Title

Contextual factors influencing parents' assessments of family-centred care in the paediatric emergency department: A qualitative study

Permalink

https://escholarship.org/uc/item/7dc5c461

Journal

Nursing Open, 10(1)

ISSN

2054-1058

Authors

Rosenthal, Jennifer L
Perez, Susan L
Young, Heather M

Publication Date

2023

DOI

10.1002/nop2.1304

Peer reviewed

RESEARCH ARTICLE

Contextual factors influencing parents' assessments of family-centred care in the paediatric emergency department: A qualitative study

Jennifer L. Rosenthal[1] | Susan L. Perez[2] | Heather M. Young[3]

[1]Department of Paediatrics, University of California Davis, Sacramento, California, USA

[2]Department of Kinesiology and Health Science, California State University, Sacramento, California, USA

[3]Betty Irene Moore School of Nursing, University of California Davis, Sacramento, California, USA

Correspondence
Jennifer L. Rosenthal, Department of Paediatrics, University of California Davis Health System, 2516 Stockton Blvd, Sacramento, California 95817, USA.
Email: rosenthal@ucdavis.edu

Abstract

Aim: To identify the contextual factors influencing parents' assessments of the family-centredness of care received during a paediatric emergency department visit.

Design: A qualitative cross-sectional case study.

Methods: We interviewed parents who were at their child's bedside during an emergency department encounter. We independently coded the first 3 transcripts and met to discuss the coding structure and to refine existing codes, add new codes and develop tentative categories. We repeated this process for every 3–5 transcripts until thematic saturation was reached.

Results: We conducted 16 interviews and identified 2 themes: (1) Not all parents expected physicians to provide family-centred care in the emergency department and (2) feeling overwhelmed and powerless influenced parents' perceptions of family-centred care. Poor family-centred care worsened parents' sense of powerlessness and reinforced parents' low expectations from physicians. Similarly, low expectations and powerlessness exacerbated poor family-centred care. Interventions are needed to break this cycle and improve family-centredness of care.

KEYWORDS
emergency department, paediatrics, parent assessment, patient-centred care, qualitative research

1 | INTRODUCTION

Family-centred care is an approach to healthcare delivery and evaluation that recognizes the collaborative partnership among patients, families and healthcare providers (IPFCC). Family-centred care benefits include improved care quality, improved patient safety, greater patient and family satisfaction and reduced costs (Charmel & Frampton, 2008; CPEM, 2007; Goldfarb et al., 2017; Kuo et al., 2012; Weingart et al., 2011; Wennberg-Capellades

et al., 2021). Family-centred care is recognized as an integral part of quality care by national health professional associations and public health policy organizations (American Nurses Association, 2016; Dudley et al., 2015; Institute of Medicine, 2001). Furthermore, the National Quality Forum determined that "measurement of person-centered care" is a priority initiative for addressing the most imperative national healthcare needs (Consortium, 2021).

Despite being a widely accepted approach, the delivery of family-centred care varies across health systems (Mirlashari et al., 2020;

Oude Maatman et al., 2020). Barriers to successful implementation include provider and family stress, competing demands and organizational challenges (Mirlashari et al., 2020; Oude Maatman et al., 2020). Delivering family-centred care to parents or guardians (referred to hereafter as "parents") in the emergency department (ED) setting poses additional challenges. Parents are in an unfamiliar setting, navigating an acute or serious illness and receiving care from providers with whom there is no existing relationship (Dudley et al., 2015). Dimensions of family-centred care that are important to parents in a paediatric ED care include support, coordination, respecting preferences, timely and attentive care, information and communication, pain management, providing a child-focused environment and continuity and transition (Byczkowski et al., 2016). Conducting family-centred care interventions that target all of the family-centred care dimensions is difficult and infrequently done (Park et al., 2018). Additionally, comprehensively measuring family-centredness of care as an outcome is inherently challenging. Most published family-centred care measures lack adequate validation (Epstein et al., 2005), and no family-centred care assessment tool is designed to be used for a paediatric ED encounter.

To inform the development of interventions and parent-reported assessment tools for family-centred care in the paediatric ED, we sought to explore how parents assess family-centredness of care. Prior research has examined parents' perceptions of the family-centredness of care received in the ED (Byczkowski et al., 2016; Wennberg-Capellades et al., 2021), but research examining the factors that influence parents' assessments of family-centredness of care is lacking. Prior research highlights that patient-reported measurements of care experience and satisfaction are prone to bias (Dunsch et al., 2018). Evidence suggests that potential factors influencing how patients assess the care received includes patient-physician gender concordance, language and ED operational factors (Carrasquillo et al., 1999; Chekijian et al., 2021; Goloback et al., 2015). Improving our understanding of how parents assess family-centredness of care would inform effective strategies to improve both the delivery of family-centredness of care as well as the evaluation of this outcome. Our objective was to identify the contextual factors that influence parents' assessments of the family-centredness of care received in the paediatric ED. This present qualitative study was conducted as part of a study to develop and evaluate an instrument to measure parent-reported family-centredness of care received in the ED. Specifically, this present study was part of the cognitive interview phase of the instrument development procedures.

2 | METHODS

We conducted a qualitative study using a cross-sectional case study design (Flick, 2007). We used semi-structured interviews and thematic analysis (Braun & Clarke, 2006). The cases of interests were events, specifically parents who experience the event of being with their child during an emergency department visit. The research team consisted of three female health services researchers with qualitative expertise, including one paediatrician and one nurse. Sixteen interviews were conducted as part of the cognitive interview phase for developing the family-centredness of care instrument. We used an interview guide (Appendix A) for the cognitive interviews that consisted of questions soliciting participants' overall reactions to the instrument as well as questions soliciting instrument content, comprehension, retrieval, response and usability. Participants were asked to "think aloud" as they completed the instrument, whereby the participant read each question out loud and described the thought process used to get to their answer. Participants were encouraged to expand upon their answers in order to develop an in-depth understanding of their experiences and perceptions of the care received in the paediatric ED that informed their responses to the instrument items.

Eligible participants included parents who were at their child's bedside during an ED encounter within the recent three months. This timeframe extending out to three months was chosen to elicit information on participants' ability to retrieve the necessary information from memory to answer the instrument items. Participants were English speaking and age 18+ years. We used convenience sampling (Richards & Morse, 2007) to recruit participants, followed by purposive sampling (Tongco, 2007) to achieve diversity among participants in regard to gender, age, race, ethnicity and education. We recruited participants in person and by flyers. In person recruitment occurred in the intensive care unit and acute care unit of a children's hospital in Northern California. This hospital is a 121 bed quaternary care children's hospital and the referral centre for children across a 33-county region covering 65,000 square miles and serving over 1 million children. The hospital routinely receives paediatric transfers from 30 hospitals in the region. Approximately half of the hospitalized children in this children's hospital are admitted from this hospital's ED, while the other half are transferred from a different hospital's ED.

Flyers were given to eligible participants in the children's hospital ED at the time of their discharge from the ED. All interviews were therefore conducted after completion of the ED visit. To facilitate recruitment by accommodating to the participants' needs and preferences, interviews were scheduled at a time convenient to the participant and using the participant's preferred mode (in-person versus telephone). All in-person interviews were conducted in a private room in the children's hospital. For telephone interviews, parents were in their own preferred setting such as their home or private office.

Sampling continued until we reached thematic saturation (Braun & Clarke, 2006). The interviewer (J. L. R.) maintained field notes. Participants provided verbal informed consent and received a $50 gift card. Interviews were audio recorded, transcribed and reviewed for accuracy by the interviewer.

2.1 | Analysis

Data were analysed concurrently with data collection, providing an opportunity to explore emerging themes. We analysed the data using

a combination of deductive and inductive strategies. We used an initial codebook of six a priori codes developed from the question-and-answer model from cognitive psychology (Tourangeau, 1984). The research team reviewed completed instruments and transcriptions. We began by independently performing memo-writing and coding of the first 3 transcripts with the a priori codes. In this initial coding, we also identified emergent codes. Our team met to discuss the relevance and definitions of the coding structure and to discuss new topics from the inductive coding. We compared codes and discussed discrepancies to ensure consensus on application of codes, refine dimensions of existing codes, add new codes and develop tentative categories. We revisited earlier transcripts as new codes were identified and categorized the final 10 codes. This process was repeated for every 3–5 transcripts.

We drafted diagrams representing relationships among codes and concepts. We drafted summary statements of recurring, notable or outlier aspects of the data. We identified major themes by reviewing our memos of emerging themes, diagrams, summaries and the final coded data. We continued this iterative process until thematic saturation (Braun & Clarke, 2006) was reached and we had critically evaluated the themes to understand the full range of variation in the phenomena. Additional strategies used to enhance trustworthiness and rigour of the findings included investigator triangulation (Patton, 1999), deviant case analysis to seek alternative explanations, the use of analytic memos and peer debriefing with regular meetings to share study findings and processes to identify bias (US Department of Health and Human Services, 2018). We reviewed the drafted diagrams, summaries and relationships between themes to develop a conceptual model. We used Dedoose version 8.3.41 for data management (SocioCultural Research Consultants, LLC).

2.2 | Ethics

This study was approved by the [REDACTED] Institutional Review Board (#1436072).

3 | RESULTS

The sixteen interviews were ~20–45 min in duration and conducted between August and November 2020. Nine interviews were in-person, and seven were by telephone. Among the seven telephone interviews, three parents were at home during the interview, one was at work and three who were in the hospital. The child was present for the hospital-based interviews; otherwise, no additional individuals were present during data collection. Table 1 shows the participant characteristics. The ED encounters referenced by the participants represented nine unique hospitals.

Two major themes and six subthemes emerged and are explored below. Participant quotes are provided to support the themes and sub-themes. Table 2 illustrates the themes and subthemes with additional quotes.

TABLE 1 Interview participant characteristics

	N (%)
Gender	
Male	4 (25.0)
Female	12 (75.0)
Age, in years	
</=29	3 (18.8)
30–39	6 (37.5)
40–49	6 (37.5)
50+	1 (6.2)
Race and Ethnicity	
Non-Hispanic White	6 (37.5)
Latinx or Hispanic	4 (25.0)
Black	2 (12.5)
Asian	2 (12.5)
Other	2 (12.5)
Highest Education Attained	
Less than high school	1 (6.2)
High school degree or GED	5 (31.2)
Some college or 2-year degree	3 (18.8)
4-year degree	5 (31.2)
More than 4-year degree	2 (12.5)
Relationship to the Patient	
Father	4 (25)
Mother	12 (75)
Patient's ED Disposition	
Discharged home	7 (43.8)
Admit to local hospital acute care unit	4 (25.0)
Transfer to different hospital acute care unit	3 (18.8)
Transfer to different hospital intensive care unit	2 (12.5)
Patient's Medical History	
Chronic condition	4 (25.0)
No chronic condition	12 (75.0)

Abbreviations: ED—emergency department; GED—general education diploma.

3.1 | Theme 1: Not all parents expected physicians to provide family-centred care in the ED

3.1.1 | Experiencing inadequate physician engagement and communication:

Participants ubiquitously wanted ED care team providers to listen, share information, provide support and collaborate. However, many parents shared examples of inadequate engagement and communication, even examples of being ignored or dismissed. These experiences caused the parent participants to expect that their interactions with their child's physicians will not be what they optimally desire from their ED visits. One parent shared, *"They didn't seem to ask or care about how worried I was. They were very removed*

TABLE 2 Interview themes with supporting quotes

Themes and subthemes	Exemplary quote
Theme 1: Not all parents expected physicians to provide family-centred care in the ED	
Experiencing inadequate physician engagement and communication	"I had other concerns that I did not feel like were getting addressed… I did not feel like I was told what was going to happen and if I was okay with it… I did not think that they were communicative with [my child] as much as I would've liked… and I think that kind of scared him a little bit because he was not giving the okay to them before touching his injury or doing things like that, which I think freaked him out." [#9]
Nurses fulfilling expectations for engagement and communication	"[The nurses] were an important piece of making me have a more positive experience than they ever would have had if my interactions had only been with the doctor maybe." [#7]
Deprioritizing family-centred care principles	"I want to feel like whoever was taking care of my kid was knowledgeable and all of that. I guess secondly would come into the kind of more of the stuff of like was I heard… and if I felt I got input and things like that." [#1]
Theme 2: Feeling overwhelmed and powerless influenced parents' perceptions of family-centred care	
Feeling unable to understand their child's needs and receive information	"So, I had this recall to my emotional state in the hospital of just feeling very confused and not feeling that I was adequately helping my child." [#5]
Pre-existing perceptions about the ED exacerbating emotions and influencing parents' assessments of care	"There is a huge difference in the care [at Hospital A] versus the care [at Hospital B], one hundred percent… I rated that one low." [#4]
Emotions overshadowing the recognition of negative parent-provider interactions	"I felt like my ideas that I have for my son's problem and his illness, the doctors would not approve of that… They did not take my ideas into consideration… It was like [the doctor] just knew everything… I did not think about that [initially]… It did not register exactly… I had to re-think about the situation and what really happened." [#12]

Abbreviation: ED—emergency department.

from it.*Obviously, I'm very worried, I'm at the hospital with my child. But they downplayed it… it felt like it was just dismissed. So, I think they didn't actually understand how worried I was or how I was.It was as if I was bringing my car in to get serviced." [#5]*.

Some parent participants spoke about effective physician-parent communication experiences but suboptimal physician-child communication. Parents recounted stories where the physicians spoke to the parent but not to the child, thus excluding the child. One parent shared, *"I kind of wanted them to be more involving [my child] and the discussion as the patient… They did speak to him, but they also would speak past him… It would have been better to engage him." [#8].* Other parents had positive physician engagement and communication, although *"the time with the actual doctor was very, very minimal." [#2]*.

3.1.2 | Nurses fulfilling expectations for engagement and communication:

The busy ED environment and limited time with the physician was a recurring topic discussed by participants. Some parents explained how the physician was too busy to be at their own child's bedside, but how their child's nurse fulfilled their needs for provider-parent engagement and communication: *"Your doctor is very limited with their time… I felt like, when the nurses came back into the room being like, 'So, this is what they think it is? And this is my question.' So, they were still able to help educate me on what the plan was."[#7].* Parents assessments of their family-centred care experience were thus positively influenced by the nurse-parent interactions.

Some parents explained that their limited interactions with the physicians were a consequence of the physician's competing demands to care for other critically ill children. Some parents assessed their care experiences in context of the busy ED setting: *"Well, based on how busy that the ER is, I do feel like we get the best care that we could receive." [#11].* Other parents, however, perceived their brief interactions with their physicians to be signs of disrespect. For these latter parents, the nurse-provided family-centred care could not overcome their overall negative feelings about their ED experience. One parent explained how feeling disrespected impacted their assessment of the family-centredness of care: *"Did your child's doctor treat you with respect and make you feel valuable or important?… Sometimes you get somebody who comes into a room and you can tell they are just trying to get out of there as fast as they possibly can… It makes you feel bad and unimportant because it's very clear that they are just trying to move on… That can have a big influence on someone's perception of their experience… Even if everything was communicated properly and the care itself was good, if you feel like you were just sort of looked down upon or disrespected, or not important, you are going to walk away unhappy." [#3].*

3.1.3 | Deprioritizing family-centred care principles:

Some parents expressed that they were so focused on the ultimate clinical outcome that they deprioritized family-centred care principles: *"When I think about medicine and emergency room, I think more solutions and not feelings about how it all was… At the end of the day, I*

want to go to the emergency room and—while I want to have all of those nice fuzzy feelings and all of that at the end, I want my kid fixed." [#1]. Parents who deprioritized family-centred care principles tended to assess their experience in the ED more favourably.

Furthermore, some parents who identified that they had suboptimal experiences with their child's physicians justified the inadequate family-centred care. Parents rationalized that the physicians were busy or stressed and thus not expected to provide family-centred care. As one parent recalled, _"I'm like, 'Oh, give them the benefit of the doubt... Maybe it wasn't as bad as I recall it being and they were doing the best they could.' I felt like I ended up trying to humanize them and be like, 'Oh, it was a really stressful night in the hospital. I'm sure they did the best they could.' So, I was just making excuses for them." [#6]._

3.2 | Theme 2: Feeling overwhelmed and powerless influenced parents' perceptions of family-centred care

3.2.1 | Feeling unable to understand their child's needs and receive information:

Parents expressed general emotional states of feeling overwhelmed and unable to understand their child's needs. Being a parent with a child whose needs were beyond what the parent could directly address was an uneasy feeling that left some parents feeling confused, afraid, and powerless. One parent explained, _"You have this natural fear for your child, but then you're also confused on top of it... you're just in this powerless position." [#5]._

Some parents explained how their emotional state made it more challenging to effectively receive information from the care team, thus impacting parents' assessments of provider-parent communication. One parent explained the importance of doctors recognizing that the parent's baseline ability to understand medical information was low, and how that baseline was worsened by their heightened emotional state during the ED visit: _"I just want [doctors] to actually understand. I took biology in high school and that was about it, and they need to kind of give me a further understanding... You're there in the middle of the night and you're completely sleep-deprived, so it does require more time for you to grasp it under duress." [#15]._

3.2.2 | Pre-existing perceptions about the ED exacerbating emotions and influencing parents' assessments of care:

Some participants expressed their lack of trust in the ED where their child received care. Such distrust cause parents to feel even more anxious while in the ED: _"Pediatrics at this rural hospital where they don't really deal with peds at all or have the supplies for peds. You know, it kind of put us on edge and got us a little uneasy. It was like, do they know how to put an IV in my daughter's arm? Or why did they just poke her three times and weren't successful at it?" [#14]._ This distrust

influenced the parents' assessments of the family-centred care received. These parents felt less confident in the clinical care and decision-making. Similarly, they expressed stronger dissatisfaction with the provider-parent communication that occurred.

3.2.3 | Emotions overshadowing the recognition of negative parent-provider interactions:

Parents who felt confused and powerless during their child's ED visit expressed that their emotions overshadowed their recognition of negative parent-provider interactions. However, upon reflection, the parents realized that their ED experience was not as family-centred as initially perceived: _"But in the process [of reflection], it kind of made me second guess—it almost made me feel more negative about my experience... This brought up some stuff that I actually had kind of dismissed... It makes you think that maybe you had more to say... In an ER visit, there's so much rush going on, and there's so much heightened emotions... And as a parent you are confused, you are emotional, you are out... And although I walked out happy and I kind of forgot about that, [reflecting back] made me think about that... go back and think about things and question and go, 'Oh, yes, I remember I kind of didn't like that'... I did feel uncomfortable." [#13]._

3.3 | Conceptual model

Figure 1 presents a conceptual model that displays the relationships between parents' expectations, powerlessness and the care received. It shows how parents' variable expectations for family-centred care contributed to the inadequate family-centredness of care received. Inadequate family-centred care contributed to confusion and poor understanding, and it reinforced parents' feelings of powerlessness: _"They just pretty much came in and said, 'Okay, we are going to transfer you to [Hospital A].'... We didn't really have a say in it. We probably would have preferred to have gone to [Hospital B], because we have family up there. But we weren't really given the option... Later we brought it up to the nurse, but she just kind of like, 'Oh, well.'" [#4]._ This powerlessness also exacerbated their poor experiences. One parent explained how their sense of powerlessness prevented them from advocating for more family-centred care: _"I just actually wouldn't have felt comfortable asking for anything... It did not feel like a situation in which I was welcomed to ask for anything. I felt like I was an inconvenience." [#5]._

Parents' real-time identification of inadequate family-centred care did not generate resolution, often as a result of their sense of feeling powerless and perceiving that the care team providers did not want to hear their concerns or preferences. Some parents did voice their concerns; however, despite their efforts, the parents felt that they had no influence over what was happening. Inadequate family-centred care was also missed opportunities to mitigate parents' feelings of powerlessness and lack of clarity on their child's needs. One parent explained how they left the ED with lack of
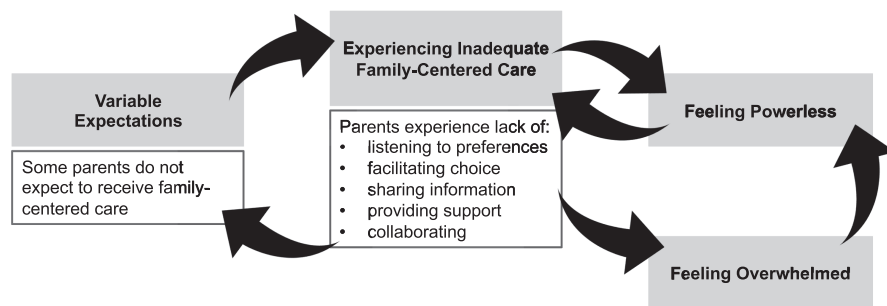
FIGURE 1 Conceptual model displaying the relationships between parents' expectations, powerlessness and care received

understanding and lack of empowerment to be able to care for their child: *"I left overall our experience very unsure of the safety of my child... It felt like they were very much eager to get me out of there... I literally was like, 'Okay my son's going to go home. He's going to die at home'... I didn't feel like I fully understood the scenario to feel empowered to take care of my child adequately after we left... I didn't feel like I had enough time with the doctors or feel like it was explained to me in a way that gave me an understanding of the problem to feel re-assured that I was capable of handling it." [#5].*

4 | DISCUSSION

This study revealed two major themes regarding how parents assessed their ED experience. First, not all parents expected physicians to provide family-centred care in the emergency department. Second, feeling overwhelmed and powerless influenced parents' perceptions of family-centred care. Importantly, poor family-centred care worsened parents' sense of powerlessness and reinforced parents' low expectations from physicians. Similarly, parents' low expectations and emotional state exacerbated poor family-centred care. This study suggests needed interventions to break this cycle and improve the ED family-centredness of care. Such interventions can target parental expectations, confusion, understanding and powerlessness as well as enhance awareness among clinicians regarding their behaviours that facilitate inclusion and engagement with parents.

This study was conducted as part of a larger study aimed to develop an instrument to measure parent-reported family-centredness of care received in the ED. Our participants shared how factors such as their expectations, confusion and powerlessness influenced the ways in which they assessed ED family-centredness of care. Therefore, these factors would likely influence the measurement of their experience in the instrument being developed. Specifically, parents with low family-centred care expectations may have inflated parent-reported experience measurements. Likewise, parents who are more confused and overwhelmed during the ED visit may overlook the negative experiences and report better experience measurements.

Patient and family-reported experience measures are ubiquitously used to assess the care provided in the ED (Male et al., 2017). For example, the ED Consumer Assessment of Healthcare Providers and Systems (CAHPS) Survey measures patients' experience of ED care in order to collect information about patients' experience and identify aspects of care that could be improved (Weinick et al., 2014). The ED CAHPS includes items to gather demographic information of the individual completing the instrument. However, our present study highlights that additional unmeasured variables are potentially influencing the survey results. Future research is needed to include these variables in order to understand these relationships, such as mediation analyses to evaluate relationships between parent expectations [or confusion or powerlessness] and parent experience. If parent-reported experience outcomes are mediated by such factors, we must understand these relationships in order to mitigate biases in the parent-reported measurement.

Future research should also examine the association of parent characteristics and their expectations, confusion, sense of powerlessness or perceived family-centredness of care received. Prior research has recognized that racial and ethnic minority parents report poor trust, lack of informative exchanges and inadequate education on their child's clinical needs (DeLemos et al., 2010; Martin et al., 2016). Children from non-English speaking families and from low-income and low-education households also have higher likelihood of not receiving family-centred care (Azuine et al., 2015). Diverse parent populations might also have different expectations and different experiences of confusion or sense of powerlessness. As additional research in this area advances, we must be cognizant of the importance of providing person-centred strategies that address structural racism and the unique needs of diverse groups. Further exploration of healthcare provider attitudes about and commitment to family-centred care would elucidate areas for intervention that advance capacity among providers to meet parental expectations for engagement.

4.1 | Limitations

This study has several limitations. Transferability is limited by inclusion of only English-speaking parents. Participants had potential response bias with atypical perceptions due to particularly negative or positive experiences. Participants also had potential memory bias; we included participants who experienced their child's ED visit up to three months prior to the interview. This study did not include care team providers, since the focus of the study was on parents. The different methods of conducting the interviews (in-person versus telephone) might have also influenced the data collected. Finally, although the interviews were conducted by a researcher who was

not an ED provider and had no prior relationship with participants, it is possible that the interviewer's role as a healthcare provider could have biased participant responses. Despite these limitations, this study provides insight into contextual factors that influence parents' assessments of ED family-centredness of care.

5 | CONCLUSION

In summary, qualitative interviews found that parents inconsistently expected to receive family-centred care in the ED and that parents' confusion and poor understanding left parents feeling powerless. Based on the conceptual model, interventions aimed at improving family-centredness of care in the ED can target parental expectations, confusion, understanding and powerlessness.

ORCID
Jennifer L. Rosenthal https://orcid.org/0000-0002-5543-4709

REFERENCES
American Nurses Association (2016). Pediatric nursing: Scope and standards of practice. In _Scope and standards of pediatric nursing practice: Silver spring_ (2nd ed.). American Nurses Association, Inc.

Azuine, R. E., Singh, G. K., Ghandour, R. M., & Kogan, M. D. (2015). Geographic, racial/ethnic, and sociodemographic disparities in parent-reported receipt of family-centered care among US children. _International Journal of Family Medicine, 2015_, 168521.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. _Qualitative Research in Psychology, 3_(2), 77–101.

Byczkowski, T. L., Gillespie, G. L., Kennebeck, S. S., Fitzgerald, M. R., Downing, K. A., & Alessandrini, E. A. (2016). Family-centered pediatric emergency care: A framework for measuring what parents want and value. _Academic Pediatrics, 16_(4), 327–335.

Carrasquillo, O., Orav, E. J., Brennan, T. A., & Burstin, H. R. (1999). Impact of language barriers on patient satisfaction in an emergency department. _Journal of General Internal Medicine, 14_(2), 82–87.

Charmel, P. A., & Frampton, S. B. (2008). Building the business case for patient-centered care. _Healthcare Financial Management, 62_(3), 80–85.

Chekijian, S., Kinsman, J., Taylor, R. A., Ravi, S., Parwani, V., Ulrich, A., … Agrawal, P. (2021). Association between patient-physician gender concordance and patient experience scores. Is there gender bias? _The American Journal of Emergency Medicine, 45_, 476–482.

Committee on Pediatric Emergency Medicine (CPEM). (2007). Patient safety in the pediatric emergency care setting. _Pediatrics, 120_(6), 1367–1375.

DeLemos, D., Chen, M., Romer, A., Brydon, K., Kastner, K., Anthony, B., & Hoehn, K. S. (2010). Building trust through communication in the intensive care unit: HICCC. _Pediatric Critical Care Medicine, 11_(3), 378–384.

Dudley, N., Ackerman, A., Brown, K. M., Snow, S. K., & American Academy of Pediatrics Committee on Pediatric Emergency Medicine, American College of Emergency Physicians Pediatric Emergency Medicine Committee, Emergency Nurses Association Pediatric Committee. (2015). Patient- and family-centered care of children in the emergency department. _Pediatrics, 135_(1), e255–e272.

Dunsch, F., Evans, D. K., Macis, M., & Wang, Q. (2018). Bias in patient satisfaction surveys: A threat to measuring healthcare quality. _BMJ Global Health, 3_(2), e000694.

Epstein, R. M., Franks, P., Fiscella, K., Shields, C. G., Meldrum, S. C., Kravitz, R. L., & Duberstein, P. R. (2005). Measuring patient-centered communication in patient–physician consultations: Theoretical and practical issues. _Social Science and Medicine, 61_(7), 1516–1528.

Flick, U. (2007). Qualitative research designs. In _Designing qualitative research_ (pp. 109–114). SAGE Publications.

Goldfarb, M. J., Bibas, L., Bartlett, V., Jones, H., & Khan, N. (2017). Outcomes of patient-and family-centered care interventions in the ICU: A systematic review and meta-analysis. _Critical Care Medicine, 45_(10), 1751–1761.

Goloback, M., McCarthy, D. M., Schmidt, M., Adams, J. G., & Pang, P. S. (2015). ED operational factors associated with patient satisfaction. _American Journal of Emergency Medicine, 33_(1), 111–112.

Institute of Medicine. (2001). _Institute of Medicine. Crossing the quality chiasm: A new healthcare for the 21st century_. US Department of Health and Human Services, National Academy of Sciences.

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-centered care: Current applications and future directions in pediatric health care. _Maternal and Child Health Journal, 16_(2), 297–305.

Male, L., Noble, A., Atkinson, J., & Marson, T. (2017). Measuring patient experience: A systematic review to evaluate psychometric properties of patient reported experience measures (PREMs) for emergency care service provision. _International Journal for Quality in Health Care, 29_(3), 314–326.

Martin, A. E., D'Agostino, J. A., Passarella, M., & Lorch, S. A. (2016). Racial differences in parental satisfaction with neonatal intensive care unit nursing care. _Journal of Perinatology, 36_(11), 1001–1007.

Mirlashari, J., Brown, H., Fomani, F. K., de Salaberry, J., Zadeh, T. K., & Khoshkhou, F. (2020). The challenges of implementing family-centered care in NICU from the perspectives of physicians and nurses. _Journal of Pediatric Nursing, 50_, e91–e98.

National Quality Forum Leadership Consortium. (2021). _National Quality Forum Leadership Consortium 2022 priorities for action_. National Quality Forum Leadership Consortium. https://www.qualityforum.org/Publications/2021/12/2022_NQF_Priorities_for_Action.aspx

Oude Maatman, S. M., Bohlin, K., Lillieskold, S., Garberg, H. T., Uitewaal-Poslawky, I., Kars, M. C., & van den Hoogen, A. (2020). Factors

influencing implementation of family-centered care in a neonatal intensive care unit. *Frontiers in Pediatrics*, *8*, 222.

Park, M., Lee, M., Jeong, H., Jeong, M., & Go, Y. (2018). Patient-and family-centered care interventions for improving the quality of health care: A review of systematic reviews. *International Journal of Nursing Studies*, *87*, 69–83.

Patton, M. Q. (1999). Enhancing the quality and credibility of qualitative analysis. *Health Services Research*, *34*(5 Pt 2), 1189–1208.

Richards, L., & Morse, J. M. (2007). *README first for an introduction to qualitative methods* (2nd ed.). SAGE.

Tongco, M. D. C. (2007). Purposive sampling as a tool for informant selection. *Ethnobotany Research and Applications*, *5*, 147–158.

Tourangeau, R. (1984). *Cognitive sciences and survey methods. Cognitive aspects of survey methodology: Building a bridge between disciplines.* National Academy Press.

US Department of Health and Human Services. (2018). *Qualitative methods in implementation science* (pp. 1–31). National Institutes of Health. Bethesda, MD, USA: National Cancer Institute.

Weingart, S. N., Zhu, J., Chiappetta, L., Stuver, S. O., Schneider, E. C., Epstein, A. M., … Weissman, J. S. (2011). Hospitalized patients' participation and its impact on quality of care and patient safety. *International Journal for Quality in Health Care*, *23*(3), 269–277.

Weinick, R. M., Becker, K., Parast, L., Stucky, B. D., Elliott, M. N., Mathews, M., … Kotzias, V. (2014). Emergency department patient experience of care survey: Development and field test. *Rand Health Quarterly*, *4*(3), 5.

Wennberg-Capellades, L., Feijoo-Cid, M., Llaurado-Serra, M., & Portell, M. (2021). Feeling informed versus being informed: Mixed-methods analysis of family perceptions and behavior following a pediatric emergency department visit. *Journal of Pediatric Nursing*, *60*, e87–e95.

APPENDIX A

Interview guide for cognitive interviews

I want to thank you for taking the time to participate in this interview today to talk about our survey that evaluates family-centred care in the emergency department. My name is [name]. The purpose of this project is to figure out how to make this survey better; we want to make sure it is easy to use and accurately measures family-centred care.

Based on what we learn from these interviews, we will update our survey to improve it. And our long-term goal is to use this survey to measure family-centred care in the emergency department with the hope that we can work towards making that ED experience more family-centred.

So, I keep saying "family-centered"—let us quickly talk about what that means. FCC is a way to provide health care that is based on a partnership between the patient, family, and providers. FCC in paediatrics recognizes the important role that the family plays in the child's health and well-being. FCC supports families in their caregiving and decision-making roles. FCC in paediatrics understands that your values and information are very important in making decisions about your child's care. In FCC, families choose how to participate in care and decision-making. Core concepts of FCC include: (1) Listening to and Respecting Experiences and Preferences, (2) Sharing Information, (3) Providing Support and (4) Collaborating and Encouraging Participation.

Interview Guide Question
I want to start by hearing your thought process as you go through the steps to take the survey. So please read the survey instructions and then each question out loud and describe aloud the thought process you used to get to your answer. Please mark/note any questions that are unclear to you or you think is not worded well. *[show survey; do not interrupt; record duration (minutes) to complete; ask probes at the end]*   • *[for any Qs where not think aloud]* How did you go about answering Q#? Tell me about what you were thinking?   • *[for any Qs where hesitated]* I noticed you hesitated before you answered Q#—what were you thinking about?   • *[for any Qs where did not paraphrase]* For Q#, can you tell me in your own words what the question is asking you?
Please tell me your overall thoughts or opinions about the survey.
How well, or not well, did the survey ask questions that are important to you?
Since the survey is measuring family-centred care, I want to know: In your opinion, what would a family-centred emergency department visit look like to you? What are the key things that need to happen in order for you to walk away feeling like that visit was very family-centred?   In what ways does this survey do a good job assessing family-centredness of care?   • What is missing?   • What questions, if any, should be removed because they aren't related to family-centred care?   • In what ways does the survey assess, or not assess, <u>listening to and respecting experiences and preferences</u>?   • In what ways does the survey assess, or not assess, <u>sharing information</u>?   • In what ways does the survey assess, or not assess, <u>providing support</u>?   • In what ways does the survey assess, or not assess, <u>collaborating and encouraging participation</u>?
How easy or difficult was it to fill out the survey?   • What questions, if any, were difficult to answer?   • [For each question] What about it was difficult?   • [For each question] How would you fix it?
How did it feel to answer these questions about that emergency department visit and choose 1 of the 4 answers: always-usually-sometimes-never?
This survey asked a lot of specific questions about that emergency department visit. How easy or difficult was it to remember those specifics?
What questions, if any, were you at all unsure of your answer?   • [For each question] Tell me more about that.
What do you think about in terms of the flow of the survey and how the questions are ordered?   • In what ways, if any, would you change up the order of the questions?
What do you think about the length of the survey and how long it takes to fill it out? *[When you took it for the first time, about how many minutes did it take you?]*
If you could make any other changes to the survey, what would they be and why?
Is there anything else that would be helpful for us to know about the survey?