The Impact on Family and Promoting Resiliency

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Breakout Session
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Financial Disclosures

• No commercial relationships to disclose
Learning Objectives

1st Learning Objective: To acknowledge the impact of enteral/parenteral dependency (and complex medical illness) on the family as a whole

2nd Learning Objective: To explore common themes amongst families

3rd Learning Objective: To consider a shift in focus to promote resiliency
For this breakout session

• Interactive
• Sharing of experiences
A Little About Us.....

• General academic pediatrician with an interest in children with medical complexity and population health

• 15 year old daughter with short bowel syndrome and liver disease

Impact on Family

• Can be all consuming
• More than a full time job
• Cha cha cha dance
  • Two small steps forward and one big step back
• Plan and expect the unexpected
Balancing It All—as a parent

• Child
  • Caregiving, parenting, and just having fun

• Siblings
  • Special time, being fair

• Yourself/Your Spouse
  • Self-care

• There is never enough time in the day!
Balancing the + and the -

• Negatives that can bring you down

• Opportunities to grow as an individual
My Sibling Experience - Ryan

NEGATIVE
• Unable to do some normal activities
• Attracts unwanted attention from others

POSITIVE
• More empathic and open-minded
• Positive opportunities and experiences
• Stronger connection with sibling
How This Has Impacted Me

• Perception of Normal
  ▪ Things such as hooking up Janie at night

• Opportunities

• Relationships
  ▪ Parents, siblings, friends are strong

• Challenges
  ▪ Conflicting interests
How I Have Evolved

• Choice of Activities
  • Family time
  • Individual activities

• Connections
  • Trust, empathy, committed

• Coping
  • Seeing the big picture

• Self
  • I am a better person overall
Shifting the Focus
Glad we are thinking and talking about this, but how can we continue to shift our way of thinking a little bit more?

- ACE: Adverse Childhood Experiences
- QoL questionnaires
Shifting the Focus

Glad we are thinking and talking about this, but how can we continue to shift our way of thinking a little bit more?

• HOPE: Healthy Outcomes from Positive Experiences: Bolstered by support, belonging, safety

• the gutsy perspective
  • a beautiful struggle
Possible Discussion Topics

• Prioritization
  • Constantly shifting and changing

• Value of time
  • Effort

• Timing
  • Acute vs. stable, planned vs. spontaneous

• Meal times
  • Time for connection

• Fairness
  • There’s no excuse for not being nice, equal expectations/consequences

• Family activities
  • Give and take, taking turns (can be inclusive but separate), centered around something else non-medical