



Family Matters

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Resources and Support to Maintain the 'Essence' of Patient- and Family-Centered Care during COVID-19

Deborah Dokken and Elizabeth Ahmann

CCOVID-19 and its devastating impact is now sweeping across the United States, as well as the world. Major metropolitan areas are literally 'under siege.' Hospitals and other parts of the health care system are overwhelmed – without sufficient protective equipment for staff or even enough ventilators for patients. In the absence, often, of national guidelines, health care leaders are making decisions for their organizations and systems, and already-beleaguered frontline staff are working under new conditions. Children and youth with special health care needs (CYSHCN) and those with cancer may be at increased risk for complications from COVID-19 and are facing disruptions in care. To ensure the safety of patients and staff, some children's hospitals have restricted the presence of family members.

In the midst of the pandemic, committed staff are wondering how to 'stay true' to the principles of patient- and family-centered care (PFCC) when the health care system is so overburdened. They are looking for answers and want ways to quickly access and understand emerging best practices. They do not have the time to reach out to colleagues for ideas or to cull through information.

Drawing on its almost 30 years of advocating for partnerships among patients, their families, and health care professionals, the Institute for Patient- and Family-

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Note from the "Family Matters" Section Editors: *In this difficult time of COVID-19, we want to provide some quick resources for nurses who are trying to balance urgent issues of safety with the need to partner with the families of their pediatric patients.*

The **Family Matters** series focuses on issues, information, and strategies relevant to working with families of pediatric patients. To suggest topics, obtain author guidelines, or to submit queries or manuscripts, contact Co-Editors Elizabeth Ahmann, ScD, RN, PCC; or Deborah Dokken, MPA, *Pediatric Nursing*; East Holly Avenue/Box 56; Pitman, NJ 08071-0056; (856) 256-2300 or FAX (856) 589-7463.

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The Institute for Patient- and Family-Centered Care (IPFCC) has become a resource and clearinghouse for how to maintain the 'essence' of patient- and family-centered care during the COVID pandemic. Suggestions for language, maintaining connection, working with patient and family advisors, and other useful strategies and best practices can be accessed on the IPFCC website (<https://www.ipfcc.org/bestpractices/covid-19/index.html>). Additionally, the Institute's online learning community *PFCCConnect* now includes a COVID-19 community (register at <https://pfcc.connect.ipfcc.org/home>).

Key Words: Patient- and family-centered care, COVID-19, pediatrics, partnerships.

Centered Care (IPFCC) has become a resource and clearinghouse for information about how to maintain the 'essence' of PFCC during the COVID-19 crisis, including the following:

1. Suggestions for language (on websites, signage) that communicate the urgency of patient and staff safety, while still respecting the role of families in health care.
2. Alternative ways, especially through use of technology, to connect patients and families when physical presence is not possible.
3. Strategies for incorporating valuable input of patient and family advisors and partners during the pandemic.

On the "PFCC Best Practices" of the IPFCC website, the IPFCC has added material about COVID-19, including Frequently Asked Questions, a resource list, 'Spotlights' of creative strategies used by hospitals and other settings, and

free access to two recently presented webinars. Although not all materials are specifically focused on pediatrics, many of them are. They will be updated on a regular basis. The materials can be accessed at the following webpage:
<https://www.ipfcc.org/bestpractices/covid-19/index.html>

IPFCC's free online learning community, **PFCC.Connect**, has over 2,000 patient/family advisors and PFCC and Patient Family Engagement staff. It has been expanded to include a special community for COVID-19. In addition to discussions generated by community members, periodic, facilitated "Informal Conversations" about COVID-19 provide a forum to share up-to-date ideas about PFCC during the pandemic. Slides from the conversations, as well as the participant chat record, are archived for later access. To register for free membership in **PFCC.Connect**, visit:
<https://pfcc.connect.ipfcc.org/home>

We hope these two key resources support your own and your institution's efforts to maintain the 'essence' of PFCC during the COVID-19 crisis. ■■■

Funded by a grant from the Lucile Packard Foundation for Children's Health, Palo Alto, California, IPFCC is offering a series of free webinars and online conversations for children's hospitals and other pediatric settings focused on PFCC during COVID-19. These special events will occur monthly from June through October 2020. Check IPFCC's website for more information: www.ipfcc.org