

The Families with Adopted Children with Thalassemia Study (FACT) Boston Children's Hospital

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Disclosures

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THANK YOU!



Introduction

- International adoption of children with special needs has become prevalent in recent years leading to growth in the number of U.S. thalassemia patients adopted from foreign countries.
- At the time of this survey, 13% of the 1,119 thalassemia patients registered in the CAF Patient Database were adopted from foreign countries, primarily China.
- Children are often developmentally normal and their growth and other health issues are often manageable once they have transitioned to appropriate transfusion and chelation management.



Introduction (cont'd)

- As the adopted patient population continues to grow, further information is needed in order to provide them with the best supportive care.



Objectives

- 1) To characterize the socio-demographics and health status of adopted children with thalassemia, as well as their siblings and legal guardians.
- 2) To describe adoptive families' motivations for adopting a child with thalassemia.
- 3) To learn more about adoptive families' experiences, perceptions, and challenges with the adoption and adoption process.
- 4) To explore if adoptive families actively encourage other families to consider adoption of children with thalassemia



Methods

- A REDCap survey, advertised on both the CAF website and CAF social media, was accessed by families of adopted children with thalassemia from January to August 2017.
- Subjects were first directed to take the following four-question screening questionnaire.



Screening Questionnaire

- 1) Do you have one or more children with a confirmed diagnosis of thalassemia?
- 2) Are any of these children adopted?
- 3) Are your adopted children receiving annual or ongoing care at a participating Thalassemia Treatment Center (TTC)* or a Hematology Office within the U.S.?



Screening Questionnaire (cont'd)

- 4.) Would you like to continue on with this survey?
- *If subjects answered yes to all four questions, they were directed to the remainder of the survey.*
 - *Respondents who were ineligible or who provided incomplete data were removed from the dataset prior to analysis.*
 - **TTC includes: BCH, HUP, Lurie, Oakland, CHLA, CHOA, CHOP, and Weill Cornell*

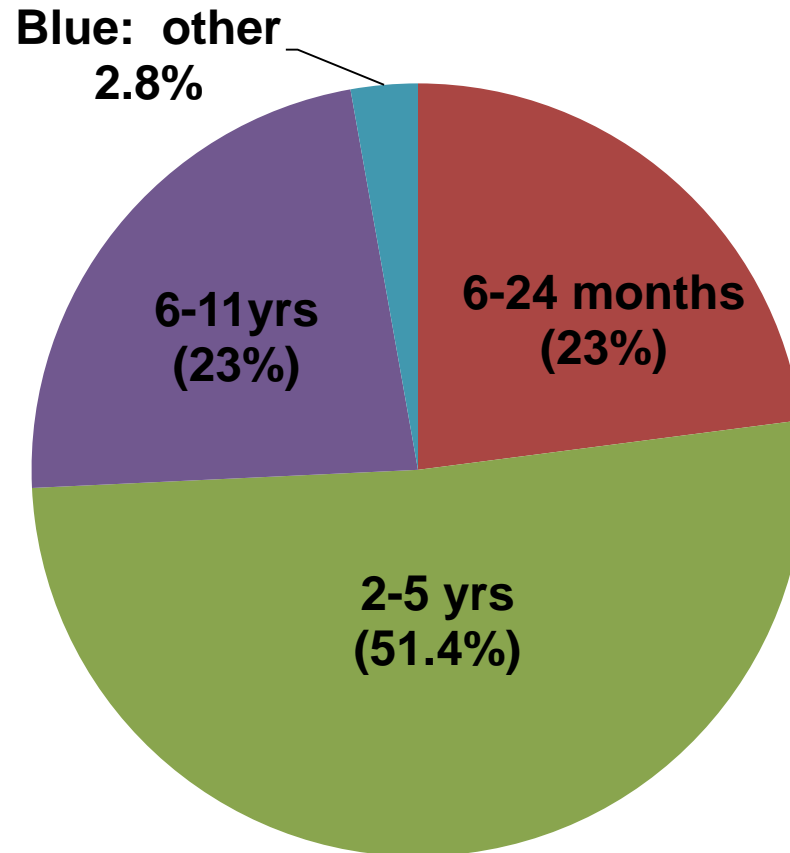


Results

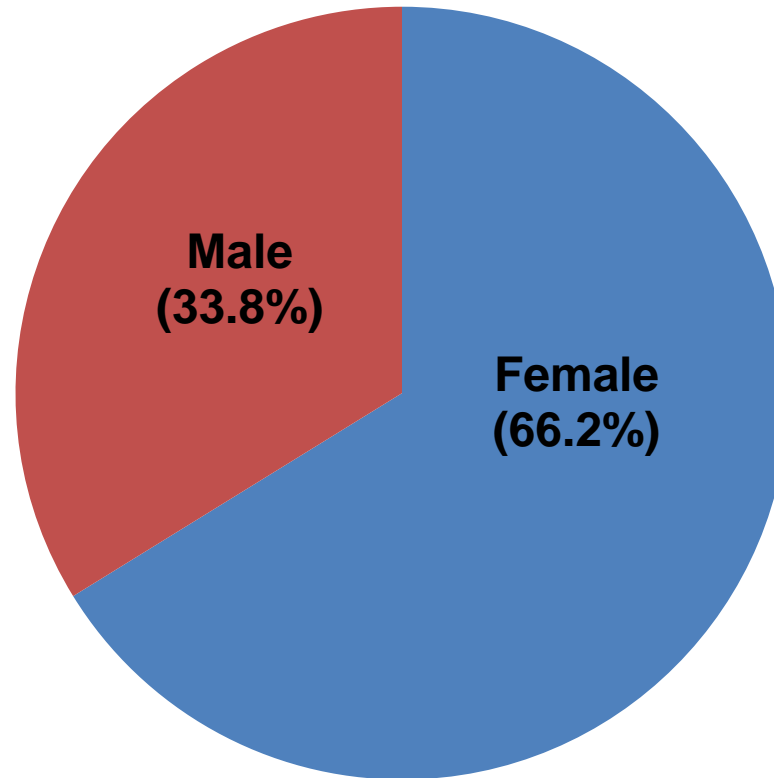
- Of 78 survey respondents, 67 qualified and completed the survey.
- These 67 households had adopted a total of 74 children with thalassemia.



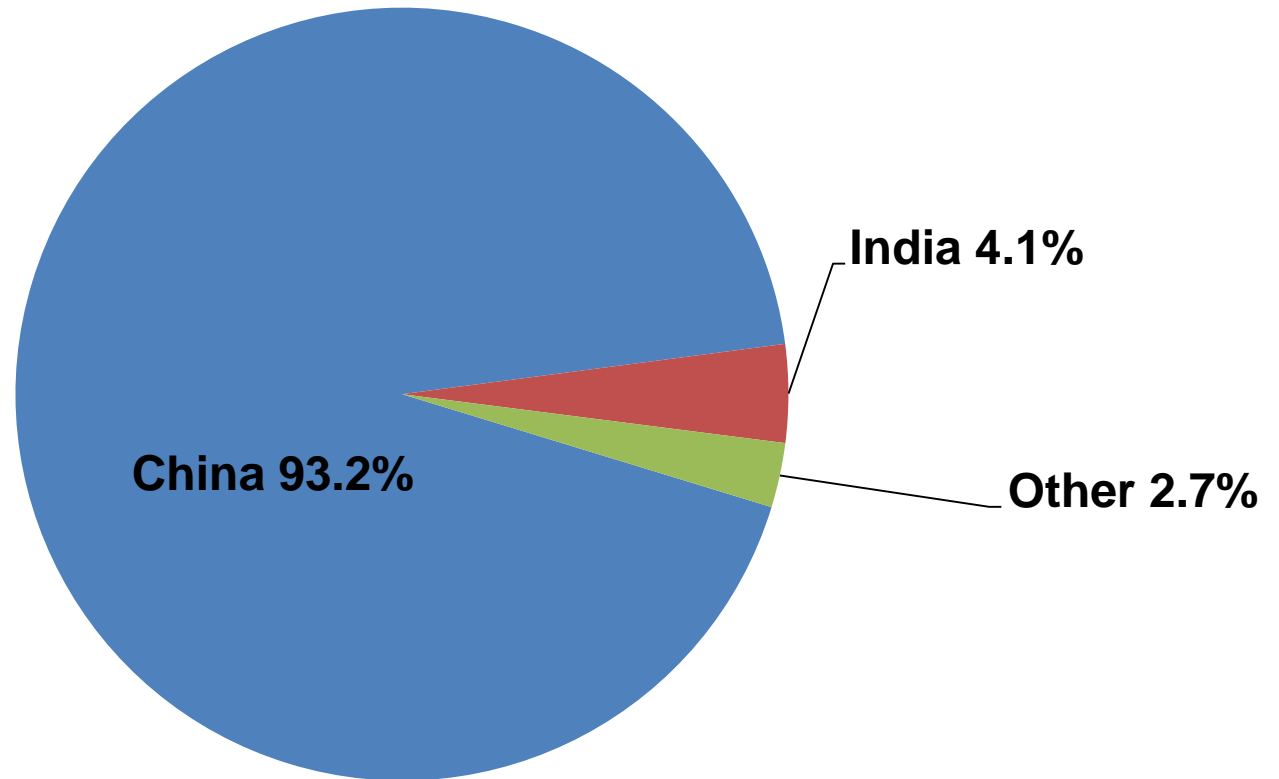
Child's Age at Time of Adoption



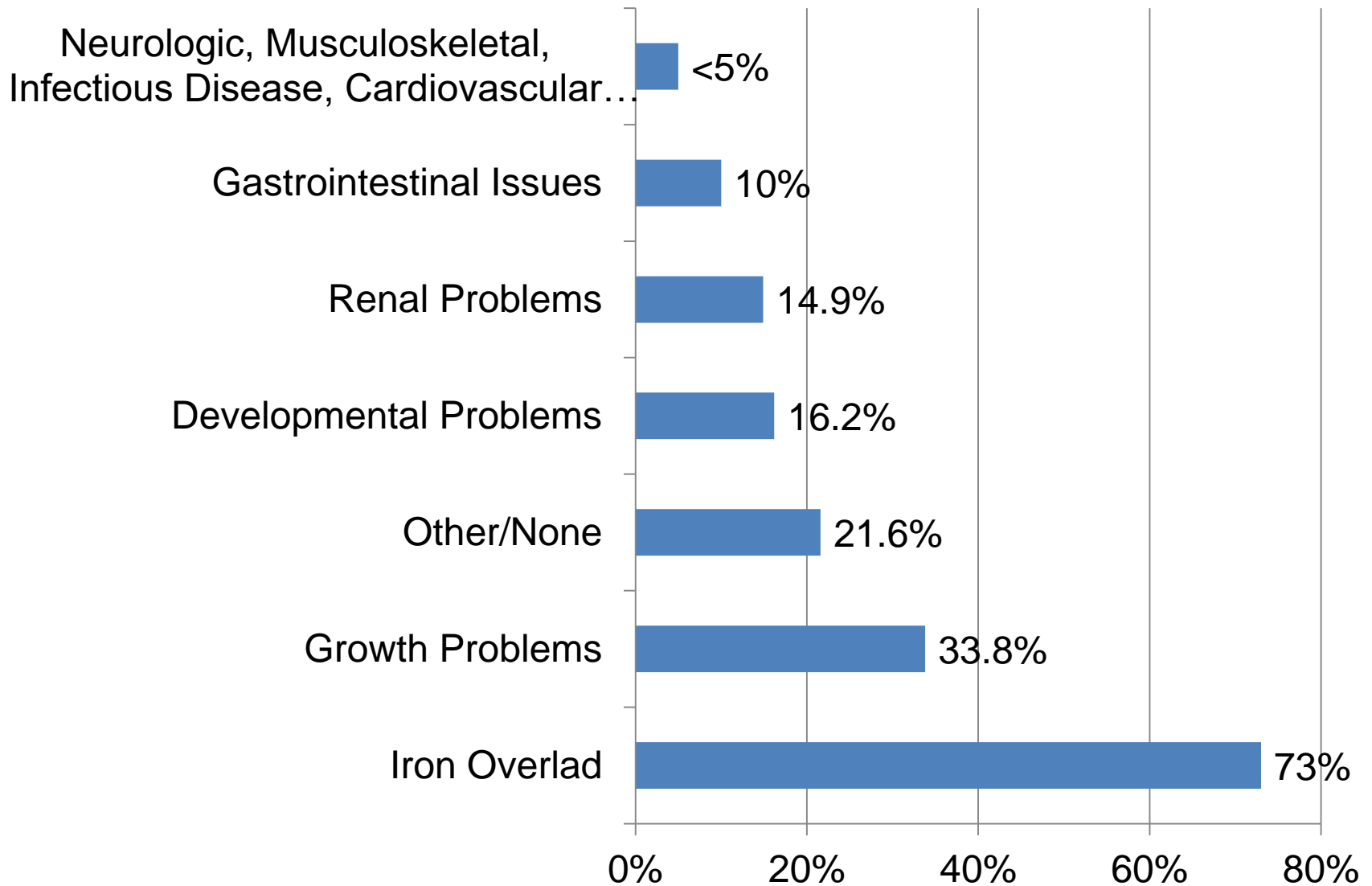
Gender Breakdown of Adopted Patients



Country-of-Origin of Adopted Patients



Secondary Health Issues



Family Demographics

- Christian (87.3%)
- In good health (73.8%)
- The majority of legal guardians had completed post-secondary education (76.9%)
- With the majority (76.1%) reporting household incomes greater than \$80,000



More Family Demographics

- 98.5% of adoptive families (most) were connected to an adoption group or community including online groups, local support groups, and adoption networks
- The average family size for this group of patients was large, with 13.4% of respondents reporting a household size of 9 or greater.



Benefits of Adoption

- The opportunity to provide a loving home to a child in need (74.5%)
- Adoption expanded the capacity to give/receive love (68.6%)
- The ability to fulfill dreams of raising another child (58.8%)

Challenges of Adoption

- Unanticipated stressors (54.9%)
- Emotional stressors (43.1%)
- Financial burdens (37.3%)



Conclusions

- Data regarding adoption experience was generally positive, the responses regarding management of care post adoption seems to indicate that adoptive families are looking for additional support and guidance.
- Findings show that adoptive families struggle with navigating the complexities of thalassemia care. They would benefit from additional outreach, education, guidance, and advocacy resources – especially in the early stages of adoption and during initiation of post-adoption medical care.



Acknowledgements

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