Published in final edited form as:

Am J Crit Care. 2016 November ; 25(6): 489–497. doi:10.4037/ajcc2016817.

Clinical Nurse Participation at Family Conferences in the Pediatric Intensive Care Unit

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Keywords

decision-making; interdisciplinary communication; intensive care; critical care nursing; child; qualitative research

INTRODUCTION

Families of critically ill children meet with clinicians to receive medical updates on the patient's status and treatment options, discuss prognosis and explore end-of-life care choices. Frequently, the format of these meetings in the pediatric intensive care unit (PICU) is the family conference (1–3). In an effort to meet the full range of patient and family needs, these family conferences are often multidisciplinary, including physicians, social workers, pastoral care, case management, and nurses (4–6). Despite multidisciplinary participation, recent data suggest these meetings are often physician-dominated and heavily focused on medical information transfer from physician to families and patients (7, 8). In addition, a growing body of literature calls for the inclusion of early, regular exploration of values and goals, and provision of emotional support to families during family conferences (9–11). There is evidence that these additional components of communication in formal family conferences infrequently occur (12–14). The role of other care providers, who have additional perspectives and information about the patient and family, is poorly understood, and is of interest given these findings.

The purpose of this study is to examine the role of the clinical nurse in family conferences, within the framework of an inter-professional approach to shared decision making (IP-SDM) that acknowledges the importance of collaboration between disciplines over time, integrated and cohesive care, symmetrical power relationships, shared mental models, and a supportive

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This project was conducted at Children's National Health Systems, Washington, DC

No conflicts of interest

institutional culture (15, 16). Clinical nurses spend a significant amount of time with patients and families, probably more time than any other clinician. The clinical nurse often has up-to-date information on the patient's status, has had the most opportunity to discuss patient values and treatment preferences, and is experienced in using a clear, sensitive, and caring vocabulary about comfort, information, emotional, and advocacy needs (17–18). This uniquely intimate involvement with patients and families can lead to deep relationships and a view into a family's values and goals (19). Clinical nurses report contributing to family conferences by sharing information with and about the patient and family, advocating for the patient and family, and providing support and comfort (5, 10). While nurses also perceive some uncertainty in their role (20), their potential to contribute is significant.

Current efforts in adult oncology, intensive care and palliative care are aimed at defining and enhancing the role of the clinical nurse in discussions around prognosis and goals of care (21–23). The American College of Critical Care Medicine and the Society of Critical Care Medicine (24) have also recommended that ICU nurses be active participants in family conferences. The purpose of the study reported here is to examine the verbal participation of clinical nurses during real-time PICU family conferences, and to explore the pediatric clinical nurse's perception of their role in family conferences.

METHODS

Setting and Design

A prospective, cross-sectional study in a PICU of a single, tertiary medical center was conducted to understand both the observed and perceived roles of clinical nurses during family conferences. In this PICU, family conferences to discuss critical treatment decisions are convened at the discretion of the attending physician on service or at the request of a family member. Critical treatment decisions are defined as a decision to initiate, escalate, or withdraw life-sustaining therapies involving an invasive procedure (e.g., tracheal tube placement), escalation or adjustment of a medical therapy (e.g., continuous renal replacement), or end-of life care (e.g., resuscitation status). Family conferences for medical updates, delivery of bad news, or discharge planning were excluded. There is no automatic trigger mechanism for family conferences or guidelines providing a standardized structure in this PICU. All formal family conferences are conducted in a conference room within the PICU.

Two approaches were taken to directly evaluate clinical nurse participation in family conferences: analysis of audio-recordings of actual family conferences and responses to a survey about family conference attendance and participation. Written consent was obtained from all participants in the family meeting. The study was approved by the hospital's Institutional Review Board.

Observed Family Conference Participation – Audio-recordings

Forty family conferences with English-speaking adults holding primary decision-making responsibilities for a critically ill child (biological parent, adopted or foster parent, or member of the extended family) were audio-recorded from April 2012 to August 2014

(enrollment rate was 87%). Mandatory participants were the primary ICU physician and family member(s) of the critically ill child. The unit social worker arranges the family conference, coordinating schedules for the ICU physician, consultants, and the family. After the date and time are set, clinical nurses are notified of the family conference and encouraged to attend.

The audio recorded conferences were coded using the Roter Interaction Analysis System (RIAS). The RIAS is a valid and reliable quantitative tool for assessing medical communication in a variety of settings and has demonstrated high levels of reliability and predictive validity (25). The unit of analysis in RIAS is a statement conveying a complete thought, communicated as a single word, simple sentence, or a clause in complex sentence. Statements are coded directly from recordings and assigned to mutually exclusive and exhaustive code categories, identified by speaker. The codes are placed into 2 large categories: medical talk and psychosocial talk. Medical talk includes items such as medical information giving or counseling. Psychosocial talk includes elements regarding lifestyle and behavior, feelings and emotions. As an example, a clinician statement, "*She has to go downstairs for the CT scans. So she's being moved around. That can increase swelling.*" would be coded as medical talk. A statement from the clinician, "*Some families say, 'There's still quality of life. I can provide joy to my child and my child can provide joy to me'*" would be coded as psychosocial talk.

Structural measures of conference communication include conference duration (minutes), the sum of all family and clinician statements as an indication of total dialogue, and a measure of clinician verbal dominance constructed as the ratio of all clinician-to-family statements. One coder, with 10 years of RIAS experience, coded all of the conference recordings. Intra-coder reliability was calculated on 4 randomly selected, double-coded recordings. The average reliability, based on Pearson's correlation, coefficients averaged 0.97 for both clinician and family codes.

Perceived Family Conference Participation - Survey

All steady day shift or rotating shift clinical nurses working in the PICU during July and August 2014 were sent a survey on their perceived role in family conferences (N=96). The survey questions reflect the framework of interdisciplinary shared decision making (15), and were developed based on findings from the literature (24,27,28,34), followed by a focus group of 5 clinical nurses in our PICU who evaluated the survey for face validity. Changes were made to the ordering of items and reductions of items after review with the focus group. The 16-question survey included basic demographic data, such as full- or part-time status, shift, and years of practice. It also included items regarding how often, in the prior 6 months, the nurse received an invitation to attend a family conference, the number of conferences attended, and whether they verbally contributed during the conference. If the nurse had not spoken, we inquired about the desire to speak. Lastly, the survey included 3 open-ended questions asking participants to describe their perceived role in family conferences, factors that influenced their ability to attend family conferences, and elaboration on any verbal contributions made.

Each nurse received an information sheet and link to complete an online survey through hospital electronic mail. The survey was created and distributed using the Research Electronic Data Capture (REDCap) application. REDCap is a free, secure, web-based program designed to support data capture, and includes the capacity for branching logic in the sequencing of survey questions. A follow-up email was automatically sent 2 weeks later to those who had not completed the survey.

Descriptive statistics were used to examine demographic variables. Content analysis, the systematic extraction and description of the intended meaning of narrative content (28), was used to examine answers to open-ended questions. The codes that emerged from this analysis were described in terms of meaning and frequency. Two independent coders (AW and TO) evaluated the narrative survey results for recurrent themes and formulated definitions for these themes. Each individual quote from the clinical nurses' responses was repeatedly compared to other responses for both overlapping and unique meaning, leading to reductions and merging of similar themes. Each response was then sorted by theme. After reduction of codes, twenty percent of the individual responses were analyzed for inter-rater reliability between the two coders, Cohen's kappa was 0.89 ($p<0.001$).

RESULTS

Observed Family Conference Participation – Audio-recordings

A clinical nurse attended 20 (50%) of the family conferences that were audio-recorded. There were no nurses who declined consent to the audio-recordings after informing the charge nurse they intended to attend. Additional attendees included a PICU physician (100%), consultant physicians (89%), social workers (86%), case managers (50%), and palliative care providers (33%). The average length of the family conference was 37 minutes ($SD=15.9$). When a clinical nurse was present, the conference length was 43 minutes, compared to 36 minutes when a clinical nurse was absent ($p=0.28$). The medical team spoke, on average, 73% of the time, compared to family speech of 27% on average. Physicians verbally dominated the interaction, encompassing 89% of medical team talk compared to contributions from other members such as the social worker (7%), case manager (2%), and clinical nurse (2%). The content of the conference was mostly medical information (79%) compared to psychosocial talk (21%). Of the 20 conferences a clinical nurse attended, the clinical nurse made a verbal contribution in 5 (25%) conferences. The average length of time the 5 clinical nurses spoke was 1.7 minutes (range= 2 seconds-3 minutes), representing 4.6% of the total conference. Due to the low verbal participation rate of clinical nurses, we were not able to perform a thematic analysis on their utterances. Three of the 5 clinical nurses who spoke added clarifying information (one to give the room number for a patient transfer, one to explain the current schedule for urinary catheterizations of the patient, and one to state when eye drops would be placed for an upcoming eye exam). The two other verbal contributions included clinical nurses adding detailed clinical updates, such as progress of ventilator weaning, feeding tolerance, and a discussion about a pulmonary toilet regimen.

Perceived Family Conference Participation - Survey

Forty-seven of 96 day or rotating day/night shift nurses (49%) completed the survey. The majority of clinical nurses who responded worked full-time and held at least a Bachelor of Science degree in nursing. Thirty-four percent had been a clinical nurse for more than 7 years, and 28% had been a PICU clinical nurse for more than 7 years (Table 1).

Forty-six respondents (98%) agreed with the statement 'it was important for the clinical nurse to attend family conferences' (Table 2). Forty-two clinical nurses (89%) reported they had been invited to at least one family conference in the preceding 6 months. Of the 42 clinical nurses who reported being invited to at least one family conference, 7 (17%) were able to attend all of the time and 33 (78%) at least most or some of the time. Among the 40 clinical nurses who attended a family conference in the last 6 months, 21 (53%) reported they made a verbal contribution during the conference. Two-thirds (12/19, 63%) of those who said they did not make a verbal contribution indicated they had no desire to speak during the conference (one clinical nurse did not respond to this question). However, 6 nurses reported that they had Wanted to speak and their reasons for not speaking included: (a) they were new to their position and uncomfortable speaking during the conference (n=5), (b) a perception that the conference was physician-led and as a clinical nurse they either did not have a role or did not understand their role in the conference (n=5), and (c) they did not want to influence the decisions being made at the conference (n=2).

Qualitatively, we analyzed responses to 3 questions regarding attendance at family conferences. Question 1: What influenced your ability to accept or decline the invitation to the family conference? (This question was asked of all clinical nurses who had been invited to a conference, n=42). We identified 5 themes after examination of 69 unique responses to this question (Table 3). Most frequently, clinical nurses made statements that intense clinical responsibilities (29/69, 42%) and inadequate staff coverage of his/her patient assignment (19/69, 28%) precluded their ability to attend. Factors that facilitated or enabled clinical nurse attendance included the importance of the topic being discussed (16%), having a special relationship with the family (7%), or because the clinical nurse perceived it as a part of his/her duties (6%).

Question #2: What did you say and why? (This question was asked of all clinical nurses who reportedly spoke at a family conference, n=21.) Five key themes emerged from 35 responses (Table 4). Most commonly, clinical nurses stated they spoke during a family conference to provide clarification or information from the clinical nurse's perspective on patient care or patient status (46%). Secondly, clinical nurses reportedly provided support and reassurance for the family (20%) followed by helping the family by asking questions on their behalf (17%). Clinical nurses also reported they brought up issues related to patient care at the end-of-life (15%).

Question 3: In your opinion, what role, if any, does the clinical nurse play in family conferences? (This question was answered by all clinical nurses, n=47). Five key themes emerged from 99 responses (Table 5). Clinical nurses stated hearing first-hand the content discussed during the family conference led to a consistent message between providers and improved both future nurse-nurse and nurse-family communication (36%). Clinical nurses

also expressed, because they had the most contact with a family, they could provide information not available to other clinicians (28%). Advocating for the patient and family (18%), providing support for families and clinicians (14%), and decoding medical jargon (4%) were also offered as roles of the clinical nurse in family conferences.

DISCUSSION

Clinical nurses are an important member of the critical care team and overwhelmingly believe they should participate in family conferences. Their desire to attend was strongest when they believed the topic of discussion was important or if they had a deep relationship with a particular family. Despite this desire to attend, only 19% of nurses reported being able to attend all of the time. Not surprisingly, the main barriers to nurse attendance were excessive workload demands, high acuity needs of their patient, and inadequate staffing, as reported in previous research (5). Increased attention to resource barriers by physician and nurse management is a first step toward improving clinical nurse involvement in formal family communication given these findings.

Clinical nurses in our study identified roles in family conferences that match what has been found in previous research (6, 21, 27). Clinical nurses reported they provide a unique perspective of the patient's care, can be an advocate for the patient and family, and can support both the family and the physician (17). Importantly, clinical nurses reported they are a critical conduit to pass information along to other clinicians and to deliver a consistent message when talking to families later.

Despite these potentially vital roles, clinical nurses rarely made verbal contributions during the family conferences. Additionally, when clinical nurses did speak, there was little discussion of psychosocial issues related to goals of care. If family conferences are not meeting all needs of families, increased verbal participation from all team members could help expand discussions around goals of care (5, 22).

"Care and Communication Bundles," modeled after other evidence-based, proactive care protocols, have been successfully designed and implemented in adult settings to standardize multidisciplinary planning, documentation, and discussions about goals of care (11, 14, 18). In one intervention study, clinical nurses in 5 adult Veterans Administration ICUs were trained using role play to 1) help convene family conferences, 2) ensure bidirectional communication and voicing of concerns, 3) name emotional reactions and respond appropriately, and 4) follow up after the family conferences (23). These protocols instantiate the key features of an expanded inter-professional team approach: "The team [which includes the patient and family] must provide integrated and cohesive care and share power among its members. The team members must be able to exercise their partnership and share their knowledge regularly and without interruptions, communicating information systematically throughout the therapeutic process and using well-designed information and communication technologies." (p. 562) (15).

A well-established conceptual framework, referred to as a "multiple goals theoretical perspective" and drawn from social psychology, communication studies, and discourse

theory, has recently been used to analyze difficult medical conversations (29, 30). This perspective provides a theoretical construct for incorporating the additional expertise and experience of clinical nurses, and other interdisciplinary team members in family communication. Human communication necessarily involves three basic and often conflicting goals: task goals, relational goals, and identity goals. Patients and families want information, support for their decisions, continuity of care, assurance that suffering will be avoided, and to participate in decision making (12, 31–34). These are task goals, or the topics of the conversation. Relational and identity goals are more subtle and nuanced. They reflect the need for establishing, monitoring, altering, or reinforcing interpersonal connections (relational), and maintaining autonomy and reciprocity in the interaction, and exploring roles (identity). It may be difficult for clinicians to address relational and identity goals when these conversations are often the first time they have met with families (35). Increased participation by other team members could help address these goals.

It is also important to consider that the clinical nurse may be silenced not by choice. Six of the 18 nurses who did not speak said they had wanted to speak, and some of the reasons provided were that they were “uncomfortable speaking,” “were not asked” to speak and that the “physicians spoke through the duration of the meeting.” Differences in the perspectives on the timing and content of end-of-life discussions, the use of inappropriate interventions, lack of informed consent, and the degree of patient and family suffering between clinical nurses, clinicians, and other family conference participants have been reported in the literature (36–39). Clinical nurses have a responsibility to be proactive in expressing their desire to participate in family conferences, especially with respect to the degree to which professional hierarchies may contribute to their lack of verbal participation during these important conversations (10,40).

Several study limitations need to be addressed. The survey was limited to formal family conferences, so information about other types of conversations occurring between clinical nurses and families, such as those at the bedside, were not evaluated and need additional examination. It has been reported clinical nurses were often observed to remain in the room with patients and families after the conference had ended, or to accompany them back to the patient’s room and remain there (7). These important interactions were not captured, nor were the non-verbal behaviors of participants during the conferences. In addition, these results arise from a single center and may not be generalizable to other ICUs. Finally, selection bias must be considered. It is possible that clinical nurses who chose to participate may be different from those who declined participation.

CONCLUSIONS

Clinical nurses identified their participation in family conferences as important. However, multiple barriers to attendance were identified. When clinical nurses did attend, they rarely made verbal contributions. Continued efforts to improve both the physical and verbal participation of the clinical nurse during the family conference are needed, with special consideration given to expanding family and patient communication in the psychosocial realm.

Acknowledgments

Financial support: Tessie October received support from grant #5K12HD047349-08 from the National Institutes of Health, Eunice Kennedy Shriver National Institute of Child Health and Human Development.

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Table 1

Demographic characteristics of respondents to the survey

Characteristic	Frequency N=47(%)
Work Schedule	
Part-time	5 (11)
Full-time	42 (89)
Shift	
Day	27 (57)
Rotating	20 (43)
Years of Nursing Experience	
< 1 year	3 (6)
1–3 years	11 (23)
3–5 years	7 (15)
5–7 years	10 (21)
> 7 years	16 (34)
Years of PICU Nursing Experience	
< 1 year	8 (17)
1–3 years	15 (32)
3–5 years	7 (15)
5–7 years	4 (9)
> 7 years	13 (28)
Education	
Bachelor's degree	36 (77)
>Bachelor's degree	10 (21)
Not reported	1 (2)

Table 2

Survey responses on nurse participation in family conferences

Survey Question	Response Frequency n (%)
Do you think it is important for the bedside nurse to attend family meetings? (N=47)	
Yes	46 (98)
No	1 (2)
How many family meetings were you invited to attend in the past 6 months? (N=47)	
None	5 (11)
1–3	18 (38)
4–6	17 (36)
>7	7 (15)
How many conferences were you able to attend in the past 6 months? (N=42) ¹	
All of them (100%)	7 (17)
Most of them (75%)	17 (40)
Some of them (25%)	16 (38)
None of them (0%)	2 (5)
Did you say anything during a family conference? (N=40) ²	
Yes	21 (53)
No	19 (7)
Did you want to speak at the conference? (N=19) ³	
Yes	6 (32)
No	12 (63)
Not Reported	1 (5)

¹ only asked if respondent said they had been invited to a family conference² only asked if respondent said they had attended a family conference³ only asked if respondent said they did not say anything at the family conference

Table 3

Thematic responses on the nurse ability to attend family conferences (n=69 responses)

Themes	Definition	Frequency	Sample Quotes
Intense clinical responsibilities	Nurse workload and/or patient acuity limits ability to leave the bedside	29 (42)	"it depends greatly on the needs of my patient assignment"
Inadequate staffing coverage	Nurse reports insufficient availability of other nurses to offload duties during meeting	19 (28)	"staffing ratios/patient assignments always play a role in if I can or cannot attend the meeting"
Important issues were going to be discussed	Nurse values the information he/she acquires from the meeting that then improves his/her ability to support families and understand the treatment plan	11 (16)	"To gain clarification from and for parents on treatment of their child"
Relationship to patient and family	Degree of familiarity or a special relationship to the family	5 (7)	"feel that an RN who is well-acquainted with the family is best suited to attend meeting"
My duty to attend	Nurse is an important member of the team and should participate in care decisions	4 (6)	"important to have entire team at the meetings"

Table 4

Thematic responses about nurses verbal contributions during family conference (n=35 responses)

Themes	Definition	Frequency	Sample Quotes
Providing Clarification	Nurse adds value by supplying unknown information or explanations from the nursing perspective	16 (46)	"providing information regarding bedside care"
Support for family	Expressed support and provided reassurances for family	7 (20)	"I usually ask the family if there is anything nursing can provide"
Act as voice for family	Nurse asks questions on behalf of the family based on previous interactions with them and intimate knowledge of the family's wishes	6 (17)	"I feel that sometimes parents say things to nurses that they wouldn't feel comfortable saying to a physician or during a family meeting"
End-of-life perspective	I brought up issues related to end of life	5 (15)	"I have commented on end of life meetings that RN staff will continue to care for children as they have before"
Support for physician	Provided support for physician plan of care	1 (3)	"underlining importance of docs recs"

Table 5

Thematic responses to the role of the bedside nurse during family conferences (n=99 responses)

Themes	Definition	Frequency	Sample Quotes
Hearing first-hand parent-physician communication	Direct knowledge of family-provider conversation provides a consistent message and improves both future nurse-nurse and nurse-family communication	35 (36)	"to listen to what is being said in the meeting in order to answer any questions the family may not ask or understand during the meeting"
Having a unique perspective	Nurse has the most contact with family, and therefore may provide information about the patient and family that is not available to other clinicians	28 (28)	"She/he sees and experiences things with the patient and family that the rest of the team does not have the opportunity to view."
Advocating for patient and family	Nurse serves as spokesperson for the family, helping to ensure that their concerns and questions are appropriately addressed	18 (18)	"As an experienced RN I can often contribute by... helping them ask questions"
Providing support for the family and physicians	Nurse acts as a comforting presence for families and can reinforce with families the plan of care laid out by physicians	14 (14)	"I think having the nurse in the meeting would be a comfort for the family to know they have someone they can trust and lean on for support and guidance"
Decoding jargon	Clarifying and translating complex medical language for the family	4 (4)	"A family in crisis needs the most basic language and simple explanations, until proven otherwise"