

Childhood heart failure impacts the whole family

26 interviews: children with heart failure and their parents

Parents:

Delicate balance of demands

Social isolation

Vigilance, fear, trauma



“...I want that quality of life to supersede all else.”

- parent of a 14-year-old with heart failure



Patient: **Resiliency**
Struggle to relate
Fatigue and physical limitations

“I don’t exactly wanna stand out and the cardiac arrest didn’t exactly make me blend in more.” -11-year-old with heart failure

Family:

Stronger family bonds

External support is limited & dwindles over time

Stress for siblings



“...our kids’ relationships have improved...life is more fragile than they had thought.”

- parent of a 17-year-old with heart failure



Unmet needs for patients, parents, and families:

- 1) Social support evaluations
- 2) Peer support programs
- 3) Mental health care
- 4) Evidence-based quality of life assessments

