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## Guest Editorial

**Deborah Dokken and Elizabeth Ahmann**

# Family Presence During Challenging Times

In March 2020, faced with the overwhelming nature of the COVID-19 pandemic, hospitals, health systems, outpatient settings, and nursing homes felt it was necessary to restrict visitors and family members to stop the spread of the virus and ensure the safety of patients and staff. Unfortunately, as a result, many patients were forced to be alone in hospitals and nursing homes – and some to die there, alone.

Even children’s hospitals were impacted, and many restricted parental presence at the bedside, even for the tiniest patients in the neonatal intensive care unit (NICU). Heart-wrenching stories have emerged – from both families and health care professionals – about the anguish caused by these restrictions.

Pre-COVID-19, an international campaign, *Better Together: Partnering with Families*, led by the Institute for Patient- and Family-Centered Care, had been instrumental in changing policy and practice in the United States and Canada. As a result, many health settings were welcoming families not as ‘visitors’ but as ‘care partners,’ recognizing their important role in the quality, safety, and experience of care (Dokken et al., 2020; Dokken, Kaufman et al., 2015; Dokken, Parent et al., 2015).

Despite recent restrictions resulting from the COVID-19 pandemic, there are some hopeful new initiatives. According to New York’s governor, Andrew Cuomo, “It is terrible to have someone in the hospital and then that person is isolated, not being able to see their family and friends” (Cuomo, in Passy, 2020). As part of a pilot program in New York State started in late May of this year, 16 hospitals are easing their restrictions on family presence. Changes are also beginning to happen in some other states.

Also at the end of May, a coalition of over 60 organizations, brought together by Planetree International and the Pioneer Network, met virtually and crafted the “Person-Centered Guidelines for Preserving Family Presence in Challenging Times” (Planetree, 2020). These new guidelines emphasize the importance of considering not only the

Dokken, D., & Ahmann, E. (2020). Family presence during challenging times. *Pediatric Nursing*, 46(4), 161-162.

risks that family presence may pose in a situation like the current pandemic, but also the risks that restrictions on such presence may cause. Some of these risks identified in the guidelines include the loss of an advocate or key decision-maker for a patient, or the loss of a patient’s emotional safety net, traumatic separations, reluctance to bring a child to the emergency department, and others.

The “Person-Centered Guidelines for Preserving Family Presence in Challenging Times” also offer suggestions for what family presence might look like in the future – finding the important balance between family engagement and considerations of safety. The guidelines, in brief, are as follows (Planetree, 2020, p. 4):

1. Assess the need for restrictions to family presence based on current factual evidence. Continually reassess as conditions evolve.
2. Minimize risk [using strategies such as screening, PPE, distancing, designated spaces, use of the outdoors, and the like].
3. Communicate what to expect [about policies] proactively and with compassion.
4. Establish compassionate exceptions...[such as] pediatric care, childbirth, patients/residents [with] communication challenges, cognitive impair[ment], or at the end-of-life.
5. Support meaningful connections to minimize feelings of isolation...when family is not able to be with their loved one physically.
6. Inform and educate [when presence is possible] adopt[ing] a shared decision-making approach to communicate...risks and benefits.
7. Enlist family as partners for quality and safety...with protocols.
8. Enhance discharge education and post-discharge follow-up [to ensure continuity in the transition]...remotely [using] care conferences, rounds, and discharge education.

In the May/June 2020 issue of *Pediatric Nursing*, the “Family Matters” section guided readers to new resources to help maintain the “essence” of patient- and family-centered care during COVID-19 (Dokken & Ahmann, 2020).

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Now, to help readers better understand the impact of restrictions on family presence, as well as strategies to address family presence in the evolving “new normal,” “Family Matters” will present two articles focused on family presence in NICUs during the pandemic.

In this issue, “Family Matters” features an innovative music therapy program in the NICU at UCSF Benioff Children’s Hospital in San Francisco. The program is designed to keep parents engaged and connected during the time of family presence restrictions. In the upcoming September/October 2020 issue, a group of family leaders involved with the Vermont Oxford Network will share experiences about restricted family presence and suggest ways to better integrate family ‘voices’ moving forward.

Since March 2020, dramatic events and changes have occurred in our country. The suffering has been great. The toll on our health care system has also been great – for those who need its services and for those who deliver them. At the beginning of the pandemic, decisions were often made in crisis mode to quickly protect safety. Restricting family presence is one example. However, with a bit of ‘breathing room,’ creative and caring individuals – clinicians and patient/family advisors – have begun to re-visit earlier decisions and are finding new ways to keep patients and families connected. These are hopeful signs. ■■■

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