Parent Participation in Pediatric Intensive Care Unit Rounds via Telemedicine: Feasibility and Impact

Phoebe H. Yager, MD, Maureen Clark, MS, Brian M. Cummings, MD, and Natan Noviski, MD, FAAP, FCCM

Objectives To evaluate feasibility and impact of telemedicine for remote parent participation in pediatric intensive care unit (PICU) rounds when parents are unable to be present at their child's bedside.

Study design Parents of patients admitted to a 14-bed PICU were approached, and those unable to attend rounds were eligible subjects. Nurse and physician caregivers were also surveyed. Parents received an iPad (Apple Inc, Cupertino, California) with an application enabling audio-video connectivity with the care team. At a predetermined time for bedside rounds with the PICU team, parents entered a virtual meeting room to participate. Following each telemedicine encounter, participants (parent, physician, nurse) completed a brief survey rating satisfaction (0 = not satisfied, 10 = completely satisfied) and disruption (0 = no disruption at all, 10 = very disruptive).

Results A total of 153 surveys were completed following 51 telemedicine encounters involving 13 patients. Parents of enrolled patients cited work demands (62%), care for other dependents (46%), and transportation difficulties (31%) as reasons for study participation. The median levels of satisfaction and disruption were 10 (range 5-10) and 0 (range 0-5), respectively. All parents reported that telemedicine encounters had a positive effect on their level of reassurance regarding their child's care and improved communication with the care team.

Conclusions This proof-of-concept study indicates that remote parent participation in PICU rounds is feasible, enhances parent-provider communication, and offers parents reassurance. Providers reported a high level of satisfaction with minimal disruption. Technological advancements to streamline teleconferencing workflow are needed to ensure program sustainability. *(J Pediatr 2017;185:181-6).*

Many parents of children admitted to a pediatric intensive care unit (PICU) suffer significant traumatic stress.[1,2] A recent meta-analysis examining post-traumatic stress disorder and the PICU concluded that 10.5%-21% of parents with a child status post PICU admission develop post-traumatic stress disorder, with symptom rates nearing 84%.[3] Two sources of stress commonly identified by parents are (1) having to be away from their sick child and (2) not receiving open, timely, and understandable information.[4] Family-centered care, including family participation on daily rounds and open visitation policies, has been linked to improved parent satisfaction, improved patient outcomes, and decreased stress for patients and parents.[5] Both the American Academy of Pediatrics and the American College of Critical Care Physicians strongly advocate for incorporation of such practices to promote family-centered care.[6]

Despite the wide-spread adoption of unrestricted intensive care unit visitation policies and the incorporation of families into daily PICU rounds, many parents face barriers preventing them from taking advantage of such offerings. These include the need to care for other dependents and an inability to miss work because of missed wages or threat of job loss (and with it loss of family health benefits).[7] The US Family and Medical Leave Act may protect some parents from losing their job when caring for a child with a serious health condition, but eligibility is limited and excludes those who work in the private sector for businesses employing fewer than 50 and those who have worked for an employer for less than 12 months.[8] Even if eligible for this job-protected leave, many parents cannot afford the associated loss of wages. Difficulties with transportation pose another hurdle; there is significant disparity across the US in terms of proximity to pediatric subspecialty care. In some regions less, than 10% of the pediatric population lives within 50 miles of a hospital with a PICU.[9]

Telemedicine has been used to improve rapid access to subspecialty critical care expertise by linking patients presenting to community hospitals with pediatric intensivists who can assist with treatment recommendations.[10-15] Nighttime telecommunication between attending pediatric intensivists on home-call with providers, families, and patients has been shown to enhance continuity of care and augment team communication with families during off hours. Parents reported increased satisfaction with these encounters and a sense of relief following updates involving the primary attending.[16] More recently, telemedicine has been used to successfully link hospitalized PICU patients with friends and family via simple, 2-way video conferencing technology. Patients reported feeling happier following these video encounters and

HIPAA	Health Insurance Portability and Accountability Act
NICU	Neonatal intensive care unit
PICU	Pediatric intensive care unit

From the Department of Pediatrics, Division of Pediatric Critical Care, Massachusetts General Hospital, Boston, MA

Funding provided by the Department of Pediatrics, Massachusetts General Hospital. The authors declare no conflicts of interest.

0022-3476/$ - see front matter.
http://dx.doi.org10.1016/j.jpeds.2017.02.054

exhibited less stress compared with patients without access to the videoconferencing program.[17,18] Based on the successes of these programs, we hypothesized that telemedicine could be used to enable families unable to be at their child's bedside to remotely join daily rounds in the PICU and that this would help decrease parental stress and increase parent and provider satisfaction.

Methods

Following Institutional Review Board approval a prospective, single center study was conducted in a university-affiliated, 14-bed PICU. Eligible subjects included (1) individuals who were parents or legal guardians of patients between 2 days and 17 years of age admitted to the PICU with an anticipated length of PICU stay greater than 48 hours and who anticipated being unable to attend rounds; and (2) PICU providers (nurses and physicians) directly involved in the care of a patient whose parents were in the study. Parent enrollment was through a convenience sample. On days when the research coordinator was available, all reachable parents of newly admitted PICU patients within the study age range and with an expected length of PICU stay greater than 48 hours were approached. Parents who indicated they would be unable to stay at their child's bedside were offered enrollment. The only exclusion criterion for parents and providers was unwillingness to participate in the study. Informed consent was obtained from all participating parents/guardians. A research information sheet containing the objectives of the study, risks, and benefits was distributed to all PICU staff. Their willingness to interact with the parents via telemedicine and complete the study questionnaire was considered implied consent and approved as such by the hospital's Institutional Review Board.

Once enrolled in the study, parents were provided with an iPad (Apple Inc, Cupertino, California) equipped with both wifi and cellular capability and loaded with free, off-the-shelf teleconferencing software enabling connectivity with the PICU's mobile telemedicine cart (Tandberg/Cisco cart estimated cost $35 000). The connection between the mobile telemedicine cart and iPad used Health Insurance Portability and Accountability Act (HIPAA)-compliant technology. This included the central administration of user names and passwords, and the encryption of protected health information in the form of data both at rest and in transit. Encounters were not recorded, obviating the need for stored protected health information protection from improper alteration or destruction. Although many parents owned an iPad or computer with video capability, they were discouraged from using these in the study because of concerns that the research coordinator might have greater difficulty troubleshooting potential problems with connectivity using unfamiliar end-user devices. Parents received verbal and written instructions from the research coordinator regarding the workflow to connect with the PICU's mobile teleconferencing unit. They were then asked about their future availability between the hours of 7:30-10:30 a.m. to remotely join bedside rounds. Study staff designated a 15-minute window for the planned video encounter and shared this with the rounding team for planning purposes. Each day parents received an e-mail confirmation of the planned video conference along with a web link and unique password to allow them to join a private virtual meeting room. The rounding PICU team joined the virtual meeting room within the predetermined 15-minute window using a mobile teleconferencing unit rolled to each patient's bedside. Parents were encouraged to participate in rounds no differently than parents who join rounds in person. Following rounds, the PICU mobile teleconferencing unit was rotated to focus on the patient, enabling parents to remotely visit with their child and continue a dialogue with their child's nurse. Assistance with the mobile teleconferencing unit was provided by a research coordinator. Parents were provided with a prepaid, pre-addressed mailing box for easy iPad return following study participation.

Following each encounter but before disconnecting, a research coordinator conducted a brief satisfaction survey with the participating parent. Answers to study questions were recorded on a paper survey. Provider surveys were distributed to the participating nurse and attending physician for completion after rounds and collected for later review. Parents and providers were asked to rate their level of satisfaction with the remote encounter based on a 10-point scale with 0 indicating not satisfied at all and 10 indicating completely satisfied. Providers were asked to rate how disruptive the remote encounter was to the workflow of rounds with 0 indicating no disruption at all and 10 indicating very disruptive. Parents were asked how the encounter impacted their level of communication with the PICU staff as well as how the encounter impacted their level of reassurance regarding their child's care in the PICU (choices included "positive effect," "no effect," and "negative effect"). Both parent and provider surveys were designed to take no more than a few minutes to complete (**Appendix**; available at www.jpeds.com).

Completed surveys were analyzed with descriptive statistics. All reported means were calculated by first averaging data within each patient based on the number of encounters completed and then averaging these results based on the total number of patients whose parents enrolled in the study.

Results

Twenty-three sets of parents who had children with expected PICU length of stay greater than 48 hours and who did not expect to be at the bedside for morning rounds were approached, and 100% enrolled in the study. However, 10 did not complete any telemedicine encounters for the following reasons: (1) the parents decided to remain at their child's bedside (n = 5); (2) the child was transferred out of the unit within less than 48 hours (n = 2); (3) the remote parent was unable to find time to join rounds because of demanding work/school schedule (n = 2); and (3) the remote parent declined to participate after initial connectivity difficulty (n = 1).A total of 153 surveys were completed following 51 telemedicine encounters involving 13 patients. One parent, 1 nurse, and