluation Scale; FES, Family Environment Scale; PCFES, Perceived Collective Family Efficacy Scale; BDI, Beck Depression Inventory-2nd ed.; BC, Brief Cope; FAD, Family Assessment Device; IFS, Impact on Family Scale; PTSRI, Posttraumatic Stress Disorder Reaction Index; PedsQL FIM, PedsQL Family Impact Module; BSI, Brief Symptom Inventory; SF-36 HS, SF-36 Health Survey; GSI, Global Severity Index; IES-R, Impact of Events Scale-Revised; NSSQ, Norbeck Social Support Questionnaire; PPUS, Parent Perception of Uncertainty Scale; PMBS/AMBS, Parent and Adolescent Medication Barriers Scales; MAM, Medication Adherence Measure Medication Module; FRI, Family Relationship Index; GHQ, General Health Questionnaire; HCOS, Health Care Orientation Scale; SSS, Study Social Support Survey; FAQ, Family Accommodation Questionnaire; PBNS, Perceived Burden of Nurturing Scale; Pir-Gas, Parent Infant Relationship Global Assessment Scale; FaMM, Family Management Measure; CHQPF50, Child Health Questionnaire Parent Form; CSI-S, Coping Strategies Inventory Short Form; MSPSS, Multidimensional Scale of Perceived Social Support; STAI, State Trait Anxiety Inventory; PDCDS, Post-Discharge Coping Difficulty Scale.

health symptoms.[22] Others have also reported that fathers endorsed greater psychiatric distress, such as depression and obsessive compulsive symptoms, when compared to mothers.[24] However, this finding has not been conclusively replicated across the literature.[21]

Rates of PTSD have also been found to be high in parents of SOT candidates and recipients. When compared to other chronic illness populations (ie, HIV and sickle cell), parents of children undergoing evaluation for transplantation (ie, solid organ and bone marrow) reported greater symptoms of PTSD.[27] Symptoms of parental PTSD may also persist years post-transplantation. In a study of 170 parents, 50.6% of the sample reported moderate levels of post-traumatic stress symptoms. Per DSM-IV criteria, nearly one-third of the sample met criteria for PTSD.[23] Similar findings were reported by Farley and colleagues.[28]

3.2.2 | Parenting stress

Although Tarbell and Komasch[24] found that general parenting stress in the months following SOT was similar to healthy comparison groups, others have reported that moderate to high levels of parenting stress and burden continue beyond the pretransplant phase and post-surgical hospitalization.[29–32] In a cross-transplant population (including liver, kidney, heart, and bone marrow recipients), parenting stress was greatest at 1 month post-transplant with 56% of mothers reporting clinically significant levels of parenting stress. Forty-one percent of mothers continued to report similar levels of parenting stress 6 months post-transplant.[30]

This may be a result of sustained stressors and worries. For example, in a sample of 10 parents of children 3-24 months post-heart transplantation, 89% of participants endorsed high amounts of stress related to the uncertainty of their child's future and extra demands on time/energy.[31] Similarly, in a sample of 20 parents of children ages 4-17 years who were post-kidney transplant, respondents stated that increasing housework, providing emotional support, and managing behavior problems were their most difficult tasks, while monitoring for signs of a rejection was a time-consuming task.[33] Many parents (89%) also described feeling as although they had little control over their child's condition.[31] Nearly a third of mothers of young kidney transplant recipients perceived that others blamed them for the child's health issues, while 57% blamed themselves.[22]

3.3 | What is the impact of pediatric SOT on family functioning?

3.3.1 | Family stress and burden

Researchers have also examined parental report of overall family stress and burden. In the pretransplant evaluation phase, mothers of liver transplant candidates reported high family stress.[34] Similarly, 77% of parents (N=26) of children actively listed for heart transplantation endorsed family stress levels greater than population norms.[35] Consistent with these findings, in a sample of only fathers of children being evaluated for transplantation (ie, liver, kidney, heart, or bone marrow), respondents described greater financial stress, family burden, and disrupted planning as a result their child's illness when compared to the normative sample.[36]

Findings from Lerret and Weiss[37] suggest that families may experience a decrease in burden from the day of hospital discharge to 3 weeks post-discharge. In a sample of 41 parents whose child underwent liver transplantation ≥4 years ago, negative impact of illness on the family system was reported to be less than other pediatric chronic illness groups.[38] Findings, however, are not consistent across the literature. For example, in a small cross-transplant longitudinal study, family burden, financial burden, and caretaker burden were greater in the post-transplant period when compared to assessments conducted during pretransplant evaluations.[30] Splinter and colleagues recently demonstrated that family impact of disease is similar in families of children post-liver transplant and those of children living at home with other chronic conditions.[39] Kaller and colleagues also found that parents of liver transplant recipients, with a mean time since transplant of 5.8 years, reported that the burdens associated with their child's condition caused greater financial impact, impact on family coping, and impact on siblings when compared to a sample of families of children with other chronic illnesses/disabilities.[40] These results have been replicated in parents of kidney transplant recipients who endorsed high levels of family burden post-transplant, particularly in the areas of emotional functioning and worries.[29]

3.3.2 | Family functioning

Fewer studies have described the relationships between pediatric SOT and family functioning. In a mixed SOT group, family conflict was greater at 6 months post-transplant when compared to 1 month post-transplant.[30] Overall, however, the limited work in this area suggests that family functioning in pediatric SOT populations is similar to healthy controls. For example, in a Japanese sample of children both pre- and post-kidney transplant, there were no differences reported in family cohesion, expressiveness, and conflict when compared to healthy controls.[41] Similar findings were reported in a small US sample of kidney transplant recipients[42] and in three studies involving liver transplant recipients.[43–45]

3.4 | What variables are associated with poorer parent and family functioning in the pediatric SOT population?

3.4.1 | Family factors

Mixed findings have been reported with regard to family SES with some studies demonstrating associations between lower SES and poorer parent and family functioning,[14,17,21] and others citing no associations.[24,26,32,33,38,42] Parental education and marital status were unrelated to parenting stress and depressive symptoms in a large sample of mothers and fathers of children prekidney transplant.[21]

Greater family conflict[24] and illness-specific parenting stress[21] have been found to be associated with poorer parental psychological

functioning. A similar relationship between unhealthy family function and decreased parental emotional and physical quality of life was detected in a Japanese post-SOT population.[46] Parents who endorse lower family functioning at time of transplant are more likely to report deficits in family functioning years post-transplant.[47]

3.4.2 | Child factors

Associations between younger child age at time of assessment with greater parenting stress,[24,29,40] caregiver demands,[33] and less family efficacy for completing necessary tasks[14] have been reported. However, two studies were unable to detect relationships between child age, parent psychological functioning, parenting stress, and family functioning.[26,30] In one study, parents of female kidney transplant recipients reported better family communication and efficacy when compared to their male counterparts.[14] Others have found no relationship between child gender and parent-reported stress or depressive symptoms in pretransplant populations.[21,26]

With regard to child psychological functioning, greater family conflict was associated with increased externalizing behavioral problems in children post-kidney transplant[16] and poorer child health-related quality of life in a mixed SOT population.[48] Similarly, greater family stress positively correlated with increased child emotional and behavioral problems in post-liver[40] and post-heart transplant populations.[32] Fewer adjustments to family routines and lifestyle (eg, moving homes, increasing supervision of child during play) following liver transplantation were associated with better child quality of life.[49]

3.4.3 | Health-related factors

In addition to family and child factors, health-related correlates of parent and family functioning have also been investigated. Type of transplant was unrelated to parent psychological functioning[24] and parent-reported levels of PTSD.[23] Time since diagnosis was unrelated to parenting stress and depressive symptoms in a prekidney transplant population.[21] Similarly, in samples of post-kidney (2-14 months) and liver (≥4 years) transplant recipients, child length of pretransplant illness, age at transplant, years post-transplant, and number of hospitalizations were unrelated to caregiver and family burden.[33,38] In accord with the above findings, length of transplant hospitalization was unrelated to parenting stress and family functioning in a cross-transplant population.[30]

Parental perception of their child's illness severity was unrelated to parenting stress in a heart transplant population.[35] Similarly, child adaptive functioning/functional status was unrelated to parental psychological functioning and general parenting stress in the pre- and perioperative transplant phases in another study.[24] Others have reported discordant findings with regards to family impact of disease and child functional status[50] and clinical course severity.[40] Consistent with the broader pediatric literature, poorer child physical health was associated with increased parent PTSD symptoms.[23] Likewise, if parents perceived their child to be more vulnerable post-SOT, family impact of disease was greater.[50]

Notably, across multiple studies, parent and family functioning was found to be related to important health-related variables, such as adherence to immunosuppressant medications.[12,13] For example, in 13 post-kidney transplant recipients, greater general parenting stress was associated with poorer adherence to immunosuppressant medications per physician review of serial laboratory levels.[13] Consistent with these findings, greater familial efficacy and flexibility have been shown to be related to fewer perceived medication adherence barriers.[14] Greater family cohesion and expressiveness, as well as less family conflict, are also associated with fewer adolescent reported medication barriers and lower disease frustration.[15]

In addition to medication-related outcomes, parent and family functioning has been found to be associated with readiness for hospital discharge[51] and number of hospitalizations. In a mixed sample of children with kidney disease, including those with end-stage renal disease and post-transplant recipients, less family cohesiveness was associated with greater number of hospitalizations, accounting for 10.24% of the variance.[16] Although no studies reviewed investigated relationships between parent and family functioning and graft survival, healthier maternal psychological functioning was positively correlated with better psychomotor development in a liver transplant population, comprising 21 children from seven different countries.[52]

4 | DISCUSSION

To our knowledge, this was the first study to systematically review and synthesize the research on parent and family functioning in pediatric SOT populations. Reviews of this nature are important, providing an accessible integration of the literature to assist in guiding future research efforts, while also identifying inconsistencies and gaps in the science to date. Consistent with findings across the pediatric chronic illness literature,[10] results of this systematic review suggest that parents of children pre- and post-SOT endorse significant parenting stress and burden. Our findings are also consistent with those reported across the adult SOT literature where high rates of caregiver psychiatric illness[53] and caregiver strain[54] have been documented well beyond the pre- and immediate post-transplant periods.

Furthermore, although findings were inconsistent across some studies, results of this review suggest that parents of pediatric SOT patients are at increased risk for depression and PTSD. For example, Young and colleagues found that one-third of parents of children post-SOT met criteria for a diagnosis of PTSD[23] compared to only 3.5% of adult community samples meeting criteria for current PTSD.[55] Rates of parental PTSD among pediatric SOT populations are similar to those of pediatric oncologic populations.[56] This review also identified consistent findings demonstrating an association between parent and family functioning and child health-related factors, such as adherence, fewer medication barriers, and number of hospitalizations. Although the direction of this association is unknown per the current literature, findings are concordant with those across other childhood chronic illness populations.[57–59]

Given associations between parent and family functioning and child health-related factors, it is critically important that we seek to identify correlates of poorer parent and family functioning, as these may serve as modifiable intervention targets. Interestingly, no family demographic factors were conclusively identified as correlates of parent and family functioning. For example, only three studies detected an association between family SES and parent and family functioning,[14,21,30] while a number of studies reported a null relationship between the variables.[15,16,33] To date, this literature has not thoroughly investigated other parent and family factors that have been identified to increase risk of poorer parental psychological outcomes in other pediatric illness groups. For example, as suggested by Mavis and colleagues[50] and findings across other pediatric illness groups,[10] it may be that parental cognitive appraisals (eg, perceived vulnerability of child, parental self-efficacy regarding disease management), best explains why some parents of pediatric SOT patients are at greater risk for poorer psychological outcomes.

Similarly, no transplant-specific factors (eg, type of transplant, time since transplant) were associated with parent and family functioning. Others have reported null relationships between illness duration and parent and family psychosocial outcomes among other pediatric illness populations.[10] Again, it may be that important health-related variables have been overlooked by the transplant literature to date. For example, review of the larger pediatric chronic illness literature suggests that parents with greater responsibility for the child's treatment regimen report greater stress and burden.[10] Thus, although differences in etiology, treatment course, and survival rates are present across the organ groups, findings underscore the importance of screening all families, regardless of organ type or other transplant-related factors, until health-related risk factors are better understood.

Across the literature, younger child age at time of assessment was associated with more negative parent and family sequelae. This may in part be due to the fact that parents of younger children take primary responsibility for the complex medical management of SOT patients. Younger children are also more likely to experience greater procedural distress and medically associated fears;[60,61] therefore, the frequent blood draws and appointments may be difficult for parents as they regularly see their child in distress. In addition, parents of younger children may be newer to the demands of parenting or with their first child. Researchers have reported similar findings in parents and families of children with diabetes,[62] cancer,[63] and other chronic illnesses.[64] Child emotional and behavioral problems were also associated with poorer parent and family functioning.[16,40] Although the direction of this relationship is unclear, parents reporting child psychological problems may also benefit the most from parent- or family-directed interventions as well.

4.1 | Limitations of the literature and future directions for research

Overall, this literature is limited by small sample sizes; thus, results must be interpreted with caution. Many studies had fewer than 30 participants. Most studies were conducted at single centers and combined various transplant groups (ie, pre- and post-transplant, organ types, SOT, and stem cell). In addition, studies span multiple decades and significant advancements have been made in SOT and survival rates throughout this vast time span. These may explain the many inconsistent findings across the literature. Some studies may have been underpowered to detect associations, while others may have included too diverse of participants. For example, heart, lung, and liver transplant patients do not have long-term alternative treatments available, whereas kidney transplant patients can be maintained on dialysis for years until a suitable organ becomes available and/or in the instance of disease re-occurrence.

Secondly, the majority of research in this area has been carried out in pediatric kidney and liver transplant populations. Very few studies investigating parent and family functioning in heart, lung, intestinal, and multivisceral populations were identified. In addition, studies used a variety of assessment measures to assess a number of different domains relevant to parent and family functioning. These differences in measurement selection and constructs of interest likely contributed to the inconsistent and discordant findings among studies. Selection bias is also of potential concern as parents who were more or less stressed may have been more agreeable to participating in the studies. Lastly, much of the work to date has been cross-sectional in nature limiting our ability to determine causality. Based upon the current literature, we cannot conclude that pediatric SOT causes increased parent and family distress. Nevertheless, it is apparent that families of children with SOT report higher levels of family stress and burden, which is worthy of further investigation.

Thus, with regard to future directions for research, longitudinal investigations are needed to better understand relationships and causality, identify times of greatest risk for parent distress and family dysfunction, and determine the long-term impact of parent and family functioning on patient health-related outcomes. In addition, family- and disease-specific factors that may impact parent and family distress should be further explored. Distance from hospital and family size are two important family-related variables that have not yet been explored. Furthermore, are parents of children with genetically inherited diseases, such as familial dilated cardiomyopathy, at greater risk due to feelings of guilt or perceptions that they "caused" transplantation for their child? Diseases with high rates of re-occurence, such as focal segmental glomerulosclerosis, may also cause greater stress and burden on family systems, as could the prospect of re-transplantation, which is imminent in some organ groups.

In addition, while associations between parent and family functioning and some patient psychosocial and health-related outcomes have been examined, additional work in this area is needed. Only two studies have tested relationships between parent and family functioning and patient adherence to treatment regimen. Research in other chronic illness groups suggests that parent and family functioning strongly predicts adherence outcomes.[57,58] Other health-related outcomes as they relate to parent and family functioning, such as graft survival, readiness for transition to adult care, involvement in medical decision-making, and health-related quality of life should also be explored.

4.2 | Clinical implications

Clinically, results of this review underscore the value of assessing parent and family functioning as part of regular pre- and post-transplant care given associations with patient health-related outcomes. It is important to note that not all stress is abnormal and actionable. Pediatric transplantation is indeed an understandably stressful intervention, and some degree of worry, burden, and impact on the family system is expected. However, it remains critically important to identify those parents and families with clinically significant psychosocial impairments.

A number of brief parent and family screening measures exist to assist providers in identifying these parents and families. Measures used across this literature vary greatly. Researchers used measures of either parental psychological functioning (symptoms of depression, PTSD, etc.) or family functioning. Measures of family functioning included assessment of general and illness-specific family stress, overall family functioning, and changes in family routines, among others. None of the measures used in the articles reviewed assess both parent psychological and family functioning in one tool. From a research standpoint, use of construct specific measures (eg, parental depression vs family stress) can yield greater clarity; however, in clinical practice, it is often most helpful to utilize brief screening measures that can be quickly administered and reviewed. The PAT, which is comprised of seven subscales (ie, Family Structure and Resources, Social Support, Child Problems, Sibling Problems, Family Problems, Parent Stress Reactions, and Family Beliefs), has been validated for use in pediatric SOT populations.[65,66] Use of a brief screening tool, such as the PAT, helps to identify parents and families in greatest need of additional intervention. Upon reviewing the PAT, more specific measures based upon areas of identified risk, like those used in the reviewed articles, can then be utilized.

Upon identifying those at greatest risk, it is necessary that appropriate follow-up intervention then be provided. For parents endorsing symptoms of depression or PTSD, for example, referral for local therapy and/or psychopharmacological evaluation may be necessary. For those reporting high rates of family stress or disruptions to family routines, intervention may include in-clinic problem-solving and psychoeducation provided by transplant-affiliated mental health professionals, such as psychologists and social workers. Given the limitations of what can be provided during transplant clinic settings, group-based interventions that serve a larger number of families in need may be particularly fruitful. Kazak and colleagues developed a 1-day family-based group cognitive behavioral intervention for those affected by childhood cancer.[67] This brief intervention aimed to decrease parent and family distress and improve family functioning. Participants reported decreases in parental anxiety and PTSD, which were sustained 6 months following participation in the group. This program could be adapted to meet the unmet needs of parents and families of the pediatric SOT population; however, concurrent investigation of its effectiveness through the conduct of randomized controlled trials would be also needed to best determine the intervention's impact on family and child psychosocial outcomes, as well as child health-related outcomes.

4.3 | Study limitations

Results of this review should be considered in light of our own study limitations. Although efforts were made to identify all relevant research, some studies may not have been identified and included in this review. Search terms were broad in an attempt to capture the many ways one may refer to parent and family functioning; however, given great variation in terminology used, studies meeting inclusion criteria may not have come up in the database searches. Furthermore, in the reviewed articles, authors use an array of terms to describe and measure family functioning (eg, family stress, family burden, family distress). Without clear definitions and/or concurrent validity tests among all of these measures, it is unclear how similar or dissimilar each construct of interest is. The inclusion criteria were also limited to studies including a quantitative measure of parent and/or family functioning. Therefore, notable qualitative studies that have highlighted issues important to understanding parent and family functioning in pediatric SOT, such as work by Mendes and Bousso,[68] Chou and colleagues,[69] and Williams and colleagues,[70] were not included in this review.

Despite these limitations, this first systematic review of its kind provides a helpful synthetization of the pediatric SOT literature and highlights necessary next steps for action. Given the high rates of parental and family psychological distress, and their impact on child health and psychosocial outcomes, it is imperative that greater attention be given to screening and intervening upon parent and family stressors during both the pre- and post-transplant period. Further research is needed to determine whether or not interventional efforts of this nature have the potential to improve long-term graft and patient survival of pediatric SOT populations.

AUTHORS' CONTRIBUTIONS

Melissa K. Cousino: Concept/design, data analysis/interpretation, drafting article, critical revision of article, and approval of article; Kelly Rea: Data analysis/interpretation, drafting article, critical revision of article, and approval of article; Kurt R. Schumacher: Concept/design, drafting article, critical revision of article, and approval of article; John C. Magee: Concept/design, critical revision of article, and approval of article; Emily M. Fredericks: Concept/design, data analysis/interpretation, critical revision of article, and approval of article.

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