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“Will she live a long happy life?” Parents' concerns for their children with Fontan circulation

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ABSTRACT

Background: Families of children at the worst end of the congenital heart disease endure a significant burden which is often not clearly delineated in the clinical literature. We examined the greatest concerns of parents whose children have a Fontan circulation.

Methods: Parents ($N = 107$) of children in the Australian and New Zealand Fontan Registry completed online surveys with open-ended and closed questions. A qualitative method approach incorporating thematic analyses was used.

Results: The greatest concerns for parents of a child with a Fontan circulation were centered on fear of death for their child and psychosocial well-being, followed by lesser themes around anti-coagulation use, pregnancy and financial burdens.

Conclusions: Fear of death and the psychological well-being of their children were the main parental concerns. It highlights the need to clearly communicate information on outcomes to families, and the need for family-focused psychological interventions to improve the psychosocial functioning of both parents and young people.

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1. Introduction

The Fontan procedure is the last in a series of operations for babies born with a single ventricle physiology. In the last decade, it has become clear that survival outcomes were better than expected, with the hope that up to 80% of those who have undergone the procedure surviving 30 years after the procedure [1–4]. This population faces a considerable burden of disease. Half of them are expected to face a major complication requiring hospitalization before adulthood, they are known to have limited exercise capacity, and they face multi-systemic complications related to elevated central venous pressures [5,6]. This extraordinary journey through the health system generates, without doubt, anxieties and, at times, extreme difficulties for the families of these children, but these pressures have not been well investigated.

Parents of complex congenital heart disease children experience elevated stress in comparison to the general population, and this is associated with adverse outcomes, including decreased physical and psychological wellbeing in both children and parents [7]. Mental health risks (particularly in the period following cardiac surgery) include anxiety, depression, high levels of distress, trauma, and symptoms consistent with PTSD [8]. Extensive financial, familial and emotional costs have also been identified in the literature of CHD parents, and this frequently co-present with uncertainty and distress which are linked to the complexity of the child's disease and parents' socioeconomic status [9,10].

We have created a bi-national Registry in Australia and New Zealand and work closely with patients and their families [11,12]. This interaction resulted in the creation of an advocacy group, the Australian and

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Abbreviations: AVSD, Atrioventricular Septal Defect; ANZFAC, Australian and New Zealand Fontan Advisory Committee; ccTGA, Congenitally Corrected Transposition of the Great Arteries; DILV, Double Inlet Left Ventricle; DORV, Double Outlet Right Ventricle; HLHS, Hypoplastic Left Heart Syndrome; INR, International Normalized Ratio; PLE, Protein Losing Enteropathy; PTSD, Post-Traumatic Stress Disorder (PTSD).

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New Zealand Fontan Advisory Committee (ANZFAC). Their first task was to survey the greatest concerns of parents of this population.

2. Methods

Ethics approval was obtained through the Royal Children's Hospital, Melbourne, Australia. An anonymous online survey assessed the needs of parents through the Australian and New Zealand Fontan Registry in 2015. In addition to basic demographics, this purpose built survey used both open-ended and closed questions (Table 1).

2.1. Analyses

The major focus of this paper is around parents' greatest self-reported concerns for their child with a Fontan circulation. We used thematic analyses to showcase the rich and complex stories of parent experiences of their child's (patient's) health care journey [13]. Survey responses were analyzed by the Fontan Registry Research Coordinator and Fontan Registry Steering Committee Chair/Founder, who both work closely with the Fontan community, the Registry, and its associated research projects. Similar to Braun and Clarke, we viewed thematic analysis as an "essentialist or realist method which reports experiences, meanings and the reality of participants" [14]. A theme was construed as a pattern found in qualitative information that describes and organizes the information [15]. The manual coding process followed a three-step progression, including (a) developing concepts and categories to organize data into a framework of ideas, (b) comparing data instances, cases and categories for similarities and differences, and (c) unifying key themes [15]. This was repeated until a point of saturation in terms of conceptual depth was reached in the themes [16], in addition to which the key themes were also checked for resonance and validity with ANZFAC (co-authors) as representatives of the parent and patient community. Where relevant, descriptive quantitative information from the rest of the survey are referenced under key themes identified.

3. Results

A total of 107 parents of children with a Fontan circulation participated in the survey from 338 Fontan Registry parents with e-mail addresses (response rate 32%). The geographical spread of participants was similar to that in the broader Australian and New Zealand Fontan Registry. The majority of parents were in married/de facto relationships ($n = 84$, 80%), and all were individual respondents, bar one couple. The majority of children (represented by parents) were male ($n = 68$, 64%), the average age was 11 years ($SD = 5$), and the average age at time of Fontan completion 4 years ($SD = 2$). No data around racial/ethnic identities, parents' gender or level of education were gathered. Major diagnoses included: Hypoplastic Left Heart Syndrome (HLHS) ($n = 39$, 36%), Tricuspid Atresia ($n = 38$, 36%), Congenitally Corrected Transposition of the Great Arteries (ccTGA) ($n = 16$, 15%), Atrioventricular Septal Defect (AVSD) ($n = 35$, 33%), Double Outlet Right Ventricle (DORV) ($n = 37$, 35%), Double Inlet Left Ventricle (DILV) ($n = 3$, 5%), and Pulmonary Atresia ($n = 4$, 7%). These diagnoses reflect an overrepresentation of participants with the more severe conditions (i.e., HLHS) in the Fontan Registry. Almost half of the parents did not know what type of Fontan operation their child had ($n = 49$, 46%), with the remaining majority reporting that their child had an extra cardiac conduit ($n = 38$, 36%).

Most of the parents who had completed the survey answered this question ($n = 93$, 87%), and responses varied from one word to several sentences per participant, many touching on several key themes in their answers. The two major themes are described below (Fig. 1).

3.1. Theme 1: fear of death/uncertainty around life expectancy

Fear of death was the greatest concern for most parents coloring the manner in which they considered their child's physical health and treatment. It was pervasive, omnipresent, and a dark burden on parents. In general, this theme was more closely related to medical/physical components, rather than socio-emotional aspects. Responses were often summarized with succinct responses to the question around 'greatest concerns' e.g., "*Death*" (Participant 24), whereas others were

Table 1
Survey questions.

Sample questions	Response options
Your greatest concern(s) for your child with a Fontan circulation is…	Open-ended
In regards to anti-coagulation, what are your greatest concerns/issues?	Open-ended
How many times a week does your child exercise?	Nil; Once a week; Twice a week; Three times a week; Four times a week; Five times a week
What type of exercise?	Open ended
How would you rate your child's capabilities, in comparison to their peers, in each of the categories below? Physical activity/exercise tolerance Emotional wellbeing Behavior Education & learning	Significantly less; Slightly less; About the same; Slightly more; Significantly more
How frequently does your child experience any of the following symptoms? Leg pains/leg muscle cramping/leg irritability Migraines (prolonged headache) Mouth ulcers Difficulty sleeping Night terrors Does your child seem sad or display signs of depression Nail biting Does your child have learning or concentration difficulties Does your child seem to get angry or lose his/her temper easily?	Always; Sometimes; Occasionally; Never; Do not know; Already present prior to Fontan
To what extent do you feel your child's school support his/her needs	Not at all; Moderately supportive; Very supportive (sliding scale)
Have you accessed psychological/psychiatric/counselling services previously in relation to your child's health?	No; Yes (please describe your experience of accessing these services below)
Would you be interested in accessing psychological/psychiatric/counselling services?	Yes; No; Not sure
Has your child's medical journey impacted you or your family financially?	No; Yes (please specify how this has impacted below, e.g., employment opportunities, financial hardship)

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