

## Pediatric Cardiac Transplant: Quality of Life of Urban Families

By

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To date, in the United States, there are approximately 122,000 individuals waiting for an organ transplant (HHS, 2015b). Of these, 2,092 are children between the ages of <1yr -17 years. In contrast, the number of living and deceased donors recovered in the United States for organ procurement in 2015 was approximately 15,067 providing 30,970 organ transplants (HHS, 2015a). With the number of patients waiting for an organ far outweighing the number of available donors, organs for transplant remain a very scarce resource. This scarcity has forced transplant centers to closely evaluate patients for listing to optimize successful transplant outcomes and maximize the quality of life of the transplant recipients.

The World Health Organization defines quality of life (QoL) as a “state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity” (WHO. Org). Significant advances have occurred in the area of pediatric cardiac transplantation to improve survival and QoL. Overall, median survival post- transplant for pediatric age groups is 12.4 to 20.6 years worldwide (Dipchand et al., 2015). However, despite these advances and having met the Organ Procurement and Transplantation Network (OPTN) requirements for social support pre-transplant, many pediatric recipients and their families in urban areas are struggling with post-transplant care. Difficulties with access to care, economic concerns, medication non-compliance, disappearing support systems, missed school and work, and family stressors present challenges for urban pediatric transplant teams.

The pediatric cardiac transplant program of an urban freestanding children's hospital is experiencing many of the aforementioned challenges within its cardiac transplant population. A significant amount of time and energy is spent by the transplant team developing creative interventions to optimize QoL for the recipients and their families. Assessment of QoL within this urban pediatric cardiac transplant population is vital, as the interpretation of the results could assist to inform the transplant team's education and support programs, including teaching/learning methods for families during informed consent, delivering of complex information regarding post-transplant care, and identification of social services that will best benefit the recovering family. Most importantly, assessing of QoL may allow for earlier recognition of transplant families in crisis. To date, no formal assessment of QoL is being conducted within this urban pediatric cardiac transplant center.

There is a consistent theme throughout transplant QoL literature. Though transplantation provides improved long-term survival of children who would otherwise succumb to end-stage heart failure, transplantation remains a substitution of one chronic health problem for another (Anthony, Barziv, & Lee Ng, 2010; Hollander et al., 2015; Shellmer, Brosig & Wray, 2014) Research reporting Quality of Life (QoL) of pediatric cardiac transplant recipients and their families concludes that the process of transplantation is difficult, challenging, and not without complications.

Post-cardiac transplant care is complex, and challenges begin as early as the time of discharge. Lerret & Weiss (2011) studied parents of pediatric solid organ transplant recipients and their readiness for discharge post-transplant. Parents were provided family impact and readiness for discharge questionnaires at the time of discharge and three weeks post discharge. Parents reported they felt ready for hospital discharge post-transplant, and were coping with the

care that the child required at home. Conversely, there were some discrepancies reported to the healthcare team when medications were reconciled, and several families had difficulties getting to the laboratory and transplant clinic for required blood draws and post-transplant follow-up. There was, however, improvement in family functioning from the time of discharge to three weeks post-discharge. The authors concluded that coordination of care by the transplant team was imperative for a successful post-transplant discharge (Lerret & Weiss).

Brosig et al. (2014) described several important factors that transplant teams should assess and monitor following pediatric solid organ transplant. These factors include transition to home, exercise and physical activity, nutrition, school, cognitive impact of transplant, family functioning, and QoL (Brosig et al.). Research suggests a formal assessment of family readiness for discharge should be conducted. Transplant teams should facilitate transition to formal cardiac rehabilitation/ physical therapy to assure return to pre-transplant lifestyle and activity. On-going nutritional assessments are essential to promote healing, appetite, and growth. Education for teachers and peers should be provided to alleviate the anxiety of both the child and school staff when returning to school. A neuropsychological assessment should be obtained as the child reenters the classroom as pediatric post-transplant recipients are at risk for neurocognitive impairments. Finally, ongoing family functioning and QoL assessments should be conducted very early post-transplant and followed longitudinally over time (Brosig et al., 2014; Kim & Marks, 2014).

QoL of pediatric cardiac transplant recipients and their families has been measured using various methods. Measurement tools have included generic versus disease specific quality of life tools, and methods of transplant patient self-report versus parent proxy report (Anthony et al., 2010). Studies describing QoL in pediatric solid organ transplant suggest that measurement of

QoL should be multidimensional, include both the transplant recipient and the caregiver, and use of an assessment battery approach (Annunziato et al., 2014; Kim & Marks, 2014).

Green, McSweeney, Ainley, and Bryant (2007) interviewed school-aged heart transplant recipients about their QoL. Several QoL themes surfaced from the interviews including, “Doing what kids do”, “Being with friends and family”, and “Being a heart transplant kid”. The children in the study reported their QoL to be “mostly good” and “easy and not easy”. Activities that were rated as “mostly good” included playing and attending school with friends, participating in activities with family, receiving emotional support from friends and family, and visiting the doctors and nurses in the clinic. Experiences that were rated as “Not easy” included feeling tired, having limitations on activities, feeling fear and pain associated with biopsies, and experiencing side effects from medications (Green, et al, 2007). Green, Meaux, Huett, and Ainley (2011) interviewed adolescent heart transplant recipients about their QoL. Three themes emerged from the interviews; “I am normal and not normal”, “I am grateful and resentful”, and “I am managing and not managing”. The adolescents were appreciative of their survival and ability to participate in “normal kid stuff” due to improved physical condition. Factors that impacted the QoL of the recipients included altered appearance due to scars and medications, strict medication regimens, self-care management and transition into independence, and wanting to “be like everyone else” (Green et al., 2011). Research of older adolescents and adult survivors of pediatric cardiac transplant supports that pediatric transplant recipients can live into adulthood, can graduate from high school and attend college, can live independently, maintain employment, and can develop close relationships (Hollander et al., 2015). Adolescent and young adult transplant survivors are, however, at risk for medical non-compliance. This noncompliant

behavior reduces QoL and has physical and psychosocial consequences (Albert, Hudalla, Traue, & Hetzer, 2012).

Research examining the parents' perspective of QoL of pediatric cardiac transplant recipients is limited. Green, McSweeney, Ainley, and Bryant (2008) interviewed the parents of school-aged heart transplant recipients as to their perception of the child's QoL post-transplant. Parents reported the overall QoL as "really very good" and "just like normal kids". Several themes emerged from the interviews that included "Enjoyable activities", "Normalcy", "Staying healthy", and "Source of strength and support". Parents felt that the children were not limited in activities, but did tire and could not always keep up with peers. They noted the importance of making the post-transplant management part of the normal routine. Several parents reported they were very strict with the medications and appointments, but that they did not "limit" the child because of the transplant. Several parents felt that family, God, and friends were a good source of strength (Green, et al., 2008). Green, Meaux, Huett, and Ainley (2009) interviewed the parents of pediatric cardiac transplant recipients who were 2 or more years post-transplant. Four themes emerged from the study including "Constantly responsible", "Constantly worried", "Constantly blessed", and "Coping with life". The parents described caregiving requirements as a constant and controlling factor in their lives. They reported having to be "constantly responsible" for medications and monitoring for infections and illness. They also described a great deal of worry about the child's health condition, medications, rejection, and normal activities. Despite the worry, parents described feeling "blessed" that the child was living. Coping strategies described by the parents included having faith, support from friends and family, and support from the transplant healthcare team (Green et al., 2009).

Weissberg-Benchell et al. (2010) recognized a gap in the literature examining QoL in pediatric transplant recipients and the lack of a tool that could measure post-transplant QoL. The authors felt that a transplant specific QoL tool would assist researchers to identify transplant recipients who were at risk for morbidity, non-compliance, and emotional distress. They suggested that a transplant specific tool for both recipients and parents would provide a better understanding of the complex nature of post-transplant QoL. Researchers investigated the feasibility, reliability and validity of the Pediatric Quality of Life Inventory™ (PedsQL™) 3.0 Transplant Module (Weissberg-Benchell et al.). Denny et al. (2012) and Mohammad et al. (2012) utilized the PedsQL™ 3.0 Transplant Module to study Health Related Quality of Life (HRQOL) of pediatric liver transplant recipients. There remains a gap in the literature with the use of this tool in measuring QoL in pediatric cardiac transplant recipients.

With the scarcity of organs for transplant, the tremendous challenges that are faced by pediatric cardiac transplant recipients and their families, and the paucity of pediatric cardiac transplant QoL literature, the purpose of this study was to describe the quality of life (QoL) of pediatric cardiac transplant recipients and their families in an urban setting, to examine differences in QoL between recipients and caregivers, and to determine if there was an effect on QoL by the number of years since transplant.

### **Theoretical Framework**

The Roy Adaptation Model (RAM) is the framework upon which this study of quality of life of urban pediatric cardiac transplant recipients was based. Roy (2009) views humans as changing and adaptive systems comprised of interdependent parts. The human adaptive system

is continually challenged with highly complex processes (stimuli). The ability of the human system to respond in a positive way to challenging stimuli is viewed by level of adaptation. Three levels of adaptation are described within the RAM: (a) integrated, (b) compensatory, and (c) compromised. According to Roy, it is the level of adaptation that affects the human system's ability to respond, thus affecting the behavior of the system. Output, or behavior, of the human system demonstrates the system's effectiveness to adapt to a given stimulus. Roy describes the resultant behaviors as fitting into one of four adaptive modes: (a) physiologic-physical, (b) self-concept group identity, (c) role function, and (d) interdependence. Adaptation of the human system is influenced directly by the ability of the system to cope with stimuli. The RAM can be applied to the individual human system or groups. The goal of nursing within the RAM is to promote system adaptation within each of the aforementioned modes (Roy, 2009).

Lefaiver, Keough, Letizia, and Lanuza (2007) utilized the RAM to guide research in the investigation of QOL in adult lung transplant candidates and their caregivers. The theory guided the researchers to identify appropriate tools to utilize within the study that would measure "stimuli", "coping", and "response", all important components of the RAM. Adaptation within Roy's adaptive modes was measured in lung transplant candidates and their caregivers using the Quality of Life Index and the Caregiver Reaction Assessment. The authors concluded that the RAM was an "excellent" framework for the study of QoL from the perspectives of adult lung transplant candidates and their caregivers (Lefaiver et al.).

Ordin, Karayurt, and Wellard (2013) used the RAM to guide research describing the experiences and adaptation of adult liver transplant recipients. An investigator developed tool was used to determine liver transplant recipient responses in the four adaptive modes contained in the RAM. The researchers concluded that the study indeed provided information as to the

adaptive behaviors of adult liver transplant recipients. They found that the transplant recipients required continued support for ineffective behaviors related to post liver transplant adaptation in all four of the modes of the RAM. Further, the authors noted that the use of the RAM was a good model to guide the care for liver transplant recipients (Ordin et al.).

For this study, pediatric post cardiac transplant management was conceptualized as a complex stimulus for both the individual pediatric recipient (Figure 1) and the recipient's caregiver and family (Figure 2). How recipients and their families coped with post cardiac transplant management, and the assessment of their levels of adaptation, were measured by demographic family data, the PedsQL™ Family Impact Module, and the PedsQL™ Transplant Module. Study variables were situated within each of the four adaptive modes as seen in Figures 1 & 2. Family Impact and QoL scores measured in the post-transplant interval reflected transplant recipients' and families' abilities to cope with and adapt to post cardiac transplant management.

## **METHODS**

### **Design**

This study used a descriptive comparative design, with a convenience sample of pediatric post-cardiac transplant recipients and their parents. Study participants received care from a freestanding urban pediatric children's hospital in the Midwest.

### **Setting and Sample**

Between January 1, 1988 and December 31, 2015, 8,297 pediatric cardiac transplants have been performed nationally (HHS, 2015c). State data within this same time period indicated



252 total pediatric cardiac transplants performed. Of the 252 pediatric cardiac transplants performed in the state since 1988, 62% were White Non-Hispanic, 31% Black, 4% Hispanic, 1.5% Asian/Pacific Islander, and 1% Mixed Race (HHS, 2015d). The total population of the city within which the study was conducted was reported to be 680,250, with the majority of the population described as being of black race (82.7%) and persons under 18 years of age making up 26.7%. Persons reported living in poverty was currently 39.8%, more than double the national poverty rate of 14.6% (census.gov). The setting of the study was the pediatric cardiac transplant clinic within a freestanding urban pediatric children's hospital. Permission to conduct the study was obtained from hospital and university Institutional Review Boards. The principal investigator (PI) spoke directly to eligible study participants receiving care from the pediatric cardiac transplant clinic. The PI described the study in detail to both parents and pediatric cardiac transplant recipients. Following introduction of the study, the informed consent process consisted of parental consent as well as adolescent assent or child oral assent. The Health Insurance Portability and Accountability Act authorization form was also presented. Of note, all recipients and caregivers who were approached readily agreed to participate. Cardiac transplant clinic was conducted twice weekly using a multidisciplinary team approach including pediatric transplant cardiologists, pediatric nurse practitioners, a transplant social worker, and a transplant dietician. Data collection occurred with pediatric cardiac transplant recipients and primary caregivers who presented to transplant clinic between December 2015 and February 2016. Inclusion criteria for study participation included pediatric cardiac transplant recipient's ages 1 month to 21 years of age. A convenience sample of forty-one recipients and caregivers met the inclusion criteria. The racial make-up of the sample included 23 (56%) Black, Non-Hispanic, 14 (34%) White, Non-Hispanic, 2 (4.8%) Asian/ Pacific Islander, 1 (2.4%) Hispanic and 1 (2.4%)

mixed-race. Exclusion criteria included patients over the age of 21 years who received care at this center, and patients who were currently in work-up or on the waitlist for cardiac transplantation.

## **Measures**

### *Demographic and Family Information*

The PedsQL™ Family Information Form was used to obtain demographics of the responders as well as the parents' perception of the child having a chronic health condition, hospital overnight and emergency room visits, days the child was sick, missed school or required additional care (in the past 30 days), missed parent work days, disruption of parent work routine, and parent inability to concentrate at work (in the past 30 days). Additional demographic characteristics surveyed by the PI included: age of primary caregiver, age of child at transplant, employment status, unable to work due to child with transplant, household income, housing, transportation, and required assistance of Child Protective Services post-transplant.

### *PedsQL™ 3.0 Transplant Module*

The PedsQL™ 3.0 Transplant Module is a transplant specific HRQOL tool. This transplant specific module consists of 46 items and is made up of 8 corresponding scales evaluating ease of taking medications, side effects of medications, social relationships, physical discomfort, worry, treatment anxiety, self-concept/appearance, and communication. The module is composed of parallel child self-report for those 5 to 18 years of age and parent proxy-report for children ages 2 to 4 years of age. Responses to the tool were evaluated on a 5-point Likert scale for the 8 to 18 year old children ranging from 0 (*never*) to 4 (*almost always*) and on a 3-point Likert scale from 0 (*not at all*), 2 (*sometimes*) and 4 (*almost always*) for young children 5

to 7 years of age. The scores were determined according to the stated information for scaling and scoring of the PedsQL™ inventory. Scores were transformed on a scale of 0-100. Higher transformed scores on the instrument indicated higher reported QoL (Weissberg-Benchell et al., 2010).

*PedsQL™ 2.0 Family Impact Module: Parent Family Impact Acute*

The PedsQL™ 2.0 Family Impact Module was developed for families with children who have a complex chronic medical condition and are residing at home. The tool contains 36 items within 8 tool dimensions assessing parent self-reported functioning including physical, emotional, social, cognitive, communication, and worry (Parent HRQOL). The tool also evaluates parent reported family functioning including daily activities and family relationships. Responses were evaluated on a 5-point Likert scale ranging from 0 (*never*) to 4 (*almost always*). The scores were determined according to the stated information for scaling and scoring of the PedsQL™ inventory. Scores were transformed on a scale of 0-100. Higher transformed scores on the instrument indicated higher reported QoL functioning. Reliability and validity of the module have been demonstrated (Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004).

## **RESULTS**

*Demographics and Transplant Impact*

Data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 23.0 (IBM). Twenty-four pediatric cardiac transplant recipients and 22 caregivers participated in the study. Two of the recipients were over the age of 18 years and did not require a caregiver at the clinic visit. Table 1 summarizes demographic characteristics of the study participants.

Precisely half of the recipients were male, 18 (75%) were 10-20 years of age, and the majority of

the recipients, 12 (50%), were Black Non-Hispanic consistent with the race of the population served in the transplant center. Eleven (45.8%) of the recipients were transplanted as an infant less than one year of age. Eighteen recipients (75%) were 10-20 years post-transplant. The majority of the primary caregivers were middle aged 35-44 yrs. (41.7%), noting that 2 (8.3%) of the caregivers were very young at 18-24ys of age. Single parent households were represented by just over 54% of the study population. Nine caregivers (37.6%) had a level of education that was high school graduate or less. Just over half of the caregivers were employed (54.2%) with a wide range of household incomes reported. Over half of the caregivers (54.2%) reported renting a dwelling, with 33.3% reporting home ownership and 12.5% living with a family member. The majority of the caregiver sample did own a car for transportation (83.3%). A one-way ANOVA was performed to determine if there was an effect on QOL by the number of years since transplant. There was significance in the Medication II domain at the  $p < .05$  level with an  $F(1, df) = 5.239$   $p = .000$ .

Table 2 summarizes transplant family impact data. Just under half of the recipients (45.8%) experienced overnight hospital stays, and 41.7% had emergency room visits, within the 12 months prior to data collection. Within thirty days prior to data collection, 29.2% of the recipients had missed school, 16.7% had been sick, and 25% required someone to care for them due to physical or mental health concerns. As a result of having a child with a cardiac transplant, 8.3% of the employed caregivers missed work, 25% experienced work interference, and 29.2% described some interference with concentration at work due to the recipient's health within 30 days of data collection. Inability to work due to the healthcare demands of a child with a transplant was reported by 16.7% of the caregivers. When asked if the child had a chronic health condition, 33.3% of the caregivers reported "yes". Twenty-five percent of the caregivers noted

that they had been reported to Child Protective Services (CPS) for possible medical neglect at some time post- transplant.

### *Quality of Life of measures*

Table 3 summarizes the post-transplant QOL scores. The overall QOL score, made up of both recipients and caregivers was  $M = 81.74$ ,  $SD = 12.53$ , *range* 53-100. Caregiver QoL ( $M = 85.68$ ,  $SD = 12.46$ , *range* 53-100) was higher than recipient QoL ( $M = 78.48$ ,  $SD = 11.89$ , *range* 57-100) with no statistical significance ( $t = 1.91$ ,  $p = 0.063$ ) between the two groups. A statistically significant difference was found between the caregivers and the recipients in three of the transplant QoL domains: Medication I ( $t = 2.56$ ,  $p = 0.014$ ), Medication II ( $t = 3.79$ ,  $p = 0.001$ ), and Transplant and Others ( $t = 2.07$ ,  $p = 0.045$ ). Lowest QoL domain scores for caregivers were Treatment Anxiety ( $M = 73.36$ ,  $SD = 32.60$ , *range* 6-100), Transplant & Others ( $M = 81.41$ ,  $SD = 17.78$ , *range* 53-100) and Pain & Hurt ( $M = 82.82$ ,  $SD = 19.73$ , *range* 33-100). The lowest QoL domain scores for the recipients were Transplant & Others ( $M = 69.97$ ,  $SD = 17.80$ , *range* 63-100), Pain & Hurt ( $M = 72.10$ ,  $SD = 18.74$ , *range* 58-100), and Worry ( $M = 75.78$ ,  $SD = 20.66$ , *range* 64-100).

Twenty-Two caregivers completed the PedsQL™ Family Impact Module 2.0. Table 4 summarizes the impact module scores. The overall mean PedsQL™ Family Impact score was  $M = 81.79$ ,  $SD = 17.491$ . The Caregiver HRQOL sub-score was higher ( $M = 82.61$ ,  $SD = 17.584$ ) than the Family Functioning sub-score ( $M = 75.14$ ,  $SD = 21.139$ ). The domains with the lowest scores included Emotional Functioning ( $M = 77.05$ ,  $SD = 22.343$ ) and Worry ( $M = 69.55$ ,  $SD = 26.498$ ).

## **DISCUSSION**

The overall QoL of pediatric cardiac transplant recipients and their families was positive in this urban setting. Despite 54.8% single parent households, 45.8% unemployment, 29.1% of the participants living in poverty, and 25% of the families having been referred to Child Protective Services for possible medical neglect at some time in the post-transplant period, family functioning and daily activities was reported as good.

When comparing the two groups, it was the recipients who scored lower QoL than the caregivers in all of the domains except treatment anxiety. The lowest reported recipient score was in the Transplant and Others domain, which surveyed recipients' feelings about being treated differently than peers, other people not understanding what they have been through, and their difficulties with talking about transplantation. Other low recipient scores included those measuring pain with procedures (blood draws; cardiac biopsy), worry about whether their medications were working, and worry about whether something was wrong with them or their transplanted heart. These findings were consistent with those reported by Green et al. (2007).

Caregiver reported QoL was encouraging, although at times perplexing. Caregivers reported higher QoL scores than those of the recipients, with the exception of the Treatment Anxiety domain. These results were consistent with the work of Green et al. (2008), where caregivers reported a more positive QoL than recipients studied by Green et al. (2007). In this study, the ranges of the caregiver scores were quite wide in every domain, indicating several of the participants reported low QoL scores. Interestingly, only 33% of the caregivers reported their child having a chronic health condition, a finding inconsistent with the literature (Anthony et al., 2010; Hollander et al., 2015; Shellmer et al., 2014) and with what had been discussed with them by transplant team members at the time of transplant evaluation. Caregiver QoL was lowest in psychosocial domains, including Emotional Functioning, Worry, and Anxiety. This

was consistent with the study by Green et al. (2009) who reported a great deal of caregiver worry related to infection, rejection, and survival. In this study, several of the caregivers voluntarily offered statements to the study PI or printed comments on the data collection forms. One caregiver stated that post cardiac transplant life has “been a nightmare”. The same caregiver printed on the survey tool that the recipient was “used to being cared for and it makes her a little lazy because she is waited on hand and foot at the hospital then expects it at home.” Another caregiver stated the need for “support groups”. Still another stated “I wish I could write how life really is instead of just circling an answer.” Finally, another caregiver wrote, “We are six years out [from transplant]. These answers would have been very different earlier after transplant.”

When viewing the QoL variables through the lens of the RAM , caregivers experienced increased demands on coping in all four modes of adaptation. Coping demands on physical functioning (exhaustion, stress), emotional functioning/role function (worry of pain and hurt, rejection, infection, re-transplant, primary caregiver demands), group identity (perceptions of others, socioeconomic challenges, single parent households ), and interdependence (lack of support, employment concerns) tested caregivers’ adaptation. Recipient coping was tested most greatly in the physiologic mode (medications, worry, and procedures) and the self -concept mode (feeling different, medication effects, speaking to others about transplant). Family functioning and interdependence modes also appeared to be to be challenged. Almost half of the recipients had an emergency room visit or overnight stay in the hospital causing disruption of daily family routines. Finally, 16.7% of the caregivers stated they were unable to work due to their child’s health “condition”, having an impact on the socioeconomic interdependence of the caregiver/family system.

## **LIMITATIONS**

The sample size of this single site study was small. Participation in the study depended on the number of recipients and caregivers who made and kept transplant clinic appointments between the study period of December, 2015 and February, 2016.

### **IMPLICATIONS FOR CLINICAL PRACTICE**

Pediatric post cardiac transplant management places extraordinary demands on both the recipient and the primary caregiver. With the scarcity of organs for transplant, some may argue that children in urban areas may not be the most suitable candidates due to a lack of required social support and struggles with healthcare disparities. This argument was challenged by the results of this study which demonstrated an overall positive QoL of both the recipients and caregivers.

Indeed, improved QoL is the goal of transplantation from the outset. As the goal of nursing in the RAM is to promote adaptation in all four modes of adaptation, transplant nurse practitioners and other members of the multidisciplinary team in urban settings must work tirelessly to achieve this goal. Continued emphasis by the transplant team on post-transplant medical management demands is essential. Ongoing post-transplant education must continue with each patient encounter.

Several practice changes should be implemented based on the results of this study to improve QoL of pediatric cardiac transplant recipients and their caregivers. This study was in agreement with other research that QoL assessment with parent proxy should be continued and performed regularly, allowing the transplant team to follow longitudinally any areas of concern and to identify post-transplant families in crisis (Brosig et al., 2014; Kim & Marks, 2014). A qualitative questionnaire should be added to the assessment. This was demonstrated by the



number of unsolicited written statements on the data collection sheets and the requests by the caregivers to write down their feelings. Psychosocial support for transplant recipients and their caregivers needs to be improved. Implementation of a pediatric transplant support group, facilitation of transplant family meet-and-greets, and better utilization of the transplant psychologist during multidisciplinary transplant clinic visits should occur. Recipients should be encouraged to participate in hospital and organ procurement organization sponsored events with other transplant recipients such as camps, transplant games, and fund raisers to foster budding relationships with other “kids just like them”. Transplant nurse practitioners and team members must promote transplant management independence with school aged and adolescent recipients to assure a more seamless transition into adult transplant centers, and support the research that cardiac transplant recipients can achieve successful positive QoL in adulthood (Hollander et al., 2015). As there was a statistical difference found in the QoL medication domains, utilization of the transplant pharmacist during multidisciplinary clinic visits should occur. Transplant pharmacists should review medications for drug related problems, and monitor the recipients for interactions related to unavoidable polypharmacy. The pharmacist should address unpleasant medication side effects, and provide medication teaching in attempt to improve medication compliance (Harrison et al., 2012; Martin & Zavala, 2004). Finally, a gap continues in the reporting of QoL of pediatric cardiac transplant recipients and their caregivers in all demographic locations. Additional research in this highly specialized area of pediatrics is essential. Study designs should include both qualitative and quantitative analysis.

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