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When and why do neonatal and pediatric critical care physicians consult palliative care?

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Abstract

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DISCLOSURE STATEMENT

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Background—Parents of children admitted to neonatal and pediatric intensive care units are at increased risk of experiencing acute and post-traumatic stress disorder. The integration of palliative care may improve child and family outcomes, yet there remains a lack of information about indicators for specialty level palliative care involvement in this setting.

Objective—To describe neonatal and pediatric critical care physician perspectives on indicators for when and why to involve palliative care consultants.

Methods—Semi-structured interviews were conducted with 22 attending physicians from neonatal, pediatric and cardiothoracic intensive care units in a single quaternary care pediatric hospital. Transcribed interviews were analyzed using content and thematic analysis.

Results—We identified two themes related to the indicators for involving palliative care consultants: 1) palliative care expertise including support and bridging communication, and 2) organizational factors influencing communication including competing priorities and fragmentation of care.

Conclusions—Palliative care was most beneficial for families at risk of experiencing communication problems that resulted from organizational factors, including those with long-lengths of stay and medical complexity. The ability of palliative care consultants to bridge communication was limited by some of these same organizational factors. Physicians valued the involvement of palliative care consultants when they improved efficiency and promoted harmony. Given the increasing number of children with complex chronic conditions it is important to support the capacity of ICU clinical teams to provide primary palliative care. We suggest comprehensive system changes and critical care physician training to include topics related to chronic illness and disability.

BACKGROUND

Parents of children admitted to neonatal and pediatric intensive care units (ICUs) seek information to support participation in their child's care and treatment decisions to give their child the best possible outcome.^{1–7} Parents experience stress when they encounter barriers to their involvement, such as receiving incomplete or conflicting information or when their expertise about their child is not incorporated into the treatment plan.^{6–10} Additionally, parents often report feelings of uncertainty and fear about their child's outcome.^{11–13} Improvements in technology have improved survival, but an increasing number of children survive with complex chronic conditions and disabilities.¹⁴ Stress during the ICU admission can persist even after the child leaves the hospital and impact family functioning and the psychological well-being of the child.^{15–17}

Improving communication by integrating palliative care (PC) in the ICU is proposed as one way to improve outcomes for children and families.^{18–20} PC is a patient and family-centered approach that strives to achieve the “best quality of life for patients and their families, consistent with their values”²¹ and provides continuity that is more typical of a primary care setting.²² ICU physicians generally involve PC consultants in only the “most complex or difficult cases”^{23,24} that require “additional expertise and time.”²⁵ Because pediatric ICU patients have varied illness trajectories and medical complexity that are not necessarily tied to a diagnosis, it can be difficult to identify patients with unmet palliative care needs.^{22,24}

The purpose of this study was to describe neonatal and pediatric ICU physician perspectives on indicators for when and why they involve PC consultants, to make recommendations for integrating PC.

METHODS

Study setting, design, and participants

The study was approved by the Institutional Review Board at Seattle Children's Hospital (SCH; approval number: 13098).²⁶ This qualitative and descriptive study was part of a larger randomized controlled trial (RCT) conducted from July 2010 through March 2014 on the impact of automatic involvement of the PC consultation team (called Pediatric Advanced Care Team or PACT) with children in the ICU for 8 days at SCH.²⁷ Many pediatric PC teams are called PACT or "supportive care" in order to make PC more acceptable to families and physicians.^{28,29} Over the study period, the PAC Team included 2 social workers, 2 nurses, 3 chaplains, 1 child life specialist, and 1 physician and provided primarily decision-making and communication support to a total of 1171 families. Details about the ICUs are described elsewhere.²⁷

Twenty-two ICU physicians responded to recruitment outreach efforts targeting only attending physicians with primary rotation assignments at SCH. Each contacted the study coordinator, provided written consent, and enrolled: 14 from the pediatric ICU (PICU), 4 from the pediatric cardiothoracic ICU (CICU), and 4 from the level IV neonatal ICU (NICU).²⁶ These represented the majority of attending physicians a range of clinical experience, including 12 with 5 or more years as an attending physician; 15 were male.

Semi-structured interviews (averaging 47 minutes) were conducted in-person in 2012 by E.B. and recorded.³⁰ Transcribed interviews were entered in Dedoose qualitative data analysis software.³¹ The interview guide (see Richards et al.²⁶) was modified after the first 3 interviews and included questions about the role of PACT and what types of situations prompted a referral to PACT (outside the RCT).

Data Analysis

We used content and thematic analysis to examine physicians' descriptions of PACT involvement across a range of clinical situations.^{32,33} C.A.R. began coding the transcripts by looking for physician values, attitudes, and beliefs about PACT and indicators for consulting PACT.³⁴ Other codes were used to identify contextual information about PACT involvement, including patient and family characteristics (e.g., patient condition, family coping, information preferences), provider characteristics (e.g. beliefs about their own skills and role), and organizational factors (e.g., competing priorities, multiple specialist providers, continuity). The analysis included examining the relationships within and between these factors to identify the perceived outcomes of communication processes (e.g., efficiency, decision-making, trust, conflict, family stress) that contributed to whether and when ICU physicians involved PACT.³⁵ C.A.R. consulted with co-author mentors (H.S., M.R.O., E.B., and A.Z.D.) about methodological decisions throughout analysis and discussed findings with experienced clinicians.^{26,36} Data analysis was conducted between May 2016 and April 2017.

RESULTS

Indicators of the need for PC were related to two complementary themes: (1) physicians' self-identified needs for PACT's expertise in supporting families and bridging communication; and (2) organizational factors such as competing priorities for clinicians' time and care fragmentation. Patients with greater medical complexity and uncertainty were described as needing PACT expertise and being susceptible to problems arising from organizational factors. Resulting communication breakdowns were sometimes the indicators for consulting PACT to help resolve disagreements and mediate the family-clinical team relationship.

1. Palliative care skills

Physicians described PACT as capable of establishing a trusting relationship with the family and negotiating a shared mental model of the problem and treatment plan between the family and clinical team that integrated the values, concerns, and perspectives of the family.

Support—Physicians said that PACT provided emotional, spiritual, and informational support that helped families cope with uncertainty and navigate a complex system. PACT was described as generally having a nonjudgmental approach and more frequent communication with families. Physicians reported that families were more open with PACT about their questions, concerns, and uncertainty. PACT provided anticipatory guidance by putting the “hills” and “valleys” in context of the child's illness trajectory and supporting families' understanding of the implications of decisions on their future quality of life:

PACT has time to sit down with them and talk about, ‘Well, this is what it means when we say we’re gonna trach your child,’ and talk about a lot of the long-term issues associated with that...because we’re intensivists, we tend to gloss over...the long-term repercussions. (PICU-03)

PACT involvement also supported families during transitions from curative to comfort-focused care or from critical to chronic disease management.

Preparing for being out of the ICU or moving to a different kind of philosophy of the care where we’re maybe transitioning not into end of life, but we’re transitioning into just a different phase where the goals are going to become different. (PICU-02)

One physician said that the longer the stay, the more the family needed, but the less support the clinical team provided, highlighting the value of PACT during this time: “The families who are in an ICU for a long time really benefit from some other team helping them because people who go into ICU medicine are not good at chronic management” (CICU-01). Physicians consulted PACT when they expected death within weeks or months. Most physicians said that they did not consult PACT when the child was dying imminently because they felt capable of providing quality end-of-life care. However, one said that not all physicians “took the time.”

Bridging communication—PACT bridged communication by relaying information on an individual basis or facilitating communication during care conferences. PACT members

listened during rounds, talked with the family afterwards, and then shared information about family concerns and/or organized a care conference: “She often finds out things that you don’t know, or changes things; or discovering like, “This family really does need an interpreter.” You’re like, “Who knew? They’ve been here for three weeks, how did you know that?” (PICU-05).

Physicians reported that they lacked the capacity to explore family goals: “Sometimes we’re missing the goals of the family ‘cause either we’re not hearing it, or we’re too busy, or we’re just not trained maybe to hear these things” (PICU-06). Additionally, physicians thought that families had difficulty asking questions due to feeling emotionally overwhelmed or uncomfortable, or because they didn’t have the necessary knowledge. PACT served as a bridge by asking or rephrasing clarifying questions on the families’ behalf, and connecting the family’s values and goals to the outcomes of the treatment plan. PACT helped physicians identify “alternatives” that met the family’s goals, especially in situations when there was no obvious best course of action.

Disagreements between the clinical team and family about expectations was another indicator for PACT who could then “bring the family around” and/or share information that helped the clinical team understand the family perspective and/or address concerns: “They can sometimes get a lot of the background and what’s leading to the family’s decisions or wishes...so that can be eye-opening” (PICU-11). Physicians also described PACT as encouraging the clinical team to continue to communicate even when it was taking more time to resolve disagreements: “It was maybe the PACT team just saying, ‘All right, I know we’ve done this three times already, but we gotta do it again’” (PICU-12). Two physicians described a few rare occasion when PACT members were “driving to their own agenda” (CICU-02) or had an unbalanced approach: “Sometimes I think appropriately, she was sticking on the family’s side... I was like, ‘but you gotta bring the medical piece into that’” (PICU-05).

2. Organizational factors

Physicians described ICU organizational factors as additional reasons for involving PACT, including competing priorities and fragmentation of care. PACT was instrumental in addressing communication needs that arose from these factors.

Competing priorities—Physicians said that their paramount responsibility was to address the physiological needs of their patients. They often lacked time for in-depth conversations with families and relied on PACT expertise and availability to fill this gap: “They have the time; they make the effort to understand families in a way that I don’t have the time to do- so we are dependent on it” (CICU-04). PACT was valuable because they identified families’ communication needs that may have been otherwise overlooked, thereby preventing or resolving disagreements and making communication more efficient.

Competing priorities meant that big-picture discussions with families were deferred in favor of acute management decisions. Physicians reported that while parental presence during daily rounds was invited, the goal of rounds was to “start the day,” not discuss goals of care which could be sensitive and needed more time. Physicians often intended to return to the

family to translate medical information or address concerns, yet that frequently did not happen: “If there’s then five admissions and procedures to do and then all those things have to take priority...then some work will be undone” (PICU-07). While care conferences were often described as the appropriate place to discuss goals of care, one physician said that she (and other physicians) avoided consulting PACT because they dreaded the “painful and life-sucking” family conferences, when they had other pressing responsibilities. One physician said that sometimes PACT involvement in family conferences made them inefficient.

Physicians also noted that some families of patients with longer stays were less likely to communicate directly with physicians because they had to return to work or household responsibilities and weren’t available for spontaneous bedside conversations. Physicians said that they also did not have time to call families. The updates these families received were incomplete: “When they do, they get updates by their nurse and sometimes by the resident, but it’s not big picture, ‘Here’s what we know and don’t know.’” (NICU-01). PACT was instrumental in keeping these families informed.

Fragmentation of care—ICU physicians said that each subspecialty team (i.e. pulmonology, cardiology) viewed the child through their discipline-specific perspective. Because these teams worked in parallel, they often missed a holistic perspective and communicated differently with families, infusing different degrees of optimism or pessimism based on which organ system they were managing. Physicians said some families wondered if members of the clinical team were communicating with each other and if they were trustworthy, causing increased stress for the family: “The family is just totally at wit’s end. They have no idea who to believe, who to trust, and they hear both ends of spectrums on multiple organs that are or are not failing...They totally fall apart” (PICU-07).

Continuity issues exacerbated problems related to the involvement of multiple subspecialty teams. Both ICU and subspecialist physicians were scheduled for weeklong rotations, which might end before they could fully accomplish communication goals with long-stay patients, such as resolving disagreements about expectations for a child’s outcome and treatment plan. Incoming physicians were expected to continue the conversations but contextual information was lost during sign-out that could facilitate progress: “I can guarantee you that a lot of the more subtle decision-making stuff gets lost” (CICU-01). As a result, physicians described PACT as being particularly helpful for patients with long ICU/hospital stays and/or readmissions.

PACT also facilitated communication by providing continuity with the family because they had regular schedules and were available throughout the hospital. They were available to establish and maintain relationships with families during the entire hospital stay and any subsequent readmissions. This allowed them to facilitate communication between the different clinicians involved in the patient’s care and with the family. PACT managed or prevented problems by getting everyone on the “same page.” PACT became like the rim of a wheel, reducing the fragmentation of care by connecting all the “spokes”:

Palliative care has helped to...be the go-between for the families at the center of the circle, and all the different people who are caring for their spokes from them to

the family... Creating a connection between all those spokes, and helping to make it a little bit easier. (PICU-01)

Several physicians said that while on service, they relied primarily on verbal communication and went “digging through the chart” for background. PACT notes included a comprehensive assessment of the family context, treatment preferences, and quality of life considerations.²⁷ However, some physicians perceived this method of communication as contributing to fragmentation by making PACT yet another “spoke” in the wheel.

It’s the same communication issue that we have with all of our subspecialists. I really would like to know directly what they’re thinking and what they’re saying and what they’re hearing... Sometimes I’ll find a note that I’m shocked at the content and didn’t know that there was this concern. (NICU-04)

DISCUSSION

This study examined neonatal and pediatric ICU physician perspectives on when and why they involve palliative care consultants. The results suggest that PACT involvement was indicated for children with greater medical complexity, longer ICU/hospital stays, readmissions, and when poor outcomes were expected and there was uncertainty related to the timing of death or the “right” course of action.²⁶ Some physicians consulted PACT when they were unsuccessful in convincing families of what they perceived to be the “right” course of action. Similar to another study, physicians were less likely to involve PC specialists in caring for imminently dying children,³⁷ possibly because they perceived less uncertainty. As others have noted, these discussions often happen later in the illness trajectory or hospital stay.³⁸

Physicians described how PACT expertise, continuity, and available time helped address organizational factors that contributed to PC needs for some families. Physicians reported being pressed to prioritize acute management decisions and having short-term and fragmented relationships with families, thus missing contextual knowledge about family perspectives and having difficulty discussing long-term quality of life outcomes. While physicians often valued that PACT had “the time” to communicate with families,³⁹ some physicians were frustrated by decreased efficiency during family conferences. This reflects tensions in pediatric critical care between goals for family participation and medical efficiency.⁷

Patients with prolonged stays were described as medically complex and susceptible to organizational problems because their care involved a longer clinical history and more opportunities for fragmentation of care. Furthermore, physicians felt fatigued by caring for patients with chronic illness and provided less support to these families. One study found that nurses reported moral distress when caring for medically complex children, resulting in less support provided to families.⁴⁰ Our results may partially explain why conflict has been found in the care of half of patients in the PICU with stays longer than a week.⁴¹

The changing demographic of the PICU makes the problems experienced by patients with longer stays more pressing. The number of pediatric patients with complex chronic

conditions (CCC) has increased and more than half of PICU patients have a CCC.^{14,42–44} Patients with CCC tend to have longer hospital stays that are characterized by higher intensity care, morbidity and mortality than patients with non-complex chronic conditions or no chronic condition.^{42,45} Parents of CCC patients are often exhausted by the care that they provide at home,⁴⁶ and remain vigilant at the child's bedside in the ICU because they are concerned about the lack of continuity and the potential for errors.^{6,8,47,48} These families may be more likely to experience organizational problems and also be more stressed by them. Thus, the capacity for the clinical team to build and sustain trusting relationships with families of patients with CCC is critical.

We suggest comprehensive system-change to reduce variability in care coordination⁴⁹ by: 1) implementing a checklist strategy upon admission and on a daily basis throughout the hospital to identify unmet palliative care needs, including family understanding of prognosis, treatment options, and goals of care;^{49,50} 2) triggering a consult to PC when the clinical team is unable to meet these needs;⁴⁹ 3) ensuring that the family and clinical team know the roles and names of all clinicians involved in a child's care with a formalized list that is consistently maintained; and 4) providing education related to chronic critical illness as quality of life outcomes, and the needs and perspectives of patients with chronic conditions and disabilities and their families.¹⁸ PC specialists may improve team cohesiveness by meeting face-to-face with the primary clinical team. However, since continuity issues can result in the loss of contextual information over time, we also suggest improvement in the readability and accessibility of electronic medical records so that documentation about patient and family values and goals can be found efficiently.

This analysis is limited by having data from only one quaternary care pediatric medical center. Due to the smaller numbers of participating NICU and CICU attending physicians we were unable to compare patterns between the ICUs.

CONCLUSIONS

We've described how structural factors related to multidisciplinary teamwork in the ICU setting necessitated PACT facilitation of care coordination and clinical team-family partnership. Those same factors also hindered the benefit of PACT. We have suggested comprehensive system change and clinician trainings to improve the capacity of the clinical team to coordinate care.

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