Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

Journal of Pediatric Nursing 58 (2021) 102–103

Contents lists available at ScienceDirect

Journal of Pediatric Nursing

journal homepage: www.pediatricnursing.org

Technology Department

Disruption of Patient and Family Centered Care Through the COVID-19 Pandemic

Karen Goldschmidt, PhD, MSN, RN, CNE [a,*], Cheryl Mele, DNP PNP AC/PC-BC NNP-BC [b]

[a] Drexel University, United States
[b] Drexel University, Acute and Dual Care Pediatric Nurse Practitioner Program, United States

Pediatric nurses know the importance of patient and family-centered care (PFCC) for hospitalized children; it is the cornerstone of pediatric nursing practice. What has been commonplace for pediatric nurses for decades may not be so familiar in other practice environments. Other disciplines look to pediatric settings as experts when considering how a PFCC model can work within their facilities (Clay & Parch, 2016). The Joint Commission (2011) standards include PFCC principles for patients in all environments because they "improve quality and safety of care, chronic disease management, patient satisfaction, reduce hospitalizations and medical errors, and lowers costs (Clay & Parsh, p. 42).

Unfortunately, the COVID-19 pandemic has disrupted PFCC in both adult and children's hospitals across the country. Perhaps pediatric nurses witnessed more stringent visitation rules for families throughout the pandemic or may have been personally affected by a loved one's hospitalization. Because PFCC is the standard of care that pediatric nurses are accustomed to providing, it may seem foreign not to be included in a hospitalized loved one's care team. In PFCC every patient and their family is an essential member of the care team. How might pediatric nurses share their knowledge with other health care teams so that they can embrace the PFCC principles to benefit their patients?

It is just as crucial for pediatric nurses to think of ways to continue to provide PFCC in a manner that they are accustomed to despite the pandemic and not slip back into a time where families were not welcome visitors all day, twenty-four hours a day. It seems as if the COVID-19 pandemic has interrupted the pediatric health care team's ability to provide PFCC. We have seen firsthand situations where only one parent was permitted to visit a critically ill child for short periods, regardless of COVID status. When parents are also in need of support, how can they be supported when their child is sick? This column will present a case study of how one extraordinary nursing team took a grave situation and assisted parents in having their wishes met despite pandemic conditions. Also, the benefits of PFCC will be reviewed, and the use of technology to connect patients with their families. We hope that it makes all nurses stop and think about the possibilities that can occur for PFCC to meet patients and their families' needs amidst a pandemic.

Case study

Baby girl S. is a 5-month-old born at 34-weeks gestation with a complex medical history of mosaic Trisomy 12, developmental delay, BPD, tracheobronchomalacia, VSD, pulmonary hypertension, and hyperinsulinemia. Consequently, due to severe tracheomalacia and chronic lung disease, Baby S. required a tracheostomy and a gastrostomy tube and has remained ventilator dependent. Over the past several months, she displayed an increase in pulmonary hypertension and congestive heart failure. Subsequent implementation of digoxin, diuretics, nitric oxide, Sildenafil, Bosentan, and Flolan infusion were required. The child continued to suffer from intermittent pulmonary hypertensive episodes and required sedation with continuous infusions, breakthrough pain medications, and paralytics. Multiple specialists were involved in Baby S′ medical management to optimize her clinical status. Ultimately, a cardiac catheterization was performed to close her VSD; however, this procedure did not improve her clinical situation. Her pulmonary pressures remained high and cardiac output did not improve. Despite optimal medical and surgical management, Baby S. could not maintain adequate oxygenation unless she was paralyzed and sedated. After a multidisciplinary meeting with all specialists, it was determined that Baby S′ cardio-pulmonary status was incurable and incompatible with life.

The Palliative Care team met with the mother and father to assist with difficult conversations, clarify patient/family goals, and establish a relationship of trust. The Covid 19 hospital visitation policy evolved into situations whereby the parents were solitary witnesses to the bedside decompensation of Baby S. This severely impacted the benefit of bedside support regarding difficult medical decisions. The family consisted of a mother, father, and three younger siblings, ages 3, 5, and 9. Baby S remained in the hospital environment, which posed a concern due to Covid 19 restrictions. Hence, the siblings and were unable to meet their newborn sister and grandparents were unable to meet their granddaughter.

The parents were aware of Baby S′ continuous decline and tearfully expressed their concern over her insufferable condition and life quality. Based on the shared goals, the Palliative Care team presented potential options for the family. Of utmost importance, the mother expressed a strong desire that Baby S. meet her siblings and die at home in the nursery prepared for the child. Of spiritual concern, the child was not

* Corresponding author.
E-mail address: kag69@drexel.edu (K. Goldschmidt).

https://doi.org/10.1016/j.pedn.2021.03.001

baptized, and the parents insisted on a ceremony despite the visitation policy. Baby S. was baptized, and the child was admitted into hospice services. Subsequently, the child was transferred to home with medical support by the transport team.

Upon arrival in the home, the hospice care team was established. Her siblings and grandparents greeted baby S. She spent the final moments of her life in the nursery created by her parents. After a spiritual blessing was performed by a Catholic priest and humane removal from the ventilator, Baby S. died peacefully in the loving arms of her mother, surrounded by the family and the hospice team. The parents were grateful for the hospice team's support, to have their wishes fulfilled, and that their beloved daughter was able to spend time with her siblings and extended family. The hospice team assisted with the end-of-life care and burial needs.

COVID-19 visitor restrictions impact Children's hospitals

The current pandemic has posed a significant obstacle to clinicians' ability to meet the psychological, spiritual, social, and emotional needs of both patients and their families. Visitor restriction has exacerbated the anxiety and trauma suffered by parents relative to a child's hospitalization displaying dire symptoms and prognosis. The pandemic has profoundly impacted the grieving and bereavement processes of parents. Undeniably, the severity of existential suffering, post-traumatic stress, and profound grief experienced by children and their parents have reached new heights due to the neoenvironment precipitated by the pandemic. Visitors may be banned from Children's hospitals; thus, parents lack extended family members' support. As in the case scenario presented, visitor restrictions forced parents to make crucial decisions in isolation without the presence of family support. The health care consequences of the Covid-19 pandemic should remind all members of the health care team of the importance of family presence, communication, symptom management, and spiritual care of the patient. The experiences of healthcare teams throughout the pandemic should act as impetus to reflect upon and renew the commitment to compassion, humanistic values, and personal approach to PFCC in the presence of a pandemic or lack thereof.

Importance of PFCC

Pediatric nurses working with the principles of PFCC recognizes that the family is essential to the patient's healing and that the family plays a significant role in meeting the physical, mental, emotional, and spiritual needs of the patient (Clay & Parch, 2016). The principles of PFCC include 1) dignity and respect, 2) communication and collaboration, 3) promoting health literacy, and 4) including the patient and the family in all care decisions (Institute for Patient-And Family-Centered Care [IPAFCC], 2021).

Using technology to connect families

Pediatric facilities are accustomed to connecting children with their families, classrooms, and friends using mobile technology. For very young children who are critically ill families can link to streaming devices that overlook their child. In some neonatal intensive care units (NICUs) parents use software on an iPad that enables them to stay connected with their newborn twenty-four hours a day and interact with the health care team. Throughout the pandemic there have been numerous stories in the press of nurses leading initiatives to connect families with their loved ones when visitation was restricted.

Some families may not have the ability to afford a Smartphone or tablet for communication. Hospitals may have older generation mobile devices on hand for families to use (Biblow, 2020). For clinicians placing hospital-specific devices in easy-to-grab areas or designated patient rooms may help to facilitate communication quickly.

Scheduling time each day where the family can connect with the health care team is of utmost importance. Practitioner's schedules start early in the morning and may not be conducive to patients who are resting, and families are often unaware of when the team rounds. Designating a time for daily virtual rounds to check in with the patient and the family will reduce anxiety for the patient and the family, and the care team can address all questions during this time.

Reinstating PFCC

It is time for children's hospitals to reinstitute PFCC and review family and other visitor guidelines. Pediatric nurses can begin by reviewing the evidence of hospital-acquired infection from child to parent or parent to child throughout this time. It is time for pediatric nurses to engage in research concerning best practices for PFCC through a pandemic. Research is just beginning to emerge from adult settings that explore the family's experience while using virtual visits with loved ones while they were in the intensive care setting (Sasangohar et al., 2020). Overall, early research indicates that families were grateful to have the ability to connect with their loved ones and suggested adding the ability for "on demand" video access in the future. Barriers identified included difficulty communicating with their critically ill loved ones (due to the severity of their illness) and the care team, technical challenges, and their desire for touch and physical presence.

Conclusion

In summary, the COVID-19 pandemic has disrupted PFCC, family presence, and participation. Pediatric nurses are experts at providing PFCC. The case study showcases how a health care team worked together to meet one family's needs with the care they chose for their child. PFCC benefits the child because the family's presence is essential to the wellbeing of their child. Technology has and can be used to connect families with their children, but it is best that it not be used to replace them. The family member also needs the ability to support one another throughout the illness of a child. Pediatric nurses know that it is not the keeping out of families that help them through this challenging time; it is inviting families and including them in the care team that produces the best outcomes for children, even amid a pandemic.

References

Biblow, R. (2020, April, 13). Keeping families and patients connected during the COVID-19 crisis. *PressGaney, (BLOG)* https://www.pressganey.com/blog/keeping-families-and-patients-connected-during-the-covid-19-crisis.

Clay, A. M., & Parch, B. (2016). Patient- and family-centered care: It's not just for pediatrics anymore. *AMA Journal of Ethics*, *18*(1), 40–44 https://doi.org/10.1001/journalofethics.2016.18.1.medu3-1601.

Institute for Patient-And Family-Centered Care [IPAFCC] (2021). Family presence during a pandemic: Guidance for decision-making. https://www.ipfcc.org/bestpractices/covid-19/IPFCC_Family_Presence.pdf.

Sasangohar, F., Dhala, A., Zheng, F., Zheng, F., Ahmandi, N., Kash, B., & Masud, F. (2020). Use of telecritical care for family visitation to ICU during the COVID-19 pandemic: An interview study and sentiment analysis. *BMJ Quality and Safety*, *0*, 1–7 https://doi.org/10.1136/bmjqs-2020-011604.

The Joint Commission (2011, February 9). *R3 Report 1: Patient-centered communication standard for hospitals, 1 https://www.jointcommission.org/-/media/tjc/documents/standards/r3-reports/r3-report-issue-1-20111.pdf.*