Enhancing Coping and Resilience in Parents/Caregivers of Hospitalized Children

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Abstract

Parents of hospitalized children may experience decreased resilience and difficulty coping associated with disruption of normative family functioning during lengthy hospital stays. Parents often experience heightened stress and tension that may translate into conflict and communication breakdowns with the healthcare team. Such conflicts can obstruct collaborative decision-making and delay the implementation of care interventions for the child. Franck et al. (2015) found that parental anxiety and coping strategies are modifiable factors that can strongly influence the post-traumatic stress families experience during the hospitalization and long after. This evidence-based project aimed to answer the question, “What are the best practices for enhancing coping and resilience in parents/caregivers of hospitalized children with chronic illnesses?” A comprehensive review of the literature identified a variety of interventions employed by the healthcare team and families to support coping and resilience, with varying degrees of success noted. In this review, two parental support programs with standardized protocols have been replicated in multiple settings and show promise for implementation at CHOC.

CHOC has several resources available to support parents and families. These resources are often underutilized because families and CHOC associates need to be made aware of their availability or have difficulty accessing them. In addition, family-centered resources are only sometimes offered across units and disciplines.

Improvement in interdisciplinary communication across the continuum of care would allow for greater support of parental coping. The primary recommendation of this EBP project is to create a CHOC “menu” of resources available to parents, including available activities, support departments, and external support services. Initially, the comprehensive menu will be provided in a print format. The plan is to explore using an online/intranet platform to provide access to all families about the CHOC resources. The communication materials, whether print or digital, can easily be applied and custom-tailored to any inpatient setting to improve parental coping during hospitalization.

Keywords
Chronic illness, coping, resilience, parents, pediatric hospitalization.
PICO(T)

What are the best practices for enhancing coping and resilience in parents/caregivers of hospitalized children with chronic conditions?

Background and Significance

Parents often experience anxiety related to their child’s chronic condition that escalates during hospitalization. Family members are separated from their typical social support systems and often are challenged to employ new coping mechanisms and strategies to deal with the challenges faced during hospitalization. In the combined 25 years, we have had in pediatric healthcare, we have both faced many situations in which increased stress and tension have led to escalation and conflict between the family and the care team, creating an unsafe work environment, inability to provide care, and a potential for delay in timely discharge. CHOC has implemented the Safe Work Intervention Team (SWIT) to respond to escalated crises once they have occurred; however, we believe that proactive efforts to improve family coping and increase resilience would be more beneficial. We wondered what tools we could give parents to help them cope with the hospitalization and identify the disciplines that could enhance their offerings to provide families with the needed support.

- Parents of children with chronic illnesses experience high levels of stress and anxiety that can lead to long-term mental health disorders (Burke et al., 2014; Franck et al., 2015; Peer & Hillman, 2014).
- Parents of children with chronic pain often feel distraught and helpless watching their children suffer from chronic conditions and healthcare interventions. A parent’s poor coping strategies can exacerbate the child’s experience of pain and suffering (Seidman et al., 2019).
- Anxiety and coping mechanisms are modifiable factors that can reduce the incidence of post-traumatic stress following difficult experiences (Franck et al., 2015).
- Stress reduction strategies may increase the parent’s coping related to their child’s illness and improve parent-child interaction (Mirghafourvand et al., 2017).
- Improving parental coping and enhancing parental support services helps maintain the integrity of the family unit as co-partners in the child’s care. Patient and Family-Centered Care (PFCC) is central to our mission.
- Healthcare providers are experiencing increased SWIT (Safe Workplace Intervention Team) meetings. SWIT meetings are required to keep staff and families safe during escalation and conflict. These meetings are time and resource-intensive, and managing conflicts with families is a source of burnout for associates.
• Departments such as nursing, social work, security, customer service, and hospital administration are invested in finding a way to better manage or prevent these situations as it aligns with CHOC’s values of collaboration.

Framework

This EBP project utilizes the “Translating Evidence into Practice: CHOC’s Approach to EBP” model, adapted from the EBPI Model © 2007 Brown & Ecoff (Ecoff, Stichler & Davidson, 2020).

Search for the Evidence

Databases searched for this review included CINAHL, PubMed, EBSCO, Medline, and Cochrane to identify interventions for enhancing coping skills in parents of hospitalized chronically ill children. Key search words: parents, coping, chronic illness, resilience, mindfulness, burnout, and hospitalization. This search yielded over 100 articles describing various interventions for enhancing parental coping and resilience. Twenty-three articles represented evidence to answer our PICOT. Of these 23, seven were Level 1 evidence, nine were Level 2, three were Level 3, two were Level 4, and two were Level 5. We discarded articles that explicitly related to the NICU or adult population and didn’t have generalizability to our population.

Personal communication with authors of articles, individuals with clinical expertise in similar settings, and champions of existing programs within CHOC were also completed to gather relevant information for this EBP project.

Critical Appraisal and Synthesis of the Evidence

• Interventions focused on improving knowledge of the condition, parent-child relationships, stress reduction, and self-compassion are effective (see Table 1).
• Improved parental coping results in improved health outcomes and long-term coping for the child.
• Various support offerings have been found to reduce parental stress and anxiety during hospitalization. Many of these are currently available at CHOC.
• Support opportunities are not available or easily accessible consistently across units at CHOC.
• Associates, providers, and families lack awareness of available family resources and how to access them during their hospitalization or as an outpatient.
Table 1 Interventions

<table>
<thead>
<tr>
<th>Therapeutic communication by bedside and/or Charge RN</th>
<th>Social Work Interventions</th>
<th>Discharge Nurse Navigator</th>
<th>Child Life activities/events</th>
<th>Music/Art therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Resource Center</td>
<td>Spiritual Care visits</td>
<td>Implementing Safe Trauma-Informed Evidence-Based Practices (STEP) rounding</td>
<td>Patient Engagement Coach/Educator</td>
<td>Safe Workplace Intervention Team (SWIT) meetings</td>
</tr>
<tr>
<td>NSU Community Outreach Empowerment Parent Empowerment (COPE)</td>
<td>Family Advisory Council</td>
<td>Beads of Courage</td>
<td>NICO Boards</td>
<td>Commitment to Care Initiative</td>
</tr>
</tbody>
</table>

Practice Recommendations

- Improve interdisciplinary communication to enhance the awareness of the interventions departments offer to support families.
- Collaborate with other departments to form a more cohesive treatment plan that may reduce parental stress.
  - Key stakeholders have been approached and are engaged in this project. These include unit managers for the medical unit and social work management. Child Life Specialists, Spiritual Care leadership, and Executive Nurse Leaders have also been included.
  - We have presented to the Family Advisory Council and, as previously stated, were directed to the Patient and Family Experience department to learn more about the Kind Concierge program.
- Discuss with Seacrest Studios the option of including stress reduction content in their daily offerings over the TV channel
- Create a “menu” of resources to support parents during a hospitalization, including available activities, resources, support activities, and external links to supportive content. Ensure the “menu” is available in multiple forms: hard copy, QR code, and generic enough for implementation on various units.
  - This menu can come in the form of a pamphlet or QR code linking to the CHOC website.
    - Track the number of parent requests for support activities to monitor the utilization of resources.
    - If utilizing a virtual platform, we can track the number of hits on the website/app.
    - There is also an opportunity for a post-discharge survey of receipt, utilization, and helpfulness of resources. It would also be beneficial to track the number of SWIT meetings to recognize any downtrend after utilizing these resources.
- Add stress reduction programming that parents can access while in their child’s room, such as deep breathing breaks during Seacrest Studios programming, TV channels with chair yoga and stretching, meditative music, etc.
• This project has a potential for significant return on investment: a decrease in SWIT meetings and the need for de-escalation interventions, and an increase in parental resilience and the ability to cope with hospitalization stressors leading to better outcomes for their child and better satisfaction scores related to the hospitalization. Ignoring the issues will lead to a continued under-utilization of programs provided for parents and an increase in high-stress parent-initiated incidents that lead to prolonged hospitalization, poor patient outcomes, and decreased parent satisfaction with care.

• We initially projected to begin work on this project in January of 2022, with the potential to roll out in Fall 2022. However, in our review of current practice, we discovered that the Patient and Family Experience Department has proposed and secured funding for an extensive family support program called the Kind Concierge, including a menu of available support resources. We hope to collaborate with this department to ensure that the offerings include what the evidence shows is effective for reducing parental stress. The timeline for the implementation of the Kind Concierge is still unclear.

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