Family-Centered Pediatric Emergency Care: A Framework for Measuring What Parents Want and Value

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ABSTRACT

OBJECTIVE: To identify and describe dimensions of family-centered care important to parents in pediatric emergency care and compare them to those currently defined in the literature.

METHODS: A qualitative study was conducted involving 8 focus groups with parents who accompanied their child to an emergency department visit at a large tertiary-care pediatric health system. Participants were identified using purposive sampling to achieve representation across demographic characteristics including child's race, insurance status, severity, and participant's relationship to child. Focus groups were segmented by patient age and presence of a chronic condition. They were moderated by a facilitator experienced in health-related topics. A 6-member multidisciplinary team completed a content analysis.

RESULTS: Sixty-eight parents participated. They were female (77%); aged 20 to 29 years (19%), 30 to 39 years (47%), more than 40 years (31%); black (44%), white (52%); and married (50%). Their child's characteristics were: public insurance (52%); black (46%), white (46%); and admitted as an inpatient (46%). The analysis resulted in 8 dimensions: 1) emotional support; 2) coordination; 3) elicit and respect preferences, and involve the patient and family in care decisions; 4) timely and attentive care; 5) information, communication, and education; 6) pain management; 7) safe and child-focused environment; and 8) continuity and transition. Compared to those published in the literature, the most notable differences were combining involving family and respect for preferences into a single dimension, and separating physical comfort into 2 dimensions: pain management and safe/child-focused environment.

CONCLUSIONS: The resulting dimensions provide a framework for measuring and improving the delivery of family-centered pediatric emergency care.

KEYWORDS: family-centered care; patient satisfaction; pediatric emergency care; qualitative research

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WHAT'S NEW

A comprehensive and validated measure of family-centered pediatric emergency care is lacking. This work contributes to the knowledge base by providing a framework for the development of such a measure needed to improve the quality of family-centered care.

IMPROVING PATIENT AND family experience of care is critical for improving the overall quality of health care in the United States. In response to the Affordable Care Act, the Department of Health and Human Services delivered a report to Congress in 2011 describing the National Quality Strategy. One of 6 priority areas is to ensure person- and family-centered care.[1] This focus on improving the quality of the care experience has been further underscored by the Centers for Medicare and Medicaid Services, which have included patient and family experience as 1 of 4 key domains within which Accountable Care Organizations must meet performance standards in order to take advantage of the Medicare Shared Saving Program.[2]

Arguably the best-known framework in the literature used to describe aspects of family-centered care important to patients and families was developed by the Picker/Commonwealth program in the 1990s.[3–5] Before their work, the term "patient satisfaction" was used to describe patients' attitudes about the care they received. The Picker Institute recognized that many factors can affect attitudes beyond the reality of the care itself. These factors, which include patient demographics, health status, and expectations, make it difficult to disentangle and isolate the effect care practices have on satisfaction.[6] The Picker Institute addressed this shortcoming by asking patients to describe aspects of care important to them, which resulted in the groundbreaking distinction between measuring “patient satisfaction” and “experience of care.” Experience of care refers to more objective reports of care rather than attitudes regarding satisfaction with care. For example, rather than patients rating their satisfaction with the information provided by the physician, they would report if their questions were answered in a way they could understand. Using this notion of experience of care, Picker Institute researchers identified and validated 8 dimensions of family-centered care: 1) emotional support and alleviation of fear and anxiety; 2) coordination and integration of care; 3) involvement of family and friends; 4) respect for patients’ values, preferences, and expressed needs; 5) access to care; 6) information and education; 7) physical comfort; and 8) continuity and transition.[5] Each dimension is defined by describing clinician behaviors and health care system characteristics important to patients.

In order to improve patient and family experience of care during a child’s emergency department (ED) visit, it is imperative that we understand what patients and families want and value. A technical report published by the American Academy of Pediatrics describes a number of important aspects of family-centered care in pediatric emergency care including family presence, cultural sensitivity, communication, shared decision making, coordination with the medical home, and discharge planning and instructions.[7] In addition, there is a significant body of literature that explores aspects of care associated with patient satisfaction. Studies in the adult emergency care literature have shown that waiting for care; understandable information provided about diagnosis and treatment; ED processes; caring, courtesy, and empathy; staff organization; perceived technical quality; interpersonal interactions; and pain management are associated with overall satisfaction.[8–24] A smaller body of literature in pediatric emergency care has resulted in similar findings with the following shown to be associated with overall satisfaction: provider interactions[25]; pain management[25–28]; information and explanations provided[25–27]; ability to stay with child[27]; staff attitude[27]; wait time[26,28,29]; how well doctors and nurses work together[28]; and engaging parents and patients in shared decision making.[30] Although the research described above share common themes, a comprehensive and unifying framework for family-centered care specific to pediatric emergency care based on parent input does not exist in the literature.

We designed a study to identify and define dimensions of family-centered pediatric emergency care important to parents and guardians. We hypothesized that the 8 dimensions of family-centered care currently defined in the literature would have to be modified and/or augmented for application to pediatric emergency care. In addition, our goal was to elicit, with as much detail as possible, specific clinician behaviors and system characteristics that characterize what parents want and value for their child’s emergency care experience. This approach will inform the development of measures and ultimately interventions to improve the quality of family-centered pediatric emergency care.

METHODS

STUDY DESIGN

We conducted a qualitative study using focus groups with parents and guardians who accompanied their child to an ED visit. We chose focus groups over in-depth individual interviews because of the interactive and dynamic nature of the group discussion, which can elucidate diverse experiences among participants. In addition, similarities and differences among participants can be explored to generate additional areas of inquiry.[31] A total of 8 focus groups were conducted from October 2010 through September 2011.

STUDY SETTING AND POPULATION

The study was conducted at a large tertiary-care pediatric health system. The affiliated teaching hospital was verified by the American College of Surgeons as a level 1 pediatric trauma center. The health system has both urban and suburban ED locations with an annual patient census of more than 87,000 and 34,000 visits, respectively. The study population consisted of parents and guardians who accompanied their child to a recent ED visit. We excluded the following groups: 1) parents younger than 18 years of age, 2) non-English-speaking adults, 3) patients evaluated for alleged physical and/or sexual abuse, 4) patients whose visit was primarily psychiatric, and 5) patients who died or were critically ill, defined by an Emergency Severity Index[32] score of 1, the most severe triage level. The needs of these patients are likely different as a result of the nature and context of their situation and would be better addressed in separate studies. Also, parents who brought a child to the ED for minor complaints and were triaged to the health system’s urgent-care setting were excluded. Although an important patient population, they would not experience the relatively complex diagnostic and therapeutic processes like those of patients requiring emergent care. These patients accounted for approximately 20% of our patient population during the study period.

SAMPLING STRATEGY

We segmented the first 6 focus groups by the age of the patient (0–3, 4–10, and 11–17 years) and if the patient had a chronic condition. Health care experiences can be very different depending on these characteristics. Parents of children with chronic conditions are much more familiar with the health care system, and older children are more likely to want to participate in their care. Also, half of