

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**



Friends

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



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