

Treatment Collaboration When the Stakes Are High: Ethnographically Studying Family-Centered Care in an Outpatient Pediatric Specialty Clinic

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Abstract

Family-centered care (FCC) is vital for children with special health-care needs and serious chronic illnesses. Family–clinician collaboration and partnership formation are key FCC elements associated with improved health outcomes. However, FCC implementation barriers persist. Although some ethnographic research examines how FCC principles align with practice in inpatient settings, more studies are needed in outpatient specialty clinics. Using an FCC-oriented research team (clinicians, social science researchers, and families) blended multidisciplinary clinical knowledge and family/patient expertise with chronic illness. Our ethnographic study in a high-risk asthma outpatient clinic examined how FCC principles align with clinical practice, identified factors affecting partnership, and compared our findings to a large ethnographic study in an inpatient setting. Qualitative data from direct observation of 14 families with lengthy clinic visits were analyzed. Codes were applied to themes using FCC principles. Clinic visits had interactional and contextual elements that both aligned and misaligned with key FCC principles: information sharing, respect, participation, and collaboration. Recommendations for advancing FCC are outlined, and the importance of this step in light of ongoing health disparities is addressed.

Keywords

family-centered care, collaboration, partnership, asthma management

Introduction

In pediatrics, family-centered care (FCC) is planned around the whole family as care recipients (1). FCC implementation and family–clinician partnerships are important for children with special health-care needs, chronic illnesses, and life-threatening diseases (2–6). Such is the case in severe pediatric asthma. Pediatric asthma affects 10% of US children with profound impacts on health, academics, and social and family lives (7,8). Asthma’s chronic nature and unpredictable exacerbations pose challenges to life including managing treatment, restrictions on daily and social activities, medication dependence, school or work absence, and sleep disturbances (9–12). Managing this “high-stake” condition requires treatment options that work in the daily lives of families.

Known management techniques reduce adverse asthma outcomes (13,14). According to the National Asthma Education and Prevention Program, achieving and maintaining

asthma control requires 4 care components (15). Three of these components involve medical management, including asthma assessment and monitoring, control of environmental

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factors and comorbid conditions, and medications. The fourth component involves behavioral management relating to family–clinician partnership formation. This partnership, a cornerstone of asthma management (16), is founded on FCC principles (17,18) including respect, communication, information sharing, collaboration, and shared decision-making (19).

Existing research on the value of FCC has shown improved outcomes, reduced symptoms (20), fewer hospitalizations (21–23), improvements in physical and mental health status (24–26), patient satisfaction (27–31), and access to systems of care (32–34).

Researchers concur that FCC is an ideal model for providing care, but it can be difficult to implement (1,33–35), and consensus about its implementation in clinical practice is lacking. Collaborative relationships are often missing between health-care professionals and families (36,37). Some of the difficulty stems from the imprecise nature of FCC, which encompasses interactional elements that are complex and involve tailoring the care approach. Therefore, it is difficult to create a single set of “best practices” of how partnership between families and clinicians emerges and is maintained. Utilization of qualitative methodology can provide rich data about interpersonal interactions that have been identified in the literature as essential in the formation of partnership. Such information can assist in mapping progress toward FCC implementation.

Ethnographic studies, qualitatively exploring FCC implementation, are scarce and mainly conducted in inpatient settings (38,39). However, they demonstrate that interactional factors, such as negotiation between families and clinical staff (40), perceived roles, communication, trust, and respect (41,42), influence the delivery of FCC. Many researchers argue that more such investigation is needed in primary care offices and outpatient hospital-based specialty clinics providing care for chronically ill children (39).

We conducted an ethnographic study in an outpatient pediatric high-risk asthma clinic examining behavioral and contextual factors influencing FCC. We used ethnographic techniques to gain a more sophisticated, nuanced understanding of how FCC affects interactions between patients, families, and health-care providers. Observations and field note recordings of family–clinician encounters and health-related communication in this setting provided data that enhanced understanding of interpersonal interactions and social dynamics during the clinical encounter. Our study contributes new knowledge about how families and clinicians form partnerships and communicate about chronic disease management in an urban pediatric high-risk asthma clinic.

Studying FCC Ethnographically

Drawing on large-scale, rich FCC ethnographic research to advance and translate knowledge across pediatric settings is valuable. We explored findings from one of the largest pediatric ethnographic case studies (43), where over

200 hours of family-centered rounds (FCR) and 185 distinct rounding events were observed. As described earlier in our Introduction section, FCC is defined as health-care delivery that focuses on the patient in the context of the family. The FCRs seek to incorporate the principles of FCC in the inpatient setting built around the tradition of “bedside rounds.” Subramony et al (44) investigated how FCC principles aligned with FCR practices on a general pediatrics inpatient service. They found incomplete alignment in 4 areas: (1) *information sharing*: FCR allowed for open information sharing between family and medical teams; however, medical jargon interfered with sharing; (2) *respect*: medical teams generally demonstrated respect by inviting families to participate but lacked bidirectional introductions, failure to obtain permission to enter rooms, and physical limitations undermined intent to show respect; (3) *patient/family participation*: FCR provided families opportunities to participate in patient care; however, issues with rounds’ organization, distractions, and time constraints limited family engagement; (4) *collaboration/partnership*: FCR provided families opportunities to express concerns, observe, and collaborate in decision-making, but FCR did not ensure collaboration. Thus, Subramony et al (43) showed that FCR offered opportunities/instances of alignment in principles and practices, yet some barriers remained.

While recognizing variation in inpatient and outpatient settings and acknowledging the scale difference between the study by Subramony et al and our study, we applied ethnographic findings from this larger project to our context. By comparing similarities and divergences, we examined partnership in an outpatient setting and translatability of FCC principles and practices across different pediatric contexts.

Additionally, in this outpatient setting, we made an effort to focus on the special and complex communication needs that go along with family–clinician partnerships in pediatrics (44). In that light, we formed a research team that incorporated parents of children with chronic illness as parent researchers/ethnographers. Scholarly work coming from different fields such as education, sociology, and medical anthropology has supported the importance and unique contribution of parent researchers and parent ethnographers (45,46). For example, in educational research, it has been shown that parent ethnographers can help gain broader and deeper insights into the continuity between home and school and the very fabric of families (45). Although a detailed discussion of the strength of parent ethnographers is beyond the scope of this article, it is important to note that similar to educational settings, parent researchers in health care and medicine can offer unique insights. Knowledge stemming from parenting children with chronic conditions, such as asthma, and experience gained from fostering collaboration across disciplinary boundaries in order to manage chronic illness effectively can advance our understanding and move this field of research forward.

The strength of parent ethnographers, the unique composition of our professionally and culturally diverse research team, its dynamics, and collaborations are

explored comprehensively by the authors in another manuscript under preparation.

Method

Design

A qualitative ethnographic study was conducted from May 2013 to August 2014 on a high-risk asthma outpatient service at a children's hospital in a large urban academic medical center. Ethnography is a qualitative research approach that is used in everyday settings to understand naturally occurring but complex and dynamic situations involving interactions (47,48). Ethnographic methods are grounded in detailed observation often combined with other techniques such as interviewing to deepen the understanding of the phenomenon of interest (49,50). All of these characteristics make an ethnographic approach highly suited to study FCC implementation in clinical care settings.

In our study, a paired team of a medical anthropologist and parent researcher together interviewed the families prior to their visit (48) and observed the clinical encounter. They also interviewed the family and clinicians separately at the end of each visit.

Prior to the clinical visit, families were asked questions about the reason for the visit, their expectations, communication with the clinic's staff, and their level of comfort asking questions. Following the initial interview, the research team shadowed the family into their clinic visit. During the visit, they mainly gathered verbal and nonverbal information silently.

Each research team member took independent detailed field notes during observation, including structured data (eg, location, clinical activities, and duration of clinic visit) and unstructured data related to interactions between the patient/family and the clinicians (eg, information about discussions, interpersonal interactions, and verbal and nonverbal communication). Over the 3-month study period, the research team observed clinic visits for 14 families; each visit was approximately 100 minutes in length.

Following the clinical visit, families were asked questions about their visit impressions and experience, communication with clinicians, and understanding of the recommendations and thoughts about following them (eg, how easy did they think it will be to follow them). Clinicians were also interviewed about their impressions of the visit, aspects and quality of communication, and impressions of the likelihood that the treatment plan would be followed as discussed. Interview responses were manually recorded by the research team members.

Setting

The high-risk asthma clinic is part of the hospital's Allergy, Asthma, and Immunology Division. This clinic offers medical, educational, and psychosocial support to families of children admitted with an asthma diagnosis.

The high-risk asthma clinic is distinctive. Located in an urban Midwestern US city facing significant economic,

social, and health challenges, this clinic addresses asthma disparities for predominantly underserved groups. Much has been written about the need to combat these disparities overall, including disparities in urban African American patient populations which this clinic serves extensively. In this care setting, issues such as poverty, education, and health literacy are recognized and the degree to which these contribute to disparities is discussed. How these issues manifest through interpersonal interactions in implementing FCC needs further investigation.

The clinic's staff is diverse in some respect. For example, clinicians who work in the clinic self-identify as African American, Asian Indian, Arab American, and European American. However, issues that remain less explored here include other key forms of diversity that can impact FCC implementation (ie, different education level, social class, background, etc). Also of note is the fact that African Americans are not represented among the attending physicians who guide providing care in this specialty clinic, although the majority of patient population identify as African Americans.

As a specialty clinic (high-risk asthma) within a specialty service (Allergy Immunology/Asthma), patients/families typically have long-term, ongoing treatment. Clinic visits are longer than routine primary care visits, averaging 100 minutes. In a teaching hospital, this clinic provides opportunities to observe family/patient interactions with resident physicians and affords training chances. Thus, this clinic provides a complex context for care interactions; efforts to support partnership-building remain challenging in this setting.

Participants

Criteria of being referred to the high-risk asthma clinic include the following. Children are considered "high risk" by assessing the patient's likelihood of exacerbations, chronic morbidity including reduced lung growth, adverse medication reactions, and shifts from episodic to multitrigger wheezing (8). Additionally, children and families are referred to this clinic due to psychosocial risk factors such as poor housing, poverty, foster home placement, poor adherence to medical regimen, and environmental stressors (Personal Communication with Division Chief Georgia Michalopoulou, PhD, May 2013).

Of 14 recruited families, 13 self-identified as African American and 1 as Arab American. Children of participating families included 10 boys and 4 girls with an age range of 1 year 5 months to 16 years. The majority of the families ($n = 13$) had a long-standing relationship with the clinic and only 1 family was new to the clinic. Patient characteristics are shown in Table 1.

Investigative Team

We formed an FCC-oriented team consisting of a nurse researcher, psychologist, medical anthropologists, immunology

Table 1. Patient Characteristics.^a

Gender	
Male	10
Female	4
Age	
Average age, years	10.7
Range of ages, years	1.5-16
Cultural self-identification	
African American	13
Arab American	1
Length of clinic relationship	
New patients	3
Long-term relationship	11

^an = 14.

and asthma specialists, and parents of chronically ill children. Our perspectives blended multidisciplinary clinical knowledge and family/patient expertise with chronic illness.

Procedures

Families were approached in the clinic's waiting room by a paired team, a medical anthropologist and parent researcher who worked together shadowing families throughout their clinic visits. The study was introduced, and informed consent from parents and assent from children 12 years and older were obtained. A US\$20.00 gift card and children's books were given to participants. Identifying information was altered for confidentiality. Hospital and university institutional review boards approved the study.

Participants were invited to a more private section of the waiting room. They were interviewed utilizing open-ended questions allowing them to express their own perceptions and impressions of the care they receive at the high-risk asthma clinic. More specifically, participants were asked questions about the purpose of the visit, what they expected to occur, past experiences in this clinic, their impressions regarding the clinical interaction, communication, and partnership with medical staff. Interview questions are listed in Appendix A.

The FCC research team followed each family throughout their visit and silently observed the clinical interaction. Each researcher independently took detailed field notes. Upon the visit's completion, families and clinicians were interviewed separately regarding visit impressions, communication, collaboration, and treatment plans. Interview questions are described in Appendix A.

Typically, the clinic protocol was the following. The family was called from the waiting room and brought in to the examination room by an assistant. Weight and vital signs were taken, and in some cases, a breathing test was administered. Following the initial part of the visit, a resident physician came to the examination room and interviewed the family and the patient. Questions focused on how the patient and the family were doing with the asthma management,

symptoms, allergies, medication adherence, doses missed, medication problems and side effects, asthma exacerbations, environmental issues such as pets in the home, smoking, and so on. The interview was followed by a clinical examination of the patient. The resident physician reported what was learned to the attending physician who in turn talked with the patient/family themselves. That conversation involved clarifying information, instructing family regarding medication use, and discussing the treatment plan. If patient/family did not speak English, interpreting services were utilized. If psychosocial stressors requiring special attention were identified, a social worker was called to assist the family.

Data Collection

Data collection occurred in 3 steps:

- 1) Initial interview at the waiting room was conducted following introduction to the study and the acquisition of informed consent and assent.
- 2) Observation of the clinical visit and field note taking.
- 3) Final interview of family and clinician following the clinical visit.

All family members (parents, children, or other care givers) participating in the study were invited to participate in the interviews. As delineated in our institutional review board, we obtained informed consent from parents and assent from children aged 12 years and older who wished to participate.

Questions were directed to all family members and they were invited to answer. They chose if they wished to and who would answer the questions. As it turned out, parents took the lead in answering interview questions and providing impressions throughout the process of their clinical visit. These comments were recorded in the field notes. The children's perspective, when offered, was recorded. Often it was bundled in the visit observation and summarized from the children's reporting to the clinicians.

Analysis

Qualitative data from direct observation of 14 lengthy clinic visits (average 100 minutes) were collected over 7 months. Data were analyzed by applying codes to the 4 FCC themes/principles emerging from observation and interviews. Following data collection (by the paired team: a medical anthropologist and parent researcher), the entire research team consisting of 8 members (nurse researcher, psychologist, medical anthropologists, immunology and asthma specialists, and parent ethnographers) had the opportunity to read all the protocols, code, and participate in the analytical process. A consensus coding process incorporated the research team's diverse perspectives. A protocol on implementing triangulation generated by members of the research team in their previous work was adopted for this study (51). This protocol enabled the integration of diverse data sources,

Table 2. FCC Principles and Practices Alignment.

FCC Principles	High-Quality Practices Aligned With FCC Principles	Low-Quality Practices Misaligned With FCC Principles
Clear and open information sharing with patients and family members	Information sharing is improved when age-appropriate explanations and guidance are given	Information sharing is lacking when patients/families or clinicians are left with questions or misunderstandings about previously discussed topics
Respect for patients and family members	Seeking to understand changing family dynamics in an empathic and nonjudgmental manner can build rapport and respect	Misunderstandings and assumptions about family dynamics can be perceived as disrespectful
Participation of patients and family members	Participation is increased when a family has opportunities to ask questions and have them answered thoughtfully	Participation can be negatively impacted by a family's unwillingness to work with particular clinicians or respond to questions Preoccupation with other things like phones interfered
Collaboration with patients and family members (especially around treatment plan decision-making)	Collaboration is aided when the medical team is willing to listen to and consider the patient's point of view regarding treatment	Collaboration is hindered by distractions and a lack of clear communication and information sharing

Abbreviation: FCC, family-centered care.

methods, and disciplinary perspectives. Triangulation involved articulation, negotiation, and accommodation of divergent viewpoints in order to reach consensus. When a disagreement occurred, special attention was given to the perspective of the parents. The team heard what the parents emphasized based on their experiences of how issues of chronic illness management unfold and impact everyday life. Following that input, the team would make final coding decisions.

Our findings, similar to the study by Subramony and colleagues, are organized around 4 FCC principles: information sharing, respect, patient/family participation, and collaboration/partnership. Case vignettes from observed interactions illustrate high or low alignment between principles and practices (Table 2).

Information Sharing

We found various communication methods improved information sharing. Using laymen's terms to explain test results, providing images and metaphors that connect with patients and families and adjusting body language/positioning enhanced information sharing.

High-quality information sharing example. Respiratory therapist provides patient (age 9) with visual and verbal description of how respiratory test is going.

After the third attempt, the therapist turned the computer so Tinesha could see it and showed different arcs between her first and next attempts. The second and third didn't have a big arc like the first. She explained that Tinesha needed to open her throat like she was yawning, and tipped her own head back to show what she meant. She had her try one more time while watching the screen to see that the arc was forming. Tinesha blew harder and longer, the therapist praised her effort.

The therapist offered the patient a clear, age-appropriate explanation, guidance, and praised efforts. The patient was able and willing to adjust her test performance, producing better results.

Alternatively, factors hindering information sharing included use of medical jargon, not explaining test results, direct questioning or speaking to the wrong family member, and body language/positioning, not inviting open communication.

Low-quality information sharing example. Conversation between Sarah (patient's mother) and ethnographer after a resident completes examination and leaves room.

The ethnographer asked Sarah: "How was the communication between you and the resident during the visit?" She said: "Excellent." "How much of what the resident said did you understand?" She replied, "Everything, but I'm not sure which new (allergy) medicine she meant." The ethnographer continued "How much of what you said do you think the resident understood?" Sarah replied, "Probably everything." The ethnographer asked her why, and she said, "I don't know; because she agreed with it."

Although the mother states the communication was "excellent" and she understood "everything," a medication was misunderstood. The resident also assumed shared understanding, but evidence showed otherwise.

Respect

Respect is conveyed, in part, by body language/positioning and speech content/tone. Awareness of family dynamics, individual perceptions, and families' broader situations contribute to respect. Being nonjudgmental, encouraging alternate explanations, and reacting in a neutral manner demonstrates respect and facilitates partnership-building.

High-quality respect example. Physician seeks explanation for a family's missed appointment, acts nonjudgmental, and requests clarification to better understand the family situation as it relates to care delivery.

Dr D pulled the stool up and sat down facing Shirley. Dr D said she was supposed to have seen Makayla in May or June, but didn't. Dr D mentioned that Makayla was hospitalized for an acute asthma flare recently. Shirley said that her daughter didn't bring Makayla for her appointment, and explained she is now the kids' legal guardian. Dr D asked empathetically if the kids and their mother live in the same house. Shirley explained that for the past 4 months, the kids have been living with her, separate from their mother.

Low-quality respect example. Respect is diminished via adverse body language positioning, tone, and assumptions about family dynamics.

Devon was with his mother Maya. During a conversation with the resident, Maya had to call Devon's grandmother to find out information regarding Devon's care and ask if Devon needed medication refills. When the attending physician arrived, there was confusion about who was the main caretaker. Dr B asked Maya in a firm tone "Are you Devon's legal guardian or is his grandmother?" Maya assured him she was but found the question disturbing. The physician made an incorrect assumption about family dynamics which undermined demonstrating respect.

Participation

Positive FCC interactions were observed when medical professionals asked for input from the patient and family and when patients and families came to the clinic prepared with pertinent medical information and/or questions.

High-quality participation example. David, father of Rachel (age 10), and his partner Monica are talking with a senior resident Dr S and a medical student.

After introductions, Dr S asked David and Monica about Rachel's health, medications, and inhaler use. They discussed possibilities for cheaper alternatives because as Monica stated the high medicine price was "tearing our pocket up!"

"David jumped in and said he had 2 questions. The first related to something he had heard. David asked "Is swimming good for asthma?" The doctor looked a bit stumped or puzzled at first, but seemed to be thinking while saying it was a good question . . . He answered generally saying that physical activity can be good for you to strengthen the lungs but he didn't know about swimming specifically, but would consult with Dr C (attending physician). David asked his second question relating to dry or humid air and how that could affect Rachel's asthma. David said the family had contemplated a move possibly out to Arizona but wanted to see how that might affect Rachel's asthma. (Family #3)

This conversation was productive. The family felt comfortable voicing their questions. The clinicians affirmed these were good questions and directly answered or stated how they would follow up. Next the medical student explained more and demonstrated with her hands what happens to people with asthma's lungs. Then David shared they had just been to a funeral for a young child who suddenly stopped breathing. Although this child's death was not due to asthma, he was concerned about Rachel's health and wanted to make sure they (he and Monica) made correct decisions. Alternate to this rich conversation, we saw other occasions when participation was hindered by preoccupation with other activities such as using one's phone and nonreceptivity to suggestions.

Low-quality participation example. Lack of mutual engagement from both families and clinicians hampers the participation process. A mother did not want to interact with the resident and to participate in the clinic's teaching process.

Resident Brown came into the room and immediately Renee (patient's mother) gave her a sharp "no" saying she only wanted to see Dr A. The resident walked right out of the room without saying anything or making eye contact. When the resident was out of the room, Renee said to the social worker that she did not like "that lady" because she asks too many questions. The social worker told Renee that this clinic is a learning facility, and it is important that the resident is able to see Renee and Max (son).

Collaboration

Collaborative decision-making flourished when a previously built relationship between the family and the medical team existed and the patient/family came well equipped with knowledge about the illness and medications.

High-quality collaboration example. A 16-year-old patient explains to the resident why he decided to take a breathing treatment rather than practice exercises while providing information and thoughts on enacting the care plan.

Resident Green asked Danny about his recent flare-up. Danny explained that he took a breathing treatment to control his flare-up instead of doing the breathing exercises because it was quicker. The resident asked Danny when he takes albuterol and continued with more questions about his asthma medications. Danny listed them and told her how often he uses them.

Conversely, collaborative decision-making was hindered by lack of mutual respect and previous relationship. Sometimes collaborative attempts were severely limited due to lack of knowledge of the previous care plan or due to preoccupation with other activities, particularly cell phone usage.

Low-quality collaboration example. The patient's mother lacks necessary information and reaches out to the patient's

grandmother to get pertinent details. Collaboration around the care plan is derailed by missing information and a reluctance to engage in more extensive conversation.

Maya called her mother again to ask if there were other refills Devon needed. After talking on the phone, Maya said that one medication was not working for Devon. Resident Fox asked “Why?” The grandmother on the phone commented “Because it’s not working” in an irritated way. Resident Fox tried to get a better understanding of what problems remained in order to suggest a different medication; Maya just said it was simply not working for him.

Discussion

Consistent with the study by Subramony et al, our findings include practices aligning/misaligning with the 4 FCC areas. The FCC principles aligned with practice when good verbal/nonverbal communication between patient/family and clinician facilitated information sharing. Optimally, clinicians provided age-appropriate clear explanations and gave guidance, positive feedback, and praise. Medical jargon hindered interactions and misaligned with FCC. Nonverbal communication was promoted by attending to body language/positioning and using visual aids.

Respect was associated with socially proper introductions, efforts to understand family dynamics, and ongoing, open dialogue. Understanding multiple viewpoints and withholding judgment were key to communicating respect. A foundation of respect enabled all parties’ participation. Interactions were better when medical professionals asked for patient/family’s input, and families were prepared with pertinent information/questions. Preoccupation with other things such as cell phones hindered participation.

Collaboration was promoted by mutual respect, good communication, and when patient and family provided information about treatment (eg, feedback on medications, symptoms). Similarly, collaboration was fostered when clinicians had information regarding medical/psychosocial issues, reviewed the medical record prior to the visit, and displayed good listening and communication skills.

Achieving partnership in a teaching hospital’s clinic is more challenging; medical personnel rotate due to training schedules and clinicians are not always familiar with the patient’s history/family dynamics. Interacting with multiple clinicians complicated interactional elements such as communication, trust, and respect.

Many clinical practice demands exist in this setting. Pressures to maintain accurate electronic documentation, increased patient loads, and other time constraints impede collaboration. Patients/families’ collaborative abilities may be hindered when the clinic environment is not comfortable to navigate and/or when experiencing multiple medical, psychological, social, environmental, familial, educational, and financial stressors.

Complex pediatric interactions make FCC evaluation difficult to accomplish in single clinic visits, even lengthy ones. It may be argued that these principles are best examined via ongoing relationships, especially in chronic illness treatment. For example, it can be hypothesized that interaction quality, information sharing, participation, and collaboration differ when the parties know each other for extended time and through different circumstances (eg, asthma flares, hospitalizations). Collaborative relationships and care partnerships may become more resilient to mishaps. In visits where respect was not fully demonstrated or high participation did not occur, it may not be as detrimental if partnership was built in past visits.

In our study, all the families with the exception of one had a long-standing relationship with the clinic; however, in the clinic’s teaching environment, families interacted with new residents routinely. As such, clinical interactions comprised of new as well as long-term relationships. The dynamics of these interactions therefore are more complex. Maintaining partnership is an ongoing process; therefore, the complexity of the clinical interaction in a teaching clinical environment merits further study and investigation. As we noted earlier, this issue has not been adequately studied in pediatric outpatient specialty settings, which are critical for chronic illness management.

Strengths and Limitations

Despite our ethnographic approach and use of an FCC-oriented research team, we acknowledge study limitations. Our study involved a small convenience sample and was conducted in 1 pediatric service of 1 institution. Our observations reflect clinic visits examined as individual units; we recognize each family has a visit trajectory which we partially saw. However, our methods including a multidisciplinary team with parent ethnographers enabled us to better understand families’ experiences.

Achieving FCC is complex and needs further research, education, and refinement. Ethnographically exploring the alignment of FCC principles and practices is important, especially in critical pediatric settings with ongoing health disparities.

Conclusion

For successful FCC implementation, patients/families and clinicians need to be engaged, well informed, and receptive. Clinicians must be skilled in establishing good interpersonal relationships and clear and respectful communication to promote collaboration. Developing these skills is ongoing (41). Attending physicians may utilize clinical opportunities to teach residents how to practice these skills. For families, learning how to best prepare for visits is useful (eg, collecting information regarding medications, reporting observations, symptoms, concerns, and asking about treatment options). The clinic must be well organized and operate in

a manner supporting partnership. Finally, to advance FCC training, institutions must enhance curricula by systematically teaching and evaluating aspects of care delivery involving communication skills, demonstrating respect and cultural sensitivity.

Appendix A

Questions Prior to Visit

1. What's your child's name?
2. How old is he/she?
3. Who are you seeing here today?
4. What do you hope to get out of this visit?
Probe: What are you expecting to happen during this visit?
5. What usually happens when you come to this clinic for a visit?
Probe: What goes on in a visit, what kinds of questions are asked/answered?
Do you feel like you get your questions answered and/or needs met?
Why or why not?

Communication Questions

An important part of visiting this clinic is being able to get your questions answered. I'd like to ask you more about communicating with the doctors and nurses here—and how to get your needs met.

6. If you have a question about [child's name]'s asthma care, who do you go to to get it answered?
Probe: Can you give an example of a time when that went well or didn't go well?
7. Tell me more about what talking with the doctors and nurses in this clinic is normally like?
Probe: What makes you say that?
Do you have any examples of good/bad communication?
8. How comfortable do you feel asking the doctors and nurses your questions about [child's name]'s care?
Probe: What makes you say that?
Could you give an example of what kinds of things you are/are not comfortable talking about?
9. How well do you think the doctors and nurses understand what it takes to manage [child's name]'s care on a daily basis?
Probe: Tell me more . . .
What kinds of things do you wish they understood better about [child's name]'s care or about what is going on in your life?

Advice Questions

10. What advice would you give a new family coming here?
Probe: What would you tell a family about communicating with the doctors and nurses that they can get what they need?
11. If you could give the doctors and nurses here some advice about communicating with families what would you tell them?
12. In your opinion, what would improve the experience of visiting this clinic?

Impressions of the Family After the Visit (Use for Each Clinician Seen)

13. How was the communication between the (doctor/nurse/resident/etc . . .) and you during the visit today?
 - a. Excellent
 - b. Good
 - c. Fair
 - d. Poor
 Probe: What makes you think that?
14. How much of what the (doctor/nurse/resident/etc . . .) said did *you* understand?
 - a. All of what was said
 - b. Some of what was said
 - c. Not much of what was said
 - d. Unsure/Don't know
 Probe: Why do you think that?
15. How much do you think *they* (doctor/nurse/resident/etc . . .) understood of what you said?
 - a. All of what was said
 - b. Some of what was said
 - c. Not much of what was said
 - d. Unsure/Don't know
 Probe: Why do you think that?
16. How easy will it be for you to follow the plan discussed today?
 - a. Very easy
 - b. Somewhat easy
 - c. Not easy
 - d. Unsure/Don't know
 Probe: Why do you think that?

Thank you so much for your time today. We really appreciate your thoughts about this clinic and how it can help meet families' needs.

Clinician's Impressions After the Visit

1. For the visit today, what is your impression of the communication between the family and you?
 - a. Excellent
 - b. Good

- c. Fair
- d. Poor

Probe: What makes you think that?

2. How much do you think the family understood what you said?
 - a. All of what was said
 - b. Some of what was said
 - c. Not much of what was said
 - d. Unsure/Don't know

Probe: Why do you think that?

3. What is the likelihood that the family will follow the plan discussed today?
 - a. Very likely
 - b. Somewhat likely
 - c. Not likely
 - d. Unsure/Don't know

Probe: Why do you think that?

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Kimberly Compton Katzer, MA, received her degree from Wayne State University where she studied applied medical anthropology and psychology. Kimberly has professional experience in direct patient care, healthcare research with a focus on patients' experiences, and in improving educational accessibility for students with disabilities. She currently provides services in the Office of Disability Resources at Delta College.

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Beverly Crider is the parent of a young woman who has multiple, significant health concerns. She is a pioneer in Parent Advocacy, and an expert in patient and family-centered care. Beverly has successfully implemented patient and family engagement strategies in public policy, managed care arrangements and in both hospital and clinic settings as the Director of Patient and Family-Centered

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Stephanie Myers-Schim, PhD, RN, is a nurse. She was an associate professor and Interim Assistant Dean for significant contributions to the Family, Community, and Mental Health Nursing at the College of Nursing at Wayne State University. Stephanie made significant contributions to the field and to this project.

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