The Pediatric Inpatient Family Care Conference: A Proposed Structure Toward Shared Decision-Making

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abstract

Over the past decade, there has been a steady increase in the medical complexity of patients on the pediatric inpatient service while at the same time, there are few data to show that families are satisfied with communication of complex issues. Family care conferences are defined as an opportunity outside of rounds to meet and discuss treatment decisions and options. They offer a potential pathway for psychosocial support and facilitated communication. The lack of consensus about the structure of these conferences impedes our ability to research patient, family, and provider outcomes related to communication. The goal of the present article was to describe a structure for family care conferences in the pediatric inpatient setting with a literature-based description of each phase of the conference. The theoretical framework for the structure is that patient and family engagement can improve communication and ultimately health care quality. This proposed model offers guidance to providers and researchers whose goal is to improve communication on the inpatient service.

The Agency for Healthcare Research and Quality has designated patient and family engagement with hospitals as an important strategy for improving quality and safety.[1] Recent changes to the structure of pediatric inpatient rounds have led to a more inclusive approach through family-centered rounds[2] that explicitly invite and encourage family participation in discussion and decision-making. Given the increasing medical complexity of patients in a pediatric inpatient setting,[3] effective communication of complex issues is imperative. In many hospital settings, families are dissatisfied with communication from providers.[4–15] Family care conferences (FCCs) offer a potential pathway for facilitated communication,[9,16,17] but the lack of consensus about the structure of these conferences impedes our ability to research patient, family, and provider outcomes related to communication.

October et al describe an FCC as "an opportunity to meet, convey serious information regarding the ill child's condition, or discuss a treatment decision, such as the need for an intrusive procedure…(It) also provides a forum to offer psychosocial support…and allows the family to participate in treatment decision making."[13] We distinguish FCCs from family-centered rounds, which have been defined as interdisciplinary work rounds at the bedside.[18] Both entities place the family at the center of decision-making, but we define FCCs as a longer meeting with an in-depth discussion of larger issues. There has been significant research regarding FCCs in the adult ICU[4–6,9,11,15,19–26] and the PICU,[7,12,13,16,17,27–29] but

there is relatively little work regarding the topic in pediatric inpatient medicine. Non-ICU inpatient clinicians do occasionally face end-of-life decisions with families, but unlike ICU clinicians, they also often deal with care coordination for a child with a new chronic diagnosis, discharge planning for children with medical technology, or treatment planning for the transition to the outpatient setting. Each of these tasks requires family engagement, and FCCs may serve as a means to that end.

The goal of the present article was to describe a structure for the FCC in the pediatric inpatient setting with a literature-based description of each phase of the conference that draws on work in many settings. The theoretical framework for the structure is that patient and family engagement can improve communication and, ultimately, health care quality.[30] The proposed model seeks to offer guidance to providers and researchers whose goal is to improve communication on the inpatient service.

WHY DO WE HAVE INPATIENT FCCS?

End-of-life decisions, delivering bad news, and discussing prognosis or major medical decisions are appropriate topics for an FCC.[17,20,31,32] Other situations in the pediatric inpatient setting that may benefit from an FCC include: a prolonged hospital stay, involvement of several consulting physicians, preparation for discharge, or a particularly confusing diagnosis. We propose a model for the FCC on the pediatric inpatient service that is flexible enough to allow for conferences with a variety of goals (Fig 1).[20,31] Parent and patient engagement are at the center of the model, and it is divided into 3 phases: pre-meeting, care conference,

and post-meeting. Each phase will be discussed in the context of existing literature.

PRE-MEETING

The most important part of the pre-meeting phase is allowing the family time to consider questions. Some parents may feel embarrassed to ask questions[33] or may be so upset that they are unable to remember simple practical questions.[17] Parents should be encouraged to write out or think of questions ahead of time. Both the medical team and the family should identify key clinicians and others who can help provide necessary information and support through participation in the FCC. Discussing in advance who will facilitate the meeting is also helpful. The presence of clinicians and family in the same location at the same time is crucial to a successful conference and cannot be substituted by key participants merely hearing about the meeting.[20]

There are several logistical tasks in the pre-meeting phase such as choosing a space for the conference. The room chosen must be the appropriate size for all participants to be seated comfortably. Conferences at the bedside may be more likely to include the patient but less likely to include a social worker or consultants; conference rooms may allow for more space and seating.[13] The setup of the seating in the room should be nonthreatening for the family, preferably with participants sitting in a circle. It is helpful to have the key providers meet before the family arrives (eg, a clinician-only meeting) (Fig 1). A brief review of the clinical situation and issues that may arise during the meeting can be discussed.

Consultants can be updated about the emotional and psychosocial condition of the family. Identifying the role of the learners, discouraging any cell phone or other interruptions, and simply having a box of tissues handy for the family are all preparations that may reduce awkward situations during the conference itself.

CARE CONFERENCE
Introductions and Overview

Meetings should begin with introductions from everyone in the room, and a brief statement about the goals of the meeting. Parents are encouraged to understand that they are a valuable member of the team, and they should feel free to participate in all aspects of the discussion. They should also feel free to interrupt if they disagree, and their advice should be sought by the team for all decision-making. If there have been mistakes (delay in diagnosis, adverse effects of treatment, or poor communication), those are best admitted openly, in an attempt to maintain or rebuild trust. As our framework indicates (Fig 1), family engagement is the key to successful shared decision-making. We describe 4 basic components that can foster this engagement: information sharing, family advocacy, medical home input, and emotional connection.

Information Sharing

Physicians may feel that sharing information is the most important task of the conference itself, but strategies to ensure effective communication are often overlooked. ICU physicians who were observed giving prognostic information often failed to ask if families wanted to hear the information before giving it and, furthermore, did not check with families about their
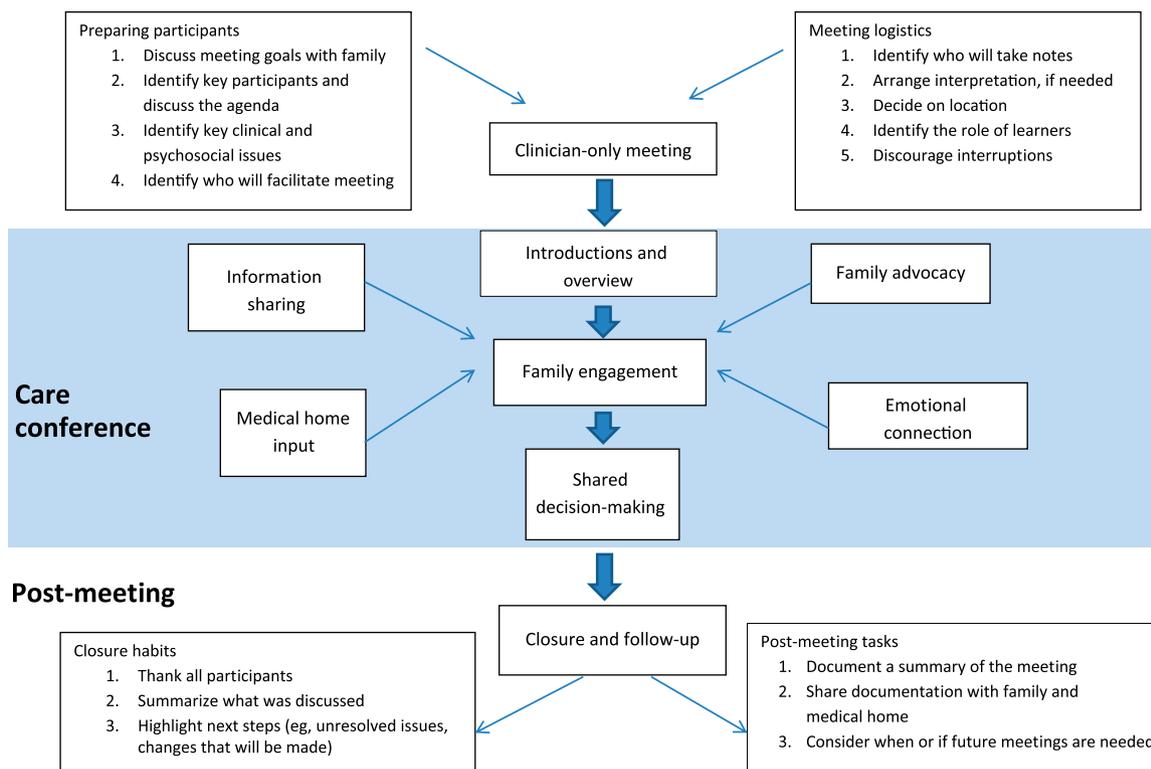
FIGURE 1 Inpatient FCC.

understanding of the information being shared.[24] Such simple strategies can combat miscommunication and confusion such as that caused by use of medical jargon or acronyms.

Family Advocacy

Families may feel intimidated about meeting with several medical professionals at 1 time. In certain cases, it is appropriate to have a family advocate present for the conference. Religious and spiritual considerations often have an important impact on the decision-making of families under stress.[27] The advocate may therefore be a religious leader or hospital chaplain, but it can also be a nurse who has developed a relationship with the family, a grandparent, family friend, or social worker.

For families with limited English proficiency, an important component of family advocacy is ensuring availability of needed interpretation services. These are required for adequate communication, family engagement, and shared decision-making. Even with interpretation services, 1 study found less information is transmitted in interpreted conferences compared with English-only conferences.[32] Research on family-centered rounds indicates that families prefer to have bilingual physicians caring for them, and if they are not available, they prefer in-person versus telephone translators.[33] The availability of professional interpreters may be limited,[34] and pediatricians often resort to ad hoc interpreters, despite the legal, ethical, and quality concerns of this option.[35,36] Given its

documented effect on communication quality, using trained interpreters for situations in which a family has limited English proficiency should be standard.[37,38]

Medical Home Input

The medical home has been touted as the ideal place to coordinate care for pediatric patients,[39] particularly those with complex medical needs.[40] Involvement of the primary care physician (PCP) in an FCC can encourage coordinated care through the medical home. It may not be practical for a PCP to attend an inpatient FCC, but telephone or videoconferencing is an option. At a minimum, the PCP should know when the conference is scheduled and be provided with a summary of the issues discussed.

Emotional Connection

The emotional connection that providers make with families is essential to successful FCCs.[20] The role that emotional connections play in the care of patients has received scant attention in medical training. The FCC can help provide the context for a successful emotional connection through a structured communication strategy.[21,31] The 5-step approach described by Curtis and White[31] uses the VALUE mnemonic, which reminds providers to value family statements, acknowledge family emotions, listen to the family, understand the patient as a person (no matter the age or condition), and elicit family questions. The goal of this strategy is to make an emotional connection with the family that will be the basis of collaborative[41] and shared[42] decision-making. Within the adult ICU literature, there is evidence that the empathic approach to family communication is associated with outcomes such as improved family satisfaction, although such evidence is lacking for the pediatric inpatient setting.[24]

Family Engagement

In a study from the PICU eliciting family and clinician perceptions about FCCs,[17] clinicians expressed more positive attitudes about the FCCs than parents did, and some parents did not even remember the conferences. Parent participation and engagement during FCCs may be an essential element to their success. One multisite study found a strong association between the percentage of time that families spoke during the FCC and their satisfaction with the conference.[11] Parental engagement often varies, and the care team should be prepared to elicit participation (Table 1). Parents can be asked to review their understanding of the situation. Alternatively, some parents may be fixated on an issue that cannot be resolved within the context of the meeting (eg, finding out the cause of a medical error, understanding the cause of a treatment failure). Strategies for redirection while acknowledging the validity of the questions may be productive.

Shared Decision-Making

A successful FCC will promote shared decision-making among the participants (Fig 1). A narrative review of communication in the ICU defined shared decision-making as the middle ground between the extremes of paternalism (the physician making the decision) and informed choice (the physician provides the information and withholds his or her opinion).[31] The authors advocate for a 3-step process in which clinicians: (1) assess prognosis; (2) assess family preferences for their role in decision-making; and (3) adapt their own communication strategy based on patient and family factors. This adaptive style of communication allows families to have different decisional approaches depending on their own preferences, the patient's condition, or the decision at hand.

One unique aspect of pediatric decision-making is the involvement of parents. A recent review examined 52 pediatric studies about parents' preferences in decision-making.[43] The authors found that parents' preferences for being involved in treatment decisions varied based on the clinical situation, their own emotions, and the relationship they have with the health care provider. Even parents who expressed a desire for a high degree of autonomy wanted input from the physician indicating the collaborative nature of the process.

POST-MEETING

Some simple habits at the end of the meeting may help to bring some

TABLE 1 Suggested Statements for FCCs

Introduction
  "Let's begin by having everyone introduce themselves and describing your role in Cody's care. I'll begin…"
  "I see that you have a list of questions. Let's begin with you asking your questions about Bryan's care."
  "Thank you for allowing us to participate in the care of Nick. I want you to know that we all have his best interests at heart."
Trying to engage the reticent family
  "Sometimes physicians use a lot of medical jargon. Do you have any questions about what Dr Wedemeyer has explained? Is there anything we should review?
  "What would you say is your main concern (or greatest fear) about Hunter?"
  "What would you say is your greatest hope for the future for Nayeli?"
Redirecting
  "I see that we only have a few minutes left, so I would like to try to summarize what we discussed and see if there is anything I have left out."
  "We have spent a lot of time discussing this particular topic, and I can see that it is important to you, but I want to make sure that we touch on all the issues."
Ending
  "We are here to support you as you, your family, and Jasmin continue to deal with this difficult situation."
  "These are very difficult decisions, and it may take time to determine the next right step for Bethany and your family…"
  "I wanted to thank you for participating in today's conference regarding Maria. I will write a summary of the issues discussed and then print and share that document with you."

satisfactory closure to the meeting even when contentious or unresolved issues remain (Table 1). The tasks after each family meeting should be the same: documentation and follow-up. The medical record should reflect that the meeting occurred, as well as the details of what was discussed and decided, and the PCP should be given a copy of the summary. Providing the family with a copy of this summary allows them to have a reminder of the issues discussed, is a tangible sign of trust and transparency, and may reduce family stress and anxiety.[25] The family should decide whether a follow-up meeting is needed, particularly when high-stakes decisions are made.[28]

DISCUSSION

Our proposed organization of FCCs places family engagement at the center of the process to help achieve high-quality care. However, our framework lacks evidence in the pediatric inpatient setting. Much of the evidence for FCCs comes from adult critical care settings, in which issues of surrogate decision-making, end-of-life decisions, and chronic care resonate in a different way than in pediatrics. Even the PICU literature may reflect a bias and focus on end-of-life concerns that are not as common on the general pediatric ward.

Research is still needed to determine the ideal structure and purpose of the FCC in the pediatric inpatient setting. More work is needed to define appropriate uses of the FCC and what parents and families want with regard to the structure, timing, and length of the conference. Qualitative work on how conferences are currently conducted could guide future educational projects. Electronic documentation templates could standardize provider practices around FCCs, improve recordkeeping, enhance the communication among providers, and provide researchers with valuable descriptive information about FCC structure and function.

We need to better understand the skills that all providers require in conducting FCCs. For example, FCCs may be facilitated by the attending of record, yet that provider may have no training whatsoever regarding how to conduct that conference. Faculty development targeted at communication training, a system of evaluation and feedback for providers, or the utilization of professional mediators may improve the outcomes of FCCs. Educational leaders should consider how communication best practices can be incorporating into medical training.

CONCLUSIONS

In the inpatient environment in which children are increasingly admitted for more complex care, providers need to develop skills managing the decisional and emotional needs of families faced with navigating the medical system. FCCs in the pediatric inpatient setting have the potential to support families in collaborative and shared decision-making. Preparing appropriately for FCCs, using a structured communication style, and engaging parents to express their concerns may improve the outcomes of these meetings.

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