

Additional file 3: Initial Coding Tree

EXPERIENCES WITH THE HEALTHCARE SYSTEM AMID THE PANDEMIC

- Lack of access to healthcare services and increased hospital restrictions
 - o Lack of access to allied health
 - o Decreased participation in supportive therapy
 - o Challenges of in-hospital visitor restrictions
 - o Other
- Negative clinical interactions and communication breakdowns
 - o Feeling disrespected by healthcare providers
 - o Insensitive care
 - o Poor communication with healthcare team
 - o Frustration with delays
 - o Other
- Virtual care use
 - o Decreased burden of in-person visits
 - o Increased connectedness
 - o Value of e-health apps
 - o Other

PANDEMIC'S IMPACT ON FC WELL-BEING

- Physical Toll
 - o Chronic and intense care demands
 - o Inability to sleep
 - o Physical demands from lifting and transfers
 - o Other
- Mental Toll
 - o Nonstop vigilance
 - o Worsening stress and mental exhaustion
 - o Guilt in asking for help
 - o Role of being more than just a parent
 - o Inability to engage in self-care
 - o Feeling of isolation
 - o Extreme fear of COVID-19
 - o Other

COMMON CHALLENGES DURING THE PANDEMIC

- Financial strain
 - o Significance of costs to meet care needs of CMC
 - o Impact of caregiving on ability to work
 - o Lack of funding and financial support
 - o Significance of administrative work
 - o Other
- Balancing multiple roles
 - o Acting as a medical professional
 - o Burden of coordinating care

- Complex administrative work associated with care
- Lack of family and homecare nursing support
- Advocating for child's needs
- Impact on family dynamics
- Other
- Inadequate homecare nursing
 - Challenges of frequent nurse turnover
 - Burden of scheduling nurses
 - Concerns with nurse competence
 - Negative experiences
 - Frustration with lack of improvement
 - Other