



2018

The pediatric emergency department care experience: A quality measure

Terri L. Byczkowski

Cincinnati Children's Hospital Medical Center and University of Cincinnati College of Medicine

Kimberly A. Downing

Institute for Policy Research, University of Cincinnati

Michael R. FitzGerald

The Rucks Group, Dayton OH

Stephanie S. Kennebeck

Cincinnati Children's Hospital Medical Center and University of Cincinnati College of Medicine

Gordon L. Gillespie

University of Cincinnati, College of Nursing

See next page for additional authors

Follow this and additional works at: <https://pxjournal.org/journal>



Part of the [Health Services Research Commons](#)

Recommended Citation

Byczkowski TL, Downing KA, FitzGerald MR, Kennebeck SS, Gillespie GL, Alessandrini EA. The pediatric emergency department care experience: A quality measure. *Patient Experience Journal*. 2018; 5(2):32-53. doi: 10.35680/2372-0247.1288.

This Research is brought to you for free and open access by Patient Experience Journal. It has been accepted for inclusion in Patient Experience Journal by an authorized editor of Patient Experience Journal.

The pediatric emergency department care experience: A quality measure

Cover Page Footnote

This research was supported in part by grant number R03HS019037 from the Agency for Healthcare Research and Quality

Authors

Terri L. Byczkowski, Kimberly A. Downing, Michael R. FitzGerald, Stephanie S. Kennebeck, Gordon L. Gillespie, and Evaline A. Alessandrini

The pediatric emergency department care experience: A quality measure

Terri L. Byczkowski, *Cincinnati Children's Hospital Medical Center & University of Cincinnati College of Medicine*,
terri.byczkowski@cchmc.org

Kimberly A. Downing, *Institute for Policy Research, University of Cincinnati*, *downink@ucmail.uc.edu*

Michael R. Fitzgerald, *The Rucks Group*, *fitzgem@gmail.com*

Stephanie S. Kennebeck, *Cincinnati Children's Hospital Medical Center & University of Cincinnati College of Medicine*,
Stephanie.Kennebeck@cchmc.org

Gordon L. Gillespie, *University of Cincinnati, College of Nursing*, *gillesgl@ucmail.uc.edu*

Evaline A. Alessandrini, *University of Cincinnati College of Medicine & Cincinnati Children's Hospital Medical Center*,
Evaline.Alessandrini@UCHealth.com

Abstract

To develop and validate a measure of the quality of the pediatric emergency department care experience from the parent perspective. This was a multiphase study conducted at a tertiary-care pediatric health system using qualitative and quantitative methods. A list of candidate questions was developed to measure each of eight dimensions of family-centered pediatric emergency care described in a published framework. This list was evaluated and refined using the Question Appraisal System (QAS-99) followed by cognitive interviewing methods. Remaining questions were field tested using survey methods via telephone interviews with randomly selected parents. Composite scores to measure each of the eight dimensions of family-centered pediatric emergency care were calculated. Reliability was evaluated using measures of internal consistency. Construct validity was evaluated by measuring the association of each question and composite scores with overall satisfaction. A pool of 77 questions was reduced to 51 using QAS-99 criteria. Cognitive interviews with 19 parents resulted in a final list of 24 questions for field testing. With a response rate of 46%, 404 parents participated in the field test. Each individual question exhibited a significant positive association with overall satisfaction. Measures of internal consistency did not support the composite scores based on the initial eight dimensions. An exploratory factor analysis resulted in alternative composite measures that exhibited acceptable reliability and construct validity. This study has resulted in a measure that can be used to inform quality improvement work aimed at improving the pediatric emergency department care experience.

Keywords

Emergency care, measurement, patient satisfaction, quality of care, patient- and family-centered care

Introduction

There is clear consensus that delivering high-quality pediatric emergency care requires a patient- and family-centered approach.¹ The Institute for Patient and Family-Centered Care writes that it is “an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families” and is focused on four core concepts: dignity and respect; information sharing; participation and collaboration.² Pediatric emergency care, however, has some unique challenges. Established relationships between patients and health care providers are lacking, visits are usually unplanned, and circumstances intense.³ A review of the evidence by Coulter and Ellins⁴ has shown that patient surveys can be used to motivate and inform quality improvement work.

A validated experience of care measure that reflects what patients and families want and value when receiving care in an emergency department (ED) setting is key to improving and ultimately providing the best care possible.

Measures of patient satisfaction with emergency care have been developed and tested for use in adult populations.⁵⁻⁷ A key consideration, however, is that we measure “experience of care” as opposed to patient satisfaction. The concept of patient satisfaction first appeared in the academic literature in the mid-1960s, but there was no consensus on how to define or measure it.⁸ While “patient satisfaction” was used to describe patients’ opinions and attitudes towards the care they received, it was recognized that many factors, including patient characteristics such as demographics and health status, and patient expectations could affect opinions and attitudes beyond the reality of

the care itself making it difficult to disentangle and isolate the effect of care practices on satisfaction.^{8,9} The Picker Institute conducted the seminal research in this area for which patients were asked to provide objective reports about what happened during their care experience (e.g., healthcare provider behaviors) and what was important to them, rather than rating their satisfaction with aspects of care. This work resulted in the phrase “patient experience of care”. Ultimately a framework consisting of eight distinct dimensions of family centered was developed and used to construct patient experience of care measures.¹⁰ Byczkowski et al modified this framework for application to the pediatric emergency care experience, resulting in the following eight 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.¹¹

The Centers for Medicare and Medicaid Services (CMS) are developing and testing an Emergency Department Patient Experience with Care (EDPEC) survey for adult patients.¹² Yet, a validated measure for pediatric emergency care does not exist. A measure specific to pediatric emergency care is important given the role of parents and guardians during an ED visit and need for engaging both parents and patients in medical decision making.^{11,13} Such a measure is critical for advancing family-centered care in pediatric emergency medicine because it will provide a tool to understand our current performance, understand the impact of improvement interventions, and explore the relationships between family-centered care and health outcomes. This is especially important given the changing landscape of medical care in which public reporting of such measures has become commonplace and public policy initiatives aimed at improving the patient experience of care through financial incentives are instituted.^{12,14-16}

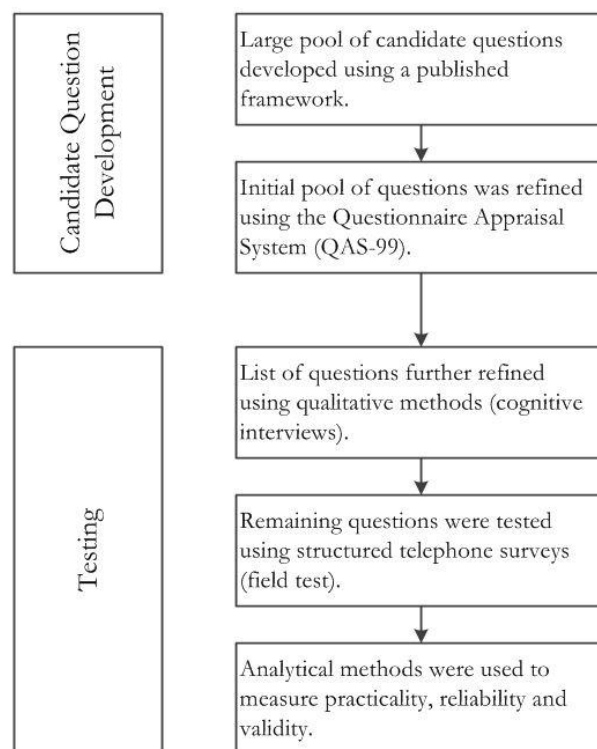
The objective of this study was to develop and test a measure of the patient and family pediatric emergency care experience for use in improving the delivery of patient- and family-centered care in pediatric emergency medicine. We hypothesized that the measure would be practical, and would exhibit acceptable levels of reliability and construct validity.

Methods

Study Design and Setting

We used a multi-phase design that employed both qualitative and quantitative methods (Figure 1) that are well known in the literature for validating surveys using Consumer Assessment of Healthcare Providers and Systems (CAHPS) questions.¹⁷⁻¹⁹ This study was conducted at a large tertiary-care pediatric health system

Figure 1: Methods Flow Diagram



with both urban and suburban locations. The affiliated teaching hospital was verified by the American College of Surgeons as a level 1 pediatric trauma center. This study was approved by the hospital's Institutional Review Board (IRB).

Phase 1—Develop and refine an initial large pool of candidate questions: We used a framework that resulted from a focus group study conducted by Byczkowski et al.¹¹ to develop a large pool of candidate questions. The framework, which consists of 8 dimensions of family-centered pediatric emergency care, ensured that we developed a comprehensive set of questions that addressed aspects of the emergency care experience most important to parents. Each member of the study team independently developed an initial list of questions using this framework. The study team debated and refined this initial pool of candidate questions until consensus was reached. We followed several guiding principles. First, we used the focus group transcripts from the focus group study to capture actual participants' words, phrases, and descriptions. Second, we developed “experience of care” questions like the behavioral-based questions included in the CAHPS surveys.²⁰ For example, rather than ask parents to subjectively rate on a Likert scale how well their doctors communicated, we asked the more objective question of whether or not doctors answered all their questions in a way they could understand using three

response categories (Yes definitely, Yes somewhat, No). Third, we considered questions applicable to patients, as well as parents. Finally, questions should pertain to most families seeking pediatric emergency care. We refined the resulting pool of candidate questions by applying the Questionnaire Appraisal System (QAS-99) developed by Lessler and Forsyth to each question. The QAS-99 is a framework and coding system that was designed to uncover issues with questions prior to testing that could potentially affect measurement error and response accuracy.²¹

Phase 2—Initial testing using qualitative methods: The resulting pool of questions was further tested using cognitive interview methods, which consisted of semi-structured interviews during which respondents formulated answers to survey questions by verbally expressing what they thought about when answering.^{22,23} This methodology is well known and has been used to develop similar questionnaires in other patient settings.²⁴ It is designed to elucidate problems with questions regarding comprehension, response categories, respondent recall, ambiguity and applicability. The cognitive interviews were conducted by the principal investigator and research assistants trained in the methodology. The qualitative data from the cognitive interviews were analyzed by the study team on an on-going basis throughout this phase so that problematic questions could be deleted or modified and tested further. Cognitive interviews were conducted January – February 2012.

Phase 3—Field test: A survey consisting of the final set of questions resulting from the cognitive interviews was administered by telephone during January – February 2013 to evaluate the experience of care measure for practicality, reliability and construct validity. The field test was conducted by an outside vendor with interviewers trained in conducting telephone surveys using Computer Assisted Telephone Interviewing (CATI) software.

Selection of Participants

For both the cognitive interviews and field test the study population consisted of parents of children up to 18 years of age who visited the ED in either the urban or suburban locations. The hospital administrative database was used to identify potential study participants who visited the ED with their child within 30 days prior to the telephone interviewing start date. Given the diversity of patients who visit a pediatric ED, we focused this initial effort by excluding the following groups: 1) teenage parents younger than 18 years of age, 2) non-English speaking parents, 3) parents of children who have experienced alleged physical and/or sexual abuse, 4) parents of children who died, 5) adult patients, and 6) parents of children who came in with a psychiatric or mental health related complaint. While these groups are very important, they likely have unique needs and

situations that warrant additional study and question development. We also excluded parents of patients who were “fast-tracked” (i.e., they came to the ED with a minor injury or illness and were treated quickly and released) in order to focus on a population with more emergent needs. Again, this is a very important population of patients who experience their care differently. While there is overlap with that of the emergent population the magnitude of their care differs in that their care is delivered in a more rapid pace and they experience relatively fewer diagnostic tests.

Cognitive Interviews: The goal of this qualitative phase was to obtain in-depth information about each question from parents using semi-structured interviewing methods. As a result, we purposively selected a small sample of parents²⁵ in order to achieve representation by the following patient characteristics: age, race, insurance status, presence of a chronic condition, admission to the hospital, the Emergency Severity Index,²⁶ and relationship to the patient. Potential participants for the cognitive interviews were recruited and consented during an ED visit. Due to the potentially hectic nature of their visit and the fact that they had a sick child with them, potential respondents were interviewed by telephone post-visit. We conducted the interviews until no new information was forthcoming. We anticipated having to complete 15 - 20 cognitive interviews. Participants were compensated for their time.

Field test: Our administrative hospital database was used to identify potential study participants. We used a stratified random sampling method based on whether or not the patient had a chronic condition. Parents of children with chronic conditions are more familiar with the health care system because their children use the healthcare system more often than children without chronic conditions.²⁷ Children with chronic conditions were identified using ICD-9 codes and the methodology described by Silber et. al.²⁸ Due to the preponderance of children with asthma, the strata containing children with chronic conditions was further stratified on whether or not the child had asthma. Our goal was to administer the questionnaire to 400 parents within 30 days of their ED visit. Assuming a non-response rate of 10% for individual questions, this sample size would provide estimates of correlation coefficients with a margin of error ranging from ± 0.04 to 0.09 for correlation coefficients ranging from 0.8 to 0.4. In addition, it would provide an estimate of coefficient alpha with a margin of error ± 0.03 and ± 0.05 for values of 0.8 and 0.7 assuming 25 questions. Sample size estimates were calculated using PASS version 13.²⁹

Analysis

Cognitive Interviews: The qualitative data from the cognitive interviews were analyzed on an on-going basis as interviews were completed. In addition to interviewers

noting problems with questions during the interview, two team members reviewed the audio tapes and noted any additional problems. The team reviewed issues as they arose and debated until consensus was reached as to whether or not to modify or delete questions. Frequency distributions were developed to describe the demographic characteristics of the participants.

Field Test: We conducted the following analyses to explore properties of the pediatric emergency care experience measure. We determined whether or not the measure was practical by developing frequency distributions for each question to assess missing data and ceiling effects. For ease of comparison, we prepared the data for further analysis by mapping each response category to a value ranging from 1 to 100 with 100 corresponding to the best answer. Next, we calculated composite scores for each of the eight dimensions of family-centered care by summing the values across the questions.

We used measures of internal consistency to evaluate reliability. Item-total correlations corrected for overlap were calculated to measure how well each question correlated with its own composite score. This was computed by summing the responses to the questions that comprised the dimension with the question of interest removed. In addition, correlations were computed for each question with all other composite scores. The goal of this analysis was to explore how well the questions measured each dimension of family-centered care, and only that dimension, by examining how the questions correlated within its own dimension and with each of the other dimensions. In order to have meaningful composite scores each question should exhibit moderate to high correlations within its own dimension of care and low correlations with all other dimensions. We considered item-total correlation coefficients ≥ 0.40 to be acceptable.³⁰ Due to the ordinal nature of the data, non-parametric Spearman's Rank Order correlations were computed for this analysis.

There were a number of questions that parents indicated were not applicable to them. For example, not all children experienced pain. Missing data in these cases were handled at the respondent level by substituting the mean value of the remaining questions within each dimension. The rationale was that if these questions were measuring the same dimension, the mean score would be an acceptable substitute allowing us to use all the data. This is an important consideration given that some of the questions were not applicable to all visits, but important to keep as part of the care experience measure based on previous qualitative work.¹¹

After examining our initial findings, we conducted an exploratory factor analysis in order to explore the underlying factor structure to further develop meaningful

composite scores. Given the ordinal nature of the data and the fact that the dimensions of care are likely correlated we used the extraction method of principal axis factors rather than principal components analysis along with the oblique factor rotation method promax.³¹ All factors with Eigen values greater or equal to 1.0 were retained. The item-total correlation analysis was repeated using revised composite measures. Finally, internal consistency was measured by calculating coefficient alpha for each composite measure. We considered acceptable coefficient alpha ≥ 0.70 to be an acceptable level of reliability.³²

We explored evidence of construct validity by measuring the association of each question with overall satisfaction with care because good care experiences have been shown to be positively associated with satisfaction. We measured overall satisfaction using a modified rating scale based on a question from the CAHPS surveys. The scale ranged from 0 = "worst care" to 10 = "best care".²⁰ Due skewed data, this measure was categorized as follows: 0 – 6, 7 – 8 and 9 – 10 for analysis purposes. This categorization is based on the CAHPS Consortium recommendations for reporting overall satisfaction scores.³³ The Mantel-Haenszel test was used to test for a linear trend in the proportion of parents giving the best response across the three overall satisfaction categories. T-tests were conducted to measure the association of each composite score with the overall satisfaction. The statistical software IBM SPSS version 24 was used to conduct all analyses.

Results

Question Development and Cognitive Interviews

An initial pool of 77 candidate questions was developed. Application of the criteria outlined in the QAS-99²¹ resulted in a reduced list of 51 questions that were tested using cognitive interviews. The questions deleted from the initial pool prior to conducting the cognitive interviews and reasons for deletions appear in Appendix 1.

Table 1 describes the demographic characteristics of the parents who completed cognitive interviews, which resulted in a final set of 24 questions to be field tested. The complete list of 51 questions with reasons for modification or deletion appear in Appendix 2. The most common reason for modifying or deleting a question was that the wording was ambiguous. For example, how parents interpreted the words "caring and sensitive" varied considerably. Also, parents struggled with the meaning of a number of phrases within the given context including: healthcare providers, personal connection, special services, and non-medical needs.

Some questions were deleted because they applied to a relatively small segment of the ED patient population. It should be noted that due to the level of importance to

Table 1: Demographic characteristics of cognitive interview participants

Characteristics ¹	Percent (n=19)
Age of patient (yrs)	
Less than 4	15.8
4 – 10	42.1
11 – 17	42.1
Patient race	
African American	26.3
White	73.7
Insurance status	
Commercial	42.1
Government	52.6
Self-pay	5.3
Patient had a chronic condition	31.6
Emergency Severity Index²	
Level 2	31.6
Level 3	52.6
Level 4	15.8
Patient admitted to the hospital from the ED (%)	15.8
Relationship to patient	
Mother	84.2
Father	15.8
¹ Chief complaints: shunt malfunction, abdominal pain, extremity injury/pain, eczema, hypoxia, migraine, fall, laceration, seizure, and allergic reaction.	
² Ranges from 1 = most severe to 5 = least severe. Levels 1 and 5 were excluded.	

parents, we chose to leave in some questions that applied to only a subset of the population. For example, we preserved questions about physician communication with the patient even though some patients could not communicate due to age or their condition. We added a “not applicable” response category to these questions. Another reason for deletions was that a similar question worked as well or better. Under this scenario a consideration for which question to keep included whether or not a broader question addressed the same issue. For example, rather than asking if the child got to ask questions, we asked if they were involved in their care as much as they wanted. Another consideration was choosing the question that focused on outcomes rather than processes. For example, rather than ask if the parent was told what to do after they were discharged home, they were asked if they understood how to care for their child at home.

The final questions included in the field test for each dimension of family-centered care appear in Table 2.

Field Test

Interviews were completed with 404 parents or guardians of patients out of 874 randomly selected patient visits resulting in an overall response rate of 46%. Of those, 94 had asthma, and 114 had some other chronic disease. At least 8 attempts were made to contact all potential respondents. The disposition of the remaining sample was: refusal 160 (18%), unavailable during study period 157 (18%), out of service/wrong number 105 (12%), not eligible for the study, 28 (3%), language barrier 14 (2%), and patient was still in hospital 6 (1%).

Table 3 summarizes the demographic characteristics of the field test participants. Response rates ranging from 40 - 50%, depending on the patient care venue, are considered acceptable for CAHPS surveys taking into account what is reasonable given the effort and expense to maximize response rates.^{34,35}

Table 2: Final field test questions and response categories by dimension of family-centered care

Information, communication and education
1. During your child's emergency department visit, how much information about your child's medical condition and treatment were you given? (Too little, Too much, Right amount)
2. When you had questions, did you get answers you could understand? (Yes always, Yes sometimes, No never, Had no questions)
3. During your emergency department visit, did the doctors, nurses and other healthcare professionals introduce themselves and explain their role in your child's care? (Yes always, Yes sometimes, No never)
4. Did the doctors and nurses talk with your child in a way he/she could understand? (Yes always, Yes sometimes, No never, Does not apply)
5. During your child's visit, were you kept informed about the next steps in your child's care? (Yes always, Yes sometimes, No never)
6. Did the doctors and nurses explain to your child what would happen during his/her care and treatment? (Yes always, Yes sometimes, No never, Does not apply)
Emotional Support
7. During your emergency department visit, did the doctors and nurses do everything they could to calm your fears and anxieties? (Yes definitely, Yes somewhat, No, Had no anxieties or fears)
8. During your emergency department visit, did the doctors and nurses do everything they could to calm your child's fears and anxieties? (Yes definitely, Yes somewhat, No, Had no anxieties or fears)
9. Did the doctors and nurses in the emergency department show interest in your child as a person, as well as their condition, illness, or injury? (Yes definitely, Yes somewhat, No)
Coordination
10. From what you saw and heard in the Emergency Department, did the doctors and nurses keep each other informed about your child's care? (Yes always, Yes sometimes, No never)
11. Your child's care in the emergency department consisted of a process with multiple steps. Overall, how well organized was your child's visit? (Very organized, Somewhat organized, Not very organized)
Elicit and respect preferences and involve the patient and family in care decisions
12. Did the doctors listen to what you had to say about your child? (Yes definitely, Yes somewhat, No)
13. Did the nurses listen to what you had to say about your child? (Yes definitely, Yes somewhat, No)
14. Were you involved in decisions about your child's care and treatment as much as you wanted? (Yes definitely, Yes somewhat, No)
15. Was your child involved in decisions about their care and treatment as much as he/she wanted? (Yes definitely, Yes somewhat, No, Does not apply)
Timely and attentive care
16. Did the doctors spend enough time with your child in the emergency department? (Yes definitely, Yes somewhat, No)
17. Did you have to wait too long for care in the emergency department? (Yes definitely, Yes somewhat, No)
18. How often did someone check on your child during your Emergency Department visit? (Too many times, Too few times, The right number of times)
Pain Management
19. How well was your child's pain managed in the emergency department? (Very well, Somewhat well, Not well, Does not apply)
20. Did the healthcare professionals do everything they could to distract your child from painful or uncomfortable tests and treatments? (Yes definitely, Yes somewhat, No, Does not apply)
Safe and child-focused environment
21. Thinking about things other than pain management, did the emergency department staff do everything they could to make your child comfortable while waiting for care and treatment? (Yes definitely, Yes somewhat, No, Does not apply)
22. Was the entire emergency room as clean as it should have been? (Yes definitely, Yes somewhat, No)

Table 3: Demographic characteristics of field test participants

Characteristic	Percent (n=404)
Age of patient (years)	
Less than 4	41.1
4 – 10	34.1
11 – 17	23.8
Unknown	1.0
Patient race	
African American	60.9
White	28.0
Multi-racial	2.7
Other	5.7
Unknown	2.7
Patient gender (% Male)	56.9
Parent gender (% Male)	13.6
Patient admitted to the hospital from the ED (%)	33.4
ED visits in the past year	
1 visit	51.5
2 visits	23.0
3 visits	10.2
4 visits	5.7
More than 4 visits	8.9
Unknown	0.7
Hospitalizations in the past year	
No hospitalizations	83.9
One hospitalization	8.2
Two hospitalizations	3.0
More than 2 hospitalizations	4.2
Unknown	0.7

Table 4 summarizes missing data and ceiling effects for each of the questions. Of the 24 questions, the percent of respondents providing the best response were 70% - 79% (5 questions), 80% - 89% (15 questions), and greater than 90% (4 questions). Missing data due to parent's inability or unwillingness to answer a question was minimal. This type of missing data occurred in only 11 of the 24

questions and ranged from 0.2% to 1.7%. Parents indicated that the question was “not applicable” in 11 questions with the percent not applicable responses ranging from 5% (parents receiving understandable answers to questions) to 57% (child involved care decisions). The item-scale correlation analysis did not support our hypothesized dimensions of family-centered care for composite scoring with many of the questions exhibiting moderate to high correlations with multiple dimensions (see Appendix 3). An exploratory factor analysis was conducted to examine the underlying factor structure in order to develop more meaningful composite measures. This analysis resulted in 5 factors (see the Appendix 4 for the factor loadings).

Table 5 summarizes the properties of the revised and renamed composite scores. Six of the 24 questions were not included in the revised composite measures. Pain management; calming parent anxieties; doctors showing interest in child; doctors listening to parents; and doctors spending time with child exhibited similar or relatively high factor loadings on multiple factors. The question addressing ED cleanliness did not load highly on any factor. Although they did not fit into one of the composite measures, these questions could still be reported as single-item measures, a common practice.³⁶ For example, pain management is an exemplar single item measure since it has been shown to be a primary driver of overall satisfaction in pediatric emergency care.³⁷⁻⁴⁰

Table 5 shows that each revised composite measure score shows an acceptable level of internal consistency as evidenced by item total correlations corrected for overlap > 0.40 within its own dimension and, with a few exceptions, low correlations with other dimensions. In addition, the revised composite scores exhibited coefficient alpha > 0.70. Each of the individual questions and the revised composite scores exhibited acceptable construct validity based on associations with overall satisfaction with care. Tables 6 and 7 show that the individual questions and revised composite measures, respectively, were positively associated with overall satisfaction (p-value < 0.001).

Discussion

The tool resulting from this study can be used to monitor and improve the ED experience of care. Parent responses to individual questions can be used to inform targeted improvement efforts. Compared to subjective rating questions, experience of care questions can provide key insights into specific healthcare provider behaviors and interactions with patients and families, and ED environmental factors needing improvement. On the other hand, composite measures can be reported to audiences, such as senior leadership or the public, who may want a higher level summary measure. Although the

Table 4: Characteristics of responses to questions (n = 404)

Question ¹	% Missing Data ²	Questions not Applicable (%)	% Ceiling ³ Effects
Information, communication, and education			
Amount of information (1)	0.0	0.0	91.3
Understandable answers to questions (2)	0.0	4.5	86.8
Providers always introduced themselves & explained roles (3)	0.2	0.0	88.8
Talk with child understandably (4)	0.0	23.8	90.3
Informed about next steps (5)	0.0	0.0	85.4
Explanations to child about care (6)	0.5	23.5	89.6
Emotional Support			
Calmed parent's anxieties (7)	0.0	23.5	78.3
Calmed child's anxieties (8)	1.7	25.0	85.8
Providers showed interest in child (9)	0.0	0.0	87.6
Coordination			
Doctors & nurses kept each other informed (10)	1.4	0.0	82.7
How well visit was organized (11)	0.2	0.0	79.7
Elicit and respect preferences and involve the patient and family in care decisions			
Doctors listened to parents (12)	0.0	0.0	87.6
Nurses listened to parents (13)	0.4	0.0	90.8
Parent involved in care decisions (14)	0.2	0.0	86.4
Child involved in care decisions (15)	0.2	57.2	78.5
Timely and attentive care			
Doctors spent enough time with child (16)	0.2	0.0	82.9
Waited too long (17)	0.7	0.0	70.3
How often patient was checked (18)	0.4	0.0	88.1
Pain Management			
Pain management (19)	0.4	38.1	77.0
Child distracted from procedures (20)	0.0	25.7	86.0
Safe and child-focused environment			
Made child comfortable for things other than pain management (21)	0.0	7.7	82.8
Emergency Department cleanliness (22)	1.4	0.0	86.9
Continuity and transition			
Understanding care after emergency department visit (23)	0.7	0.0	93.5
Know who to call if problems post visit (24)	1.2	0.0	89.2
¹ See Table 2 for the complete wording. The parentheses contain the question number.			
² Parents did not know or refused to answer.			
³ Percent parents giving the best response. Missing and “not applicable” responses were not included in the denominator.			

initial eight dimensions of ED family-centered care used to develop these questions¹¹ did not result in meaningful composite measures, it provided a comprehensive framework for ensuring that we included questions that addressed what was important to parents. While the five

composite scores that the resulted from this study could be used to calculate summary scores for such audiences, additional validation work using confirmatory factor analysis methods is needed.

Table 5: Scale properties of revised composite measures

Question ¹	Item total correlation ²
Composite 1: Partnerships in Care (coefficient alpha = 0.83)	
Parent involved in care decisions (14)	0.53
Explanations to child about care (6)	0.61
Nurses listened to parents (13)	0.41
Doctors & nurses kept each other informed (10)	0.53
How well visit was organized (11)	0.54
Providers always introduced themselves & explained roles (3)	0.45
Informed about next steps (5)	0.46
Composite 2: Waiting for Care (coefficient alpha = NA)	
Waited too long (17)	0.42
How often patient was checked (18) ³	0.42
Composite 3: Focus on Child's Comfort (coefficient alpha = 0.88)	
Child involved in care decisions (15)	0.83
Made child comfortable for things other than pain management (21) ³	0.70
Calmed child's anxieties (8)	0.72
Child distracted from procedures (20)	0.70
Composite 4: Continuity & Transition (coefficient alpha = NA)	
Know who to call for post-visit problems (24)	0.41
Understanding care after emergency department visit (23)	0.41
Composite 5: Information About Diagnosis & Treatment (coefficient alpha = 0.75)	
Understandable answers to questions (2) ³	0.65
Talk with child understandably(4)	0.61
Amount of information (1)	0.56
¹ See Table 2 for the complete wording. The parentheses contain the question number.	
² Corrected for item overlap	
³ Correlated with one other composite measure with correlation coefficients ranging from 0.40 to 0.41.	

This study has limitations. First, it was conducted at a single health system and even though it has both urban and suburban ED locations, the findings may not be generalizable to other settings. Further validation work will be important in order to test this measure in settings, especially adult focused EDs that account for the majority of pediatric ED visits.⁴¹ Second, we excluded some groups of patients to whom these results may not be generalizable. These groups included parents of patients who died, or were critically ill; patients who were “fast tracked” due to relatively minor complaints; parents of children who have experienced alleged physical and/or sexual abuse; teenage parents younger than 18 years of age; and non-English speaking patients. These are important populations for whom further more targeted work is needed. This initial core set of questions needs to be tested in these populations. In addition, there may be

important aspects of care that would require supplemental questions.

A validated and comprehensive measure of the pediatric ED experience of care is critical to improving the delivery of patient- and family-centered care. This study resulted in a pediatric specific tool that focuses on aspects of ED care important to parents. Public reporting of quality measures for healthcare providers and institutions is becoming more commonplace with the goal of creating incentives for quality improvement and for creating accountability through increased transparency. A validated measure of pediatric emergency care is imperative given that public comparative reporting has already become a reality for inpatient care and outpatient clinics and an adult emergency care measure under development.

Table 6: Percent of parents giving the best response by overall satisfaction

Question ²	n	Overall Satisfaction Rating ¹		
		0 - 6	7 - 8	9 - 10
Amount of information (1)	403	44.4	87.1	96.4
Understandable answers to questions (2)	386	26.9	80.6	93.3
Providers always introduced themselves & explained roles (3)	402	63.0	81.4	92.8
Talk with child understandably (4)	307	55.6	83.7	94.2
Informed about next steps (5)	403	37.0	71.4	93.1
Explanations to child about care & treatment (6)	306	47.4	84.8	93.8
Calmed parent's anxieties (7)	309	12.0	58.3	89.4
Calmed child's anxieties (8)	296	53.3	63.6	92.0
Providers showed interest in child (9)	403	29.6	80.0	94.4
Doctors & nurses kept each other informed (10)	397	20.8	69.1	90.8
How well visit was organized (11)	402	18.5	57.1	90.2
Doctors listened to parents (12)	403	37.0	71.4	95.8
Nurses listened to parents (13)	401	50.0	80.0	96.7
Parent involved in care decisions (14)	402	25.9	75.4	94.1
Child involved in care decisions (15)	171	30.0	54.8	87.7
Doctors spent enough time with child (16)	402	19.2	68.6	91.5
Waited too long (17)	400	29.6	52.9	78.2
How often patient was checked (18)	401	37.0	79.4	94.8
Pain management (19)	248	29.4	48.8	87.4
Child distracted from procedures (20)	300	61.1	74.0	90.5
Made child comfortable for things other than pain management (21)	372	26.1	58.7	92.7
Emergency Department cleanliness (22)	397	52.0	74.3	92.7
Understanding care after emergency department visit (23)	400	74.1	86.8	96.7
Know who to call for post-visit problems (24)	398	69.2	80.6	92.8
¹ Scale ranged from 0 = “worst care possible” to 10 = “best possible care”.				
² See Table 2 for the complete wording. The parentheses contain the question number.				
Note: All questions were significantly associated with overall satisfaction with p-values < 0.001.				

Table 7: Mean revised composite scores by overall satisfaction ratings

Revised Composite Measures	n	Overall satisfaction rating ¹		
		Rating 0 - 6	Rating 7 - 8	Rating 9 - 10
Partnerships in Care	403	58.0	85.6	96.3
Waiting for Care	403	37.0	70.4	90.5
Focus on Child's Comfort	395	52.7	80.5	94.9
Continuity & Transition	400	79.6	89.7	96.5
Information About Diagnosis & Treatment	403	56.2	89.9	96.5
¹ Scale ranged from 0 = “worst care possible” to 10 = “best possible care”.				
Note: All composite score were significantly associated with overall satisfaction ratings with p-values < 0.001.				

References

1. Dudley N, Ackerman A, Brown KM, Snow SK. Patient- and family-centered care of children in the emergency department. *Pediatrics*. Jan 2015;135(1):e255-272.
2. IPFCC. Patient- and Family-Centered Care. <http://www.ipfcc.org/about/pfcc.html>. 2017.
3. O'Malley P, Brown K, Mace SE. Patient- and family-centered care and the role of the emergency physician providing care to a child in the emergency department. *Pediatrics*. Nov 2006;118(5):2242-2244.
4. Coulter A, Ellins J. *Patient-focused interventions: A review of the evidence*. The Health Foundation and Picker Institute Europe; 2006: 209-230.
5. Davis BA, Kiesel CK, McFarland J, Collard A, Coston K, Keeton A. Evaluating instruments for quality: testing convergent validity of the consumer emergency care satisfaction scale. *Journal of nursing care quality*. 2005;20(4):364-368.
6. de la Orden SG, García AC, Gijón LFR, Rieiro CR, de Blas CS, Pérez PR. Development and validation of a questionnaire to assess satisfaction with hospital emergency care. *Emergency Medicine Journal*. 2010;emj. 2009.084996.
7. Kristensson J, Ekwall A. Psychometric properties of the consumer emergency care satisfaction scale: tested on persons accompanying patients in emergency department. *Journal of nursing care quality*. 2008;23(3):277-282.
8. Sitzia J, Wood N. Patient satisfaction: a review of issues and concepts. *Soc Sci Med*. Dec 1997;45(12):1829-1843.
9. Linder-Pelz SU. Toward a theory of patient satisfaction. *Soc Sci Med*. 1982;16(5):577-582.
10. Picker Institute. Principles of Patient-Centered Care. 2016; <http://pickerinstitute.org/about/picker-principles/>.
11. Byczkowski TL, Gillespie GL, Kennebeck SS, Fitzgerald MR, Downing KA, Alessandrini EA. Family-centered pediatric emergency care: a framework for measuring what parents want and value. *Academic pediatrics*. 2016;16(4):327-335.
12. CMS.gov. Emergency Department Patient Experiences with Care (EDPEC) Survey. 2017; <https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/CAHPS/ed.html>.
13. Committee on Hospital Care and Institute for Patient- and Family-Centered Care. Patient-and family-centered care and the pediatrician's role. *Pediatrics*. 2012;129(2):394 - 404.
14. Centers for Medicare & Medicaid Services. Accountable Care Organization 2014 Program analysis quality performance standards narrative measure specifications. 2014; http://www.healthreform.ct.gov/ohri/lib/ohri/workgroups/quality/2014-09-03/aco_narrative_measures_specs_1.pdf. Accessed August 15, 2014.
15. CMS. The HCAHPS Survey - Frequently Asked Questions. 2017; <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/HospitalQualityInits/Downloads/HospitalHCAHPSFactSheet201007.pdf>.
16. CMS.gov. Quality Data and Physician Compare 2016; <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/physician-compare-initiative/Quality-Data-and-Physician-Compare-.html>.
17. Solomon LS, Hays RD, Zaslavsky AM, Ding L, Cleary PD. Psychometric properties of a group-level Consumer Assessment of Health Plans Study (CAHPS) instrument. *Medical care*. Jan 2005;43(1):53-60.
18. Weidmer BA, Brach C, Hays RD. Development and evaluation of CAHPS survey items assessing how well healthcare providers address health literacy. *Medical care*. Sep 2012;50(9 Suppl 2):S3-11.
19. Scholle SH, Vuong O, Ding L, Fry S, Gallagher P, Brown JA, Hays RD, Cleary PD. Development of and field test results for the CAHPS PCMH Survey. *Medical care*. Nov 2012;50 Suppl:S2-10.
20. Agency for Healthcare and Research Quality. (CAHPS) Consumer Assessment of Healthcare Providers and Systems. 1995; <http://www.ahrq.gov/cahps/index.html>. Accessed May 23, 2013.
21. Lessler JT, Forsyth BH. A coding system for appraising questionnaires. In: Schwartz N, Sudman S, eds. *Answering questions: Methodology for determining cognitive and communicative processes in survey research*. San Francisco, CA: Jossey-Bass, Inc; 1996:259-291.
22. DeMaio T, Rothgeb J. In the lab and in the field. In: Schwartz N, Sudman S, eds. *Answering questions : methodology for determining cognitive and communicative processes in survey research*. First edition ed. San Francisco, CA: Jossey -Bass, Inc; 1996:177-195.
23. Sudman S, Bradburn NM, Schwarz N. Thinking about answers : the application of cognitive processes to survey methodology. 1st ed. San Francisco: Jossey-Bass Publishers; 1996:15-54.
24. Levine RE, Fowler FJ, Jr., Brown JA. Role of cognitive testing in the development of the CAHPS Hospital Survey. *Health services research*. Dec 2005;40(6 Pt 2):2037-2056.
25. Crabtree BF, Miller WL. Doing qualitative research. *Annual North American Primary Care Research Group Meeting, 19th, May, 1989, Quebec, PQ, Canada*. 1992:33-35.
26. Gilboy N, Agency for Healthcare and Research Quality. Emergency severity index. Version 4 implemtation handbook. AHRQ publication no 12-0014. 2012; <http://purl.fdlp.gov/GPO/gpo23161>. Accessed August 23, 2016.

27. Newacheck PW, Kim SE. A national profile of health care utilization and expenditures for children with special health care needs. *Archives of Pediatrics & Adolescent Medicine*. 2005;159(1):10-17.
28. Silber JH, Gleeson SP, Zhao H. The influence of chronic disease on resource utilization in common acute pediatric conditions: financial concerns for children's hospitals. *Archives of pediatrics & adolescent medicine*. 1999;153(2):169-179.
29. Software NS. PASS Sample Size. 2016; <https://www.ncss.com/software/pass/>. Accessed September 6, 2016.
30. Lohr KN, Aaronson NK, Alonso J, Burnam MA, Patrick DL, Perrin EB, Roberts JS. Evaluating quality-of-life and health status instruments: development of scientific review criteria. *Clinical therapeutics*. Sep-Oct 1996;18(5):979-992.
31. Osborne JW, Costello AB. Best practices in exploratory factor analysis: Four recommendations for getting the most from your analysis. *Pan-Pacific Management Review*. 2009;12(2):131-146.
32. Nunnally JC. *Psychometric Theory*, 2nd edition 2nd ed. New York: McGraw-Hill Book Company; 1978.
33. Agency for Healthcare and Research Quality. Frequently Asked Questions About CAHPS. 2016; <https://www.ahrq.gov/cahps/faq/index.html>. Accessed March 2012.
34. Agency for Healthcare and Research Quality. CAHPS Health Plan Survey: Methodology. 2015; https://cahpsdatabase.ahrq.gov/cahpsidb/Public/Files/Doc4_CAHPSHP_Methodology_2015.pdf. Accessed October 2015.
35. Agency for Healthcare and Research Quality. Fielding the CAHPS Clinician & Group Survey. 2017; <https://www.ahrq.gov/sites/default/files/wysiwyg/cahps/surveys-guidance/cg/survey3.0/fielding-the-survey-cg30-2033.pdf>. Accessed June 2017.
36. Agency for Healthcare and Research Quality. Patient Experience Measures from the CAHPS Health Plan Survey. 2015; https://www.ahrq.gov/sites/default/files/wysiwyg/cahps/surveys-guidance/hp/about/measures_hp50_2109.pdf. Accessed October 2015.
37. Pagnamenta R, Bengner JR. Factors influencing parent satisfaction in a children's emergency department: prospective questionnaire-based study. *Emergency medicine journal : EMJ*. Jul 2008;25(7):417-419.
38. Locke R, Stefano M, Koster A, Taylor B, Greenspan J. Optimizing patient/caregiver satisfaction through quality of communication in the pediatric emergency department. *Pediatr Emerg Care*. Nov 2011;27(11):1016-1021.
39. Magaret ND, Clark TA, Warden CR, Magnusson AR, Hedges JR. Patient satisfaction in the emergency department--a survey of pediatric patients and their parents. *Academic emergency medicine : official journal of the Society for Academic Emergency Medicine*. Dec 2002;9(12):1379-1388.
40. Byczkowski TL, Fitzgerald M, Kennebeck S, Vaughn L, Myers K, Kachelmeyer A, Timm N. A Comprehensive View of Parental Satisfaction With Pediatric Emergency Department Visits. *Annals of Emergency Medicine*. 10 / 2013;62(4):340-350.
41. Bourgeois FT, Shannon MW. Emergency care for children in pediatric and general emergency departments. *Pediatr Emerg Care*. Feb 2007;23(2):94-102.

Appendix 1: Questions Deleted Prior to Cognitive Interviewing and Reasons

1. Did you get all the emotional support you needed?	
2. Did your child get all the emotional support he/she needed?	<i>Reason: These questions were considered to be too broad and ambiguous.</i>
3. Did the physicians and nurses treat your child with compassion and understanding as though he or she was their own child?	<i>Reason: The words “as though he or she were their own child” were considered to be superfluous. Also, the question is double-barreled. Instead we asked two questions about being treated in a “caring and sensitive manner” by doctors and nurses (Appendix 2: Questions 5 and 6).</i>
4. Did you ever feel like you were being treated as a number and not as a parent of a child with a medical issue?	<i>Reason: We felt it more likely that parents might feel as though their child was viewed as a condition or illness (Appendix 2: Question 7).</i>
5. Did the doctors and nurses make eye contact with you when talking to you about your child?	<i>Reason: We felt that introductions and explanations of roles was more substantive than making eye contact (Appendix 2, Question 29).</i>
6. Did the doctors and nurses make you feel like you were doing the right thing for your child by bringing them to the emergency department?	
7. During your visit, did any doctors or nurses make you feel like you should not have brought your child to the emergency department?	
8. Did your healthcare providers help you feel like you are doing a good job caring for your child?	<i>Reason: It was felt that these questions were likely appropriate for a relatively small segment of parents.</i>
9. Did the Emergency Department doctors and nurses do everything they could to prepare for your child’s Emergency Department visit?	<i>Reason: A more appropriate question, which focused on the child’s medical history was substituted (Appendix 2: Question 13).</i>
10. During your child’s emergency department visit were all the healthcare providers who cared for your child always on the same page?	<i>Reason: The words “on the same page” did not focus on healthcare provider behaviors and was deleted in favor of more specific behaviors (Appendix 2: Questions 10 and 11).</i>
11. Did you have questions about your child’s care or treatment that you wanted to discuss but did not get the chance?	<i>Reason: This question was deleted in favor of including questions about getting understandable answers to important questions (Appendix 2, Questions 32 and 33).</i>
12. During your child’s emergency department visit, did the healthcare providers talk in front of you as if you weren’t there?	<i>Reason: We felt that parents’ interpretation of this question would be too variable.</i>
13. Did you have enough say about your child’s care?	<i>Reason: This question was too broad and ambiguous.</i>
14. Did your child’s provider explain why your child needed tests in a way that you could understand?	
15. Did your child’s provider explain to you what would happen to your child during this test?	
16. Did your child’s provider explain to your child what would happen during this test?	<i>Reason: These questions were deleted since some patients do not receive tests.</i>
17. Did someone explain how to take the new medications?	
18. Did someone tell you about side effects the medications might have?	<i>Reason: In the interest of keeping the survey to a reasonable length and the fact that not all patients go home with a new prescription, only one medication question was included (Appendix 2: Question 48).</i>

Appendix 1 (cont): Questions Deleted Prior to Cognitive Interviewing and Reasons

19. Was the information about his or her condition discussed with your child in a way he or she could understand?
20. Did the physicians and nurses inform your child as to what they were doing using words your child could understand? <i>Reason: These questions were deleted in favor of a question regarding communicating with their child in an understanding way (Appendix 2: Questions 34 and 37).</i>
21. Was the noise level in the emergency department as quiet as it should have been? <i>Reason: Given the sometimes unavoidable chaotic emergency department environment this question was deemed not appropriate.</i>
22. During your Emergency Department visit did you ever feel like your child was being exposed to germs needlessly? <i>Reason: This question was deleted because parents may not feel they could accurately answer.</i>
23. Were you told what activities your child could or could not do when he or she got home, such as eating, bathing, playing sports, or returning to school?
24. Were you told what danger signs about your child's illness or injury to watch out for when you got home? <i>Reason: These questions were deleted in favor of a question that addressed ongoing problems or symptoms (Appendix 2: Question 47).</i>
25. Did the doctor in the Emergency Department inform your child's primary care doctor about your visit?
26. Did the doctor in the Emergency Department follow-up with your child's primary care doctor? <i>Reason: Contacting their primary care physician may not be necessary or appropriate.</i>

Appendix 2: Cognitive Interview Results (Bold text denotes the final questions included in the field test)

Emotional Support
<p><i>Question 1:</i> If you expressed or voiced any anxieties or fears about your child's condition or treatment, did a <i>doctor</i> discuss them with you? (Yes definitely, Yes somewhat, No, or had no anxieties or fears).</p> <p><i>Question 2:</i> If you expressed or voiced any anxieties or fears about your child's condition or treatment, did a <i>nurse</i> discuss them with you? (Yes definitely, Yes somewhat, No, Had no anxieties or fears)</p> <p><i>Result:</i> Deleted both questions. Parents tended to give the same explanations for both questions (i.e., they did not differentiate between doctors and nurses). These questions were similar to question #3 to which parents provided more detailed responses. They described steps healthcare providers took to alleviate anxiety in addition to talking with them. Also, parents may not outwardly express that they are anxious, but exhibit other signs of anxiousness. We felt that question #3 encompassed this broader view.</p>
<p><i>Question 3:</i> Did the healthcare providers do everything they could to calm <i>your</i> fears and anxieties? (Yes definitely, Yes somewhat, No, Had no anxieties or fears)</p> <p><i>Question 4:</i> Did the healthcare providers do everything they could to calm <i>your child's</i> fears and anxieties? (Yes definitely, Yes somewhat, No, Had no anxieties or fears)</p> <p><i>Result:</i> Included both questions with minor modifications. We changed "healthcare providers" to "doctors and nurses" because some parents did not know what "healthcare provider" meant. Also, we prefaced the questions with "During your emergency department visit...."</p> <p><i>Modified Questions:</i></p> <p>During your emergency department visit did the doctors and nurses do everything they could to calm <i>your</i> fears and anxieties? (Yes definitely, Yes somewhat, No, Had no anxieties or fears)</p> <p>During your emergency department visit did the doctors and nurses do everything they could to calm <i>your child's</i> fears and anxieties? (Yes definitely, Yes somewhat, No, Had no anxieties or fears).</p>
<p><i>Question 5:</i> During your child's visit did the <i>doctors</i> treat your child in a caring and sensitive manner? (Yes definitely, Yes somewhat, No)</p> <p><i>Question 6:</i> During your child's visit did the <i>nurses</i> treat your child in a caring and sensitive manner? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Deleted. These questions were interpreted very broadly by parents. Parents talked about aspects of care covered by other questions. For example, parents talked about pain management; healthcare providers talking to their child in a way the child could relate; and how well doctors listened to their child.</p>
<p><i>Question 7:</i> Did the healthcare providers in the Emergency Department show interest in your child as a person, as well as their condition, illness, or injury? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Included with minor modifications. We changed "healthcare providers" to "doctors and nurses" because some parents did not know what "healthcare provider" meant.</p> <p><i>Modified Question:</i> Did the doctors and nurses in the Emergency Department show interest in your child as a person, as well as their condition, illness, or injury? (Yes definitely, Yes somewhat, No)</p>
<p><i>Question 8:</i> Did the healthcare providers say, or do things to establish a personal connection with your child? (Yes definitely, Yes somewhat, No)</p> <p><i>Question 9:</i> Did the healthcare providers say, or do things to establish a personal connection with you? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Deleted. Multiple parents did not know what we meant by "personal connection."</p>

Appendix 2 (cont): Cognitive Interview Results (Bold text denotes the final questions included in the field test)
Coordination

<p><i>Question 10:</i> Sometimes in the emergency department one doctor or nurse will say one thing and another will say something quite different. Did this happen during your child's emergency department visit? (Yes often, Yes sometimes, No never)</p> <p><i>Result:</i> Deleted. This question was deleted in favor of question #11 that, per parent responses, addressed a broader concept.</p>
<p><i>Question 11:</i> From what you saw and heard in the Emergency Department, did the doctors and nurses keep <i>each other</i> informed about your child's care? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Included with no modifications</p>
<p><i>Question 12:</i> During your child's visit, did you have to repeat information more than you wanted? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Deleted. Overall, this question worked well, but was also deleted in favor of question #11 to which parent responses sometimes addressed this issue.</p>
<p><i>Question 13:</i> Did the doctors know what you thought they should know about your child's medical history? (Yes definitely, Yes somewhat, No, Not applicable)</p> <p><i>Result:</i> Deleted. This question resonated only with parents of children with a chronic condition because they expected that physicians reviewed their child's electronic health record prior to entering the exam room. Otherwise, this question confused parents.</p>
<p><i>Question 14:</i> Your child's care in the emergency department consisted of a process with multiple steps. Overall, how well organized was your child's visit? (Very organized, Somewhat organized, Not very organized)</p> <p><i>Result:</i> Included with no modifications.</p>
<p>Elicit and Respect Preferences</p>
<p><i>Question 15:</i> Did the <i>doctors</i> listen to what you had to say about your child? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Included without modification.</p>
<p><i>Question 16:</i> Did the <i>nurses</i> listen to what you had to say about your child? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Included without modification.</p>
<p><i>Question 17:</i> Did the doctors pay enough attention to your experiences and suggestions in diagnosing and treating your child? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Deleted. Overall, the question worked well, but was deleted because it addressed the same aspect of care addressed by question #18.</p>

Appendix 2 (cont): Cognitive Interview Results (Bold text denotes the final questions included in the field test)

<p><i>Question 18:</i> Were <i>you</i> involved in decisions about your child's treatment as much as you wanted? (Yes definitely, Yes somewhat, No)</p> <p><i>Question 19:</i> Was <i>your child</i> involved in decisions about their treatment as much as he/she wanted? (Yes definitely, Yes somewhat, No, Not applicable)</p> <p><i>Result:</i> Included with minor modifications. Some parents indicated that their child did not need or receive any treatment in the ED. As a result we replaced the word "treatment" with "care and treatment". Further testing showed that this change ameliorated the issue.</p> <p><i>Modified Questions:</i> Were <i>you</i> involved in decisions about your child's care and treatment as much as you wanted? (Yes definitely, Yes somewhat, No)</p> <p>Was <i>your child</i> involved in decisions about their care and treatment as much as he/she wanted? (Yes definitely, Yes somewhat, No, Not applicable)</p>
<p><i>Question 20:</i> Were you allowed to stay with your child as much as you wanted? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Deleted. This question did not work well in our ED setting because it is a policy to allow parents to always be with their child with few exceptions. Other emergency departments might, however, consider including this question.</p>
<p><i>Question 21:</i> Did your child's healthcare provider give your child a chance to ask questions about his/her care? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Deleted. Parents talked about their child asking questions and getting answers in response to question #19.</p>
Timely and Attentive Care
<p><i>Question 22:</i> Did the doctors spend enough time with your child in the emergency department? (Yes, completely, Yes somewhat, No)</p> <p><i>Result:</i> Included with no modifications</p>
<p><i>Question 23:</i> How would you rate your waiting time in the emergency department? (Excellent, Very Good, Good, Fair, Poor)</p> <p><i>Result:</i> Developed and tested a substitution question. Rather than use a subjective rating question, we substituted a more objective question (see below) and continued testing.</p> <p><i>Modified Question:</i> Did you have to wait too long for care in the emergency department? (Yes, definitely, Yes somewhat, No)</p>
<p><i>Question 24:</i> If there were any delays, did someone explain to you the reason for the delays during your child's visit to the Emergency Department? (Yes definitely, Yes somewhat, No, No delays)</p> <p><i>Result:</i> Deleted. Although parents had no problems answering this question, we deleted it in favor of the revised question #23 and question #36 in which parents talked about delays.</p>
<p><i>Question 25:</i> How often did someone check on your child during your Emergency Department visit? (Too many times, Too few times, The right number of times)</p> <p><i>Result:</i> Included with no modifications</p>
<p><i>Question 26:</i> If your child needed specialty services and/or doctors, were they readily available to you during your Emergency Department visit? (Yes definitely, Yes somewhat, No, No specialty doctors or services)</p> <p><i>Result:</i> Deleted. This question had multiple issues. First, a few parents did not know what we meant by "specialty services". Second, two parents answered negatively because even though the ED physician consulted with a specialist their child did not actually see the specialist. Finally, some parents indicated their child did not require a specialist.</p>

Appendix 2 (cont): Cognitive Interview Results (Bold text denotes the final questions included in the field test)

<p><i>Question 27:</i> Was your child checked on often enough during your stay in the emergency department? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Deleted. We deleted this question in favor of question #25 because we thought it possible that parents may think that healthcare providers checked in too often.</p>
<p>Information, communication and education</p>
<p><i>Question 28:</i> Did you have a clear understanding of each healthcare provider's role during your emergency department visit? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Deleted. We deleted this question in favor of question #29 because in response to that question parents talked about having a clear understanding due to health care providers introducing themselves and describing their job or what they were going to do.</p>
<p><i>Question 29:</i> Did the healthcare providers in the emergency department introduce themselves and explain their roles in your child's care? (Always, Sometimes, Never)</p> <p><i>Result:</i> Included with modifications. Changed "healthcare providers" to "doctors, nurses and other healthcare professionals." One notable response from a parent was that when her son was in the "trauma room" no one introduced themselves. She understood that and did not consider that part of the visit in her answer.</p> <p>Modified Question: During your emergency department visit did the doctors, nurses and other healthcare professionals introduce themselves and explain their roles in your child's care? (Always, Sometimes, Never)</p>
<p><i>Question 30:</i> While you were in the emergency department, did you get enough information about your child's medical condition and treatment? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Deleted. We deleted this question in favor of question #31 for two main reasons. First, parent responses to question #31 regarding what they were thinking about were much richer in detail. Second, it is conceivable that parents could feel like they received too much information.</p>
<p><i>Question 31:</i> During your child's emergency department visit, how much information about your child's medical condition and treatment were you given? (Too little, Too much, The right amount)</p> <p><i>Result:</i> Included with no modifications.</p>
<p><i>Question 32:</i> When you had important questions to ask a <u>doctor</u>, did you get answers you could understand? (Yes definitely, Yes somewhat, No)</p> <p><i>Question 33:</i> When you had important questions to ask a <u>nurse</u>, did you get answers you could understand? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> We combined these questions in to one in order to simplify since the desired outcome is whether or not all their questions were answered by nurses, doctors or some other provider. In addition, we changed the wording from "important questions" to "questions" because all questions are important. Finally, some parents indicated that they had no questions. So, we added a "not applicable" category to accommodate that.</p> <p>Modified Question: When you had questions, did you get answers you could understand? (Yes definitely, Yes somewhat, No, Had no questions)</p>
<p><i>Question 34:</i> Did your child's healthcare providers talk with your child in a way he/she could understand? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Included with minor modifications. Changed "your child's healthcare providers" to "the doctors and nurses." Also, we added a "not applicable" category as some parents indicated their child was not able to "understand" due to age or disability.</p> <p>Modified Question: Did the doctors and nurses talk with your child in a way he/she could understand? (Yes definitely, Yes somewhat, No, Not applicable)</p>

Appendix 2 (cont): Cognitive Interview Results (Bold text denotes the final questions included in the field test)

<p><i>Question 35:</i> Did the healthcare providers keep you well informed so that you always knew what was going to happen next? (Always, Sometimes, Never)</p> <p><i>Result:</i> Deleted. We deleted this question in favor of question #36. Although both questions appeared to work equally well and elicited the same information from parents, we chose question #36 because we liked the focus on the child's care.</p>
<p><i>Question 36:</i> During your child's visit, were you kept informed about the next steps in your child's care? (Always, Sometimes, Never)</p> <p><i>Result:</i> Included with no modifications.</p>
<p><i>Question 37:</i> Did your child's healthcare providers explain to <i>your child</i> what would happen during his/her care and treatment? (Always, Sometimes, Never)</p> <p><i>Result:</i> Included with minor modifications. Changed "your child's healthcare providers" to "the doctors and nurses."</p> <p><i>Modified Question:</i> Did the doctors and nurses explain to <i>your child</i> what would happen during his/her care and treatment? (Always, Sometimes, Never)</p>
<p>Pain Management</p>
<p><i>Question 38:</i> Overall, how much pain medicine did your child get? (Not enough, Right amount, Too much, Not applicable)</p> <p><i>Result:</i> Deleted. We deleted this question in favor of question #39. Some parents struggled with this question because they indicated that they did not have the knowledge to determine the "right amount of pain medicine."</p>
<p><i>Question 39:</i> How would you rate how well your child's pain was managed in the Emergency Department? (Excellent, Very Good, Good, Fair, Poor, Not applicable)</p> <p><i>Result:</i> Included a substitute question. We simplified the question and the scale since the difference between two points on the excellent to poor scale is very subjective.</p> <p><i>Modified Question:</i> How well was your child's pain managed in the emergency department? (Very well, Somewhat Well, Not Well, Does Not Apply)</p>
<p><i>Question 40:</i> Did the healthcare providers do everything they could to distract your child from painful or uncomfortable tests and treatments? (Yes definitely, Yes somewhat, No, Not applicable)</p> <p><i>Result:</i> Included with minor modifications. Changed the word "providers" to "professionals" because distracting a child can be accomplished by a variety of individuals including Child Life.</p> <p><i>Modified Question:</i> Did the healthcare professionals do everything they could to distract your child from painful or uncomfortable tests and treatments? (Yes definitely, Yes somewhat, No, Not applicable)</p>
<p><i>Question 41:</i> Think about things other than pain control. Did the Emergency Department staff do everything they could to keep your child comfortable? (Yes definitely, Yes somewhat, No, Not applicable)</p> <p><i>Result:</i> Deleted. Our intent with this question was to capture the alleviation of other symptoms that made the child uncomfortable. Instead the word "comfortable" invoked responses regarding things like hunger and warmth.</p>
<p>Safe and Child Focused Environment</p>
<p><i>Question 42:</i> Was the entire emergency room as clean as it should have been? (Yes definitely, Yes somewhat, No, Not applicable)</p> <p><i>Result:</i> Included with no modifications.</p>
<p><i>Question 43:</i> Did the Emergency Department staff do everything they could to make your child comfortable by addressing any non-medical needs? (Yes definitely, Yes somewhat, No, Not applicable)</p> <p><i>Result:</i> Deleted. We deleted this question in favor of a modified question #45 since a few parents struggled with the words "non-medical needs."</p>

Appendix 2 (cont'd): Cognitive Interview Results (Bold text denotes the final questions included in the field test)

<p><i>Question 44:</i> During your Emergency Department visit, did the healthcare providers help and support you so that you could take time out to tend to other personal or family needs? (Yes definitely, Yes somewhat, No, Not applicable)</p> <p><i>Result:</i> Deleted. Tending to personal or family needs did not resonate with the majority of parents as something important.</p>
<p><i>Question 45:</i> Did the healthcare providers do what they could to make <i>your child</i> comfortable while waiting for care and treatment? (Yes definitely, Yes somewhat, No, Not applicable)</p> <p><i>Result:</i> Included with modifications. Initially some parents thought about pain management. As a result, we prefaced the question with an instruction to think about things other than pain management. In addition, we changed the words “healthcare providers” to “emergency department staff” because any staff member could tend to the types of needs that we wanted the parent to think about. Additional testing showed that after these modifications parents focused on issues including warmth, hunger, and boredom.</p> <p><i>Modified Question:</i> Thinking about things other than pain management, did the emergency department staff do everything they could to make your child comfortable while waiting for care and treatment? (Yes definitely, Yes somewhat, No, Not applicable)</p>
<p><i>Question 46:</i> Did the healthcare providers do what they could to make <u>you</u> comfortable while your child waited for care and treatment? (Yes definitely, Yes somewhat, No, Not applicable)</p> <p><i>Result:</i> Deleted. Overall, this question worked well. Like question #44, however, this was not important to some parents. They talked about keeping the focus on their child and not on them.</p>
<p>Continuity and Transition</p>
<p><i>Question 47:</i> Did a healthcare provider explain what to do if problems or symptoms continued, got worse, or came back? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Deleted. We felt that this question addressed a process and not an outcome. So, we deleted this question in favor of a modified question #49, which addresses an important outcome. That is, whether or not parents <i>understood</i> what to do.</p>
<p><i>Question 48:</i> Did a healthcare provider explain the purpose of any prescribed medicines in a way that you could understand? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Deleted. Too many parents indicated that they did not receive prescribed medications.</p>
<p><i>Question 49:</i> Were you told what care you were supposed to provide for your child after the visit? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Included with modifications. We substituted the words “were you told” with “did you have a clear understanding” because understanding is more family-centered than the process measure of “being told”. We also added a “not applicable” response category for children who were admitted.</p> <p><i>Modified Question:</i> Did you have a clear understanding about the care you were supposed to provide for your child after your emergency department visit? (Yes definitely, Yes somewhat, No)</p>
<p><i>Question 50:</i> Did you know who to call if you needed help or had more questions after you left the emergency department? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Included with minor modifications. We added a “not applicable” response category for children who were admitted.</p> <p><i>Modified Question:</i> Did you know who to call if you needed help or had more questions after you left the emergency department? (Yes definitely, Yes somewhat, No, Not applicable)</p>
<p><i>Question 51:</i> Would you have liked a nurse or doctor to have spent more time with you discussing how to care for your child at home? (Yes definitely, Yes somewhat, No)</p> <p><i>Result:</i> Deleted. Like question #47, we felt that this question addressed a process and not an outcome. So, we deleted this question in favor of a modified question #49, which addresses an important outcome.</p>

Appendix 3: Item-scale correlations¹ corrected for item overlap

Question ²	Information	Emotional Support	Coordination	Respect Preferences	Timely & Attentive	Pain Mgmt	Environment	Continuity & transition
Information, communication, and education								
Amount of information (1)	0.40	0.34	0.25	0.38	0.38	0.17	0.29	0.25
Understandable answers to questions (2)	0.59	0.50	0.33	0.48	0.42	0.21	0.31	0.25
Providers always introduced themselves & explained roles (3)	0.41	0.29	0.34	0.39	0.19	0.26	0.24	0.19
Talk with child understandably (4)	0.56	0.42	0.29	0.34	0.29	0.25	0.31	0.26
Informed about next steps (5)	0.48	0.34	0.38	0.43	0.29	0.20	0.31	0.33
Explanations to child about care (6)	0.62	0.46	0.37	0.41	0.30	0.23	0.27	0.31
Emotional Support								
Calmed parent's anxieties (7)	0.51	0.70	0.50	0.52	0.40	0.33	0.40	0.31
Calmed child's anxieties (8)	0.45	0.68	0.33	0.42	0.33	0.39	0.35	0.23
Providers showed interest in child (9)	0.46	0.55	0.37	0.46	0.36	0.34	0.35	0.24
Coordination								
Doctors & nurses kept each other informed (10)	0.39	0.42	0.44	0.46	0.37	0.24	0.36	0.23
How well visit was organized (11)	0.42	0.44	0.44	0.39	0.41	0.33	0.40	0.24
Elicit and respect preferences and involve the patient and family in care decisions								
Doctors listened to parents (12)	0.49	0.48	0.37	0.64	0.41	0.30	0.43	0.31
Nurses listened to parents (13)	0.39	0.34	0.33	0.53	0.29	0.28	0.40	0.23
Parent involved in care decisions (14)	0.47	0.44	0.46	0.66	0.39	0.36	0.44	0.37
Child involved in care decisions (15)	0.50	0.46	0.40	0.74	0.41	0.37	0.49	0.33
Timely and attentive care								
Doctors spent enough time with child (16)	0.46	0.45	0.46	0.51	0.31	0.32	0.38	0.40
Waited too long (17)	0.28	0.26	0.27	0.23	0.38	0.25	0.33	0.13
How often patient was checked (18)	0.34	0.36	0.42	0.37	0.46	0.28	0.37	0.25
Pain Management								
Pain management (19)	0.24	0.39	0.33	0.36	0.32	0.60	0.40	0.16
Child distracted from procedures (20)	0.16	0.33	0.16	0.30	0.24	0.60	0.44	0.19
Safe and child-focused environment								
Made child comfortable for things other than pain management (21)	0.36	0.35	0.36	0.47	0.42	0.50	0.38	0.23
Emergency department cleanliness (22)	0.25	0.26	0.27	0.37	0.31	0.27	0.38	0.15
Continuity and transition								
Understanding care after emergency department visit (23)	0.32	0.33	0.29	0.33	0.25	0.23	0.31	0.41
Know who to call for post-visit problems (24)	0.31	0.23	0.20	0.29	0.26	0.16	0.16	0.41
¹ Correlations are Spearman's Rank Order. Bolded entries: correlations of each question with its own dimension with the question removed. Highlighted cells: instances in which questions correlate with other dimensions. ² See Table 2 for the complete wording. The parentheses contain the question number.								

Appendix 4: Factor analysis¹ results: factor loadings²

Question ³	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
Calmed parents' anxieties (7)	.783	.604	.564	.601	.421
Parent involved in care decisions (14)	.720	.634	.389	.539	.464
How well visit was organized (11)	.683	.438	.562	.412	.357
Doctors listened to parents (12)	.680	.606	.382	.652	.428
Doctors spent enough time with child (16)	.672	.578	.467	.648	.558
Explanations to child about care & treatment (6)	.667	.435	.274	.544	.422
Doctors & nurses kept each other informed (10)	.666	.411	.484	.376	.327
Providers showed interest in child (9)	.664	.553	.393	.649	.318
Nurses listened to parents (13)	.654	.550	.322	.521	.307
Pain Management (19)	.571	.516	.374	.360	.272
Providers always introduced themselves & explained roles (3)	.552	.339	.073	.399	.176
Informed about next steps (5)	.540	.262	.249	.378	.364
Child involved in care decisions (15)	.485	.735	.450	.432	.416
Made child comfortable for things other than pain management (21)	.556	.690	.502	.425	.235
Calmed child's anxieties (8)	.562	.683	.345	.591	.333
Child distracted from procedures (20)	.334	.609	.222	.315	.205
Waited too long (17)	.296	.321	.657	.301	.216
How often patient was checked (18)	.499	.422	.647	.448	.353
Emergency department cleanliness (22)	.341	.444	.465	.317	.243
Understandable answers to questions (2)	.619	.411	.435	.752	.407
Talk with child understandably (4)	.492	.532	.248	.653	.391
Amount of information (1)	.430	.394	.476	.639	.328
Know who to call for post-visit problems (24)	.290	.233	.218	.282	.662
Understanding care after emergency department visit (23)	.457	.398	.263	.462	.598
¹ Principal axis factor analysis with promax rotation					
² Bolded entries denote the highest factor loading for that question.					
³ See Table 2 for the complete wording. The parentheses contain the question number.					