

# Family functioning in the families of paediatric heart transplant recipients prior to outpatient visits and procedures

## Brief Report

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### Abstract

In a cross-sectional study, we assessed family functioning prior to outpatient visits and routine heart catheterisations in the families of paediatric heart transplant recipients. Caregivers rated higher short-term family functioning prior to outpatient visits, but not prior to catheterisations. This finding may indicate that family functioning benefits from the support provided during outpatient visits.

Heart transplantation provides a means of survival to otherwise fatal conditions in the paediatric population. Nonetheless, with transplantation comes risk of rejection, strict medical regimens, lifelong monitoring, invasive procedures, and frequent hospitalisations. It has been reported that chronic medical conditions cause family stress, and thus, may affect family functioning.<sup>1,2</sup>

Our previous study demonstrated that the following factors are associated with poorer family functioning after paediatric heart transplantation: the presence of developmental delay in the patient, higher parental educational status, and increased parental-perceived barriers to medication adherence.<sup>3</sup> However, the acute and chronic effects of frequent medical visits on family functioning is not known.

## Methods

### Study population

We conducted a cross-sectional study with the guardians of paediatric heart transplant patients presenting to clinic visits and for routine cardiac catheterisation. Caregivers were already enrolled in a larger study examining the effects of heart transplantation on chronic family functioning.<sup>3</sup> As such, our inclusion criteria included guardians of paediatric heart transplant recipients followed at the University of Florida Health Congenital Heart Centre; patients <21 years of age still dependent on their guardians. Exclusion criteria included participants declining to consent, participants with unavailable past medical history, and patients admitted for acute decompensation or undergoing catheterisations due to concern for rejection.

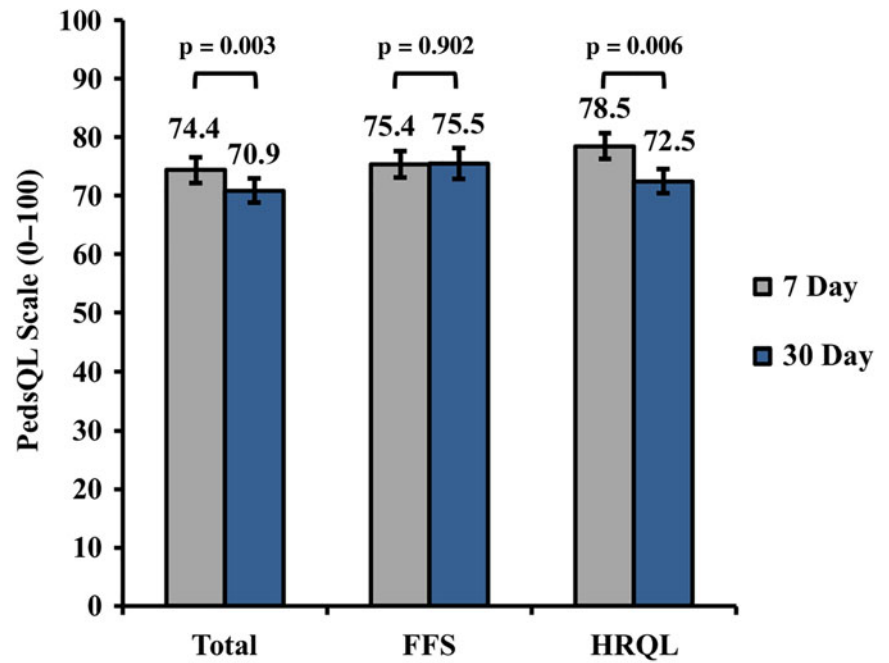
### Psychometric measures

Parents completed the acute (7-day) and chronic (30-day) Paediatric Quality of Life Family Impact Module during their in-person visits. The Paediatric Quality of Life Family Impact Module has 36-items distributed between 8 subscales and 3 combination scales assessing family functioning. Scores are calculated as: Never, 100; Almost Never, 75; Sometimes, 50; Often, 25; Always, 0, where higher scores indicate higher quality of life. The Combination Scales (i.e., Total Impact, Family Functioning Summary, and Parent Health-Related Quality of Life (HRQL)) scores were calculated by addition of their respective subscales and division by the number of items. All participants were instructed to complete questionnaires in reference to the time frames indicated on the module (i.e., past 7 days and past 30 days).

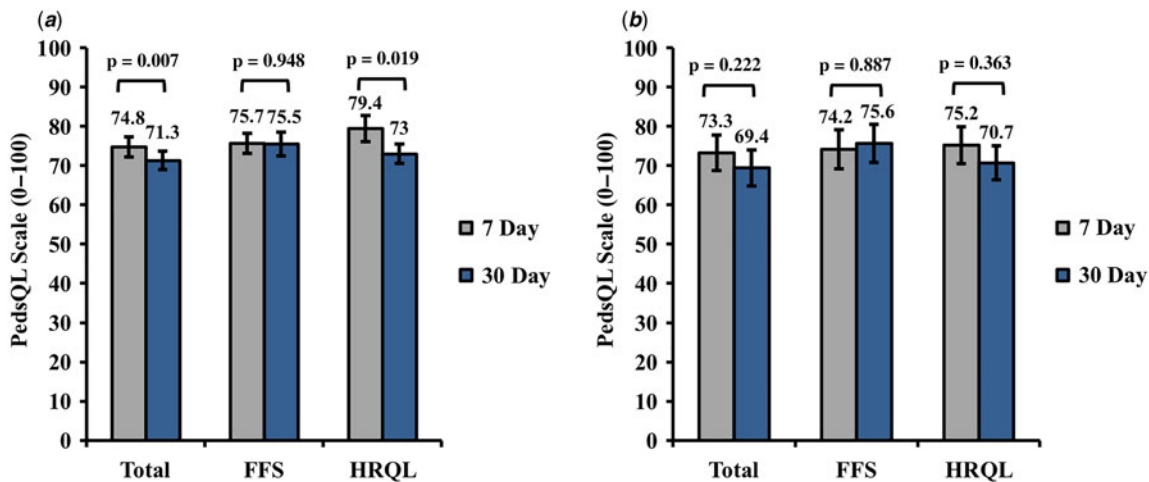
### Outpatient visits and routine procedures

Outpatient visits consist of assessments by a transplant physician, coordinator, and social worker. These visits also include laboratory tests, electrocardiogram, and echocardiogram. Visits for routine surveillance catheterisations include all of the above plus catheterisation under general or local anaesthesia, as determined by patient and physician preference. Recipients' families are provided with medical, financial (i.e., gas cards), and social support as needed during these visits.

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**Figure 1.** 7-day (grey)–30-day (blue) family functioning comparisons of Total Scores (Total), family functioning summary (FFS), and parent health-related quality of life (HRQL) in all participants.



**Figure 2.** (a) 7-day (grey)–30-day (blue) family functioning comparisons of Total Scores (Total), family functioning summary (FFS), and parent health-related quality of life (HRQL) in outpatient clinic visits. (b) 7-day (grey)–30-day (blue) family functioning comparisons of Total Scores (Total), family functioning summary (FFS), and parent health-related quality of life (HRQL) in the surveillance, heart catheterisation cohort.

**Statistics**

Numerical variables are presented as means with standard error of mean and categorical variables as percentages. Both the 7-day and 30-day surveys were compared with paired t-tests or Wilcoxon rank sum tests, depending on the distribution of the data, with the latter for non-normal distributions. All statistical analysis was conducted utilising SPSS Version 25 (SAS Institute, Cary, NC, United States of America) and G\* Power (version 3.1.9.4).

**Results**

**Cohort**

In our outpatient cohort, 71 guardians of 71 paediatric heart transplant recipients completed questionnaires, of which 56 were in

clinic and 15 were following routine cardiac catheterisation. The characteristics of our cohort were described in a previous study.<sup>4</sup> None of the patients required admission after their clinic or catheterisation visits.

**Family functioning impact module in cohort**

The surveys of four participants were excluded per Paediatric Quality of Life Scoring Guidelines,<sup>5</sup> leaving 67 participants. Average 7-day total impact scores were 74.4 ± 2.23 compared to 30-day at 70.9 ± 2.06 (p = 0.003) and 7-day HRQL was 78.5 ± 2.78 compared to 30-day at 72.5 ± 2.11 (p = 0.006). This is illustrated in Figure 1. Differences were also found in subscales including Parent Self-Reported Emotional Functioning (7-day:

75.4 ± 2.24 versus 30-day: 70.9 ± 2.29;  $p = 0.014$ ) and Family Relationships (7-day: 62.5 ± 2.86 versus 30-day: 56.4 ± 2.67;  $p = 0.032$ ).

### Family functioning stratified by setting

We then sought to analyse family functioning in outpatient clinic and catheterisation visits separately. No significant demographic differences were evident between groups based upon gender ( $p = 0.435$ ), race ( $p = 0.451$ ), pre-transplant diagnosis ( $p = 0.760$ ), age at transplant ( $p = 0.121$ ), age at visit ( $p = 0.103$ ), and time since transplant ( $p = 0.275$ ). In patients presenting to outpatient visits, the average 7-day total impact score was 74.8 ± 2.58 and the average 30-day was 71.3 ± 2.38 ( $p = 0.007$ ). Parent HRQL scores were 79.4 ± 3.33 in the 7-day results as compared to 73.0 ± 2.43 in the 30-day results ( $p = 0.019$ ) illustrated in Figure 2a. In regards to subscales, significant differences were found in the Parent Self-Reported Emotional Functioning (7-day: 75.5 ± 2.52 versus 30-day: 71.9 ± 2.71;  $p = 0.041$ ) and Family Relationships Scale scores (7-day: 83.7 ± 3.47 versus 30-day: 79.9 ± 3.23;  $p = 0.038$ ). In our catheterisation cohort, there were no significant differences detected on the 7-day versus 30-day cumulative scales (Total: 73.3 versus 69.4; FFS: 74.2 versus 75.6; HRQL: 75.2 versus 70.7,  $p > 0.05$ ; Fig 2b) or subscales. It should be noted that the sample is only powered to detect large effect sizes ( $d = 0.8$ ) in the catheterisation cohort due to small sample size.

### Discussion

Paediatric heart transplantation continues to provide a strong avenue of recovery, with patients frequently being able to return to age-appropriate activities following transplant. Family functioning, on the other hand, is frequently affected by paediatric chronic conditions and has significant effects on quality of life for both the patient and their family. A component of this effect could include the frequent outpatient visits and routine procedures, which may cause familial stress and disruption, coupled with financial factors like costs of transportation and missed work.

We anticipated that potential anxiety related to test results, changes in therapy, and/or long-term prognosis might impact functioning. On the contrary, our findings indicate normative family functioning in the acute setting leading up to and during a visit. Outpatient visits may have become a routine aspect of the lives of paediatric heart transplant recipients and their families; such visits, possibly associated with the provision of support services, may provide a sense of normalcy in the ongoing management of the patient. Therefore, in clinically stable patients, families may anticipate a favourable evaluation leading up to the visit, leading to the

short-term family functioning rates observed. In addition, these visits may provide them with an opportunity to have other, non-medical, concerns (e.g., financial) addressed.

Our study is limited by a small sample size. Further, social and family-related issues prior to or within the 7- and 30-day timeframes of our study could not be taken into account due to unavailable data and may plausibly influence overall perceived family functioning.

### Conclusion

Taken together, our findings indicate that scheduled catheterisations and outpatient visits in recipients of paediatric cardiac transplants may not be associated with decreased family functioning prior to clinic visits, despite the significant time and resource burden. While the current study measured parent report of functioning, it will be important for future studies to measure patient perceptions of their pre-clinic experience (e.g., anxiety/stress) as well.

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**Conflicts of interest.** None.

**Ethical standards.** The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008, and has been approved by the institutional review board at the University of Florida.

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