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Development and Validation of a Cystic Fibrosis Patient and Family Member Experience of Care Survey

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Objective: *The purpose of this study was to develop a cystic fibrosis (CF)-specific patient and family experience of care survey that CF care centers could use to inform quality improvement efforts.*
Methods: *A literature search and query of CF care centers was conducted to identify existing surveys. Individuals with CF, their families, and health care professionals were also asked what to include. Following this process, a draft survey was developed and then reviewed by focus groups. Finally, a version was piloted at 25 CF care centers to validate and further refine the instrument.*
Results: *No CF-specific surveys were found in the literature. Focus group participants stated that they understood the survey questions and that they covered important aspects of care, particularly infection control. The pilot test of the instrument with 485 participants supported its validity by demonstrating significant differences across centers and that most of the 3 care dimensions had acceptable internal consistency (Cronbach α: adults, 0.71-0.85; children, 0.68-0.79).*
Conclusion: *A CF-specific patient and family experience of care survey was developed with input from individuals with CF, their families, and health care professionals. The instrument was validated and has been deployed to CF care centers.*

Key words: *cystic fibrosis, health care surveys, patient experience of care, quality of care*

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Cystic fibrosis (CF) is an inherited chronic life-shortening disease affecting the lungs, pancreas, liver, and intestines. Individuals with CF are challenged with various clinical manifestations, such as poor growth despite adequate caloric intake, and impaired mucociliary clearance, which leads to chronic infection and inflammation of the airways resulting in bronchiectasis.[1] Advances in screening, management, and treatment have provided individuals with CF an improved life expectancy.[2,3]

Founded in 1955, the CF Foundation's mission is to find a cure for CF and to improve the quality of life for those with the disease. The CF Foundation pursues this mission in various ways, such as supporting drug discovery and development, tracking and publically reporting medical outcomes via a patient registry, accelerating improvement in care by implementing evidence-based guidelines and quality improvement science, and advancing patient and family-centered care. The CF Foundation accredits more than 110 CF care centers in the United States and offers various resources on its Web site (www.cff.org).

The CF Foundation supported the development of a patient and family experience of care survey to provide accredited CF care centers with additional information, beyond the process and medical outcome measures reported from the patient registry, to inform quality improvement efforts. To ensure that a patient-centered, CF-specific instrument was developed, individuals with CF, their families, and health care professionals were intentionally engaged using e-mail listservs sponsored by the CF Foundation; CF care centers with patient and family advisory councils were also solicited for input. This report reviews the methods used to develop and validate a patient with CF and family experience of care survey.

METHODS

To develop and pilot test a survey, the CF Foundation engaged internal leaders, CF health care professionals, parents and individuals with CF, and experts from The Dartmouth Institute for Health Policy and Clinical Practice and from Quality Data Management (QDM). The Dartmouth team led the research and survey development effort. QDM managed the data collection process and psychometric analyses in partnership with the CF Foundation, Dartmouth, and the CF care centers.

Phase 1

The first phase of survey development involved conducting a literature search for existing experience of care instruments; querying CF care centers for copies of patient satisfaction and care experience surveys; and soliciting ideas for topics and questions from individuals with CF, family members, and health care professionals via an online questionnaire. From these sources of information, a first draft of the survey was developed targeting CF adult care.

Phase 2

Focus groups with individuals with CF and family members, in a process approved by the Dartmouth College Committee for the Protection of Human Subjects (Hanover, New Hampshire), were asked to provide feedback on the first draft of the survey. Questions were reviewed to determine whether the intended purpose and meaning were understood and whether an important aspect of the care experience was being covered. The focus group sessions were recorded and transcribed.

A new version of the survey was created as a result of the focus groups' comments. In addition, a pediatric survey to be completed by parents on behalf of individuals with CF younger than 18 years was also created. The modifications included appropriate introductory instructions and adaptations to the questions, such as "your child's care" versus "your care." Parents with more than 1 child with CF were instructed to respond with regard to the child who experienced more clinical visits or who had been hospitalized more frequently over the last 12 months. Both the adult and pediatric versions of the survey were distributed by e-mail to CF Foundation-sponsored listservs along with a Web-based questionnaire to

obtain further feedback. A third version of the survey was developed.

Phase 3

The last phase of development involved pilot testing in collaboration with 25 US CF care centers (approved by the Dartmouth College Committee for the Protection of Human Subjects). Figure 1 shows the location of CF Foundation–accredited care centers and highlights those that participated in the pilot study.

Each participating center recruited patients and family members by mail, e-mail, or during clinical encounters in the outpatient or inpatient setting. Centers were provided with template letters and documents for recruitment. To avoid duplicate responses and to identify respondents by center, each center was provided with a list of unique codes to assign and distribute. Respondents were anonymous (CF care centers did not have access to the completed survey with the unique codes and researchers did not have access to the file with patient names and assigned codes). The templates contained instructions for potential respondents to complete the questionnaire in 1 of 2 ways, via a Web-based survey or phone (toll-free line and using voice recognition software). Respondents were asked to complete the survey all at once within a 30- to 40-minute time frame.

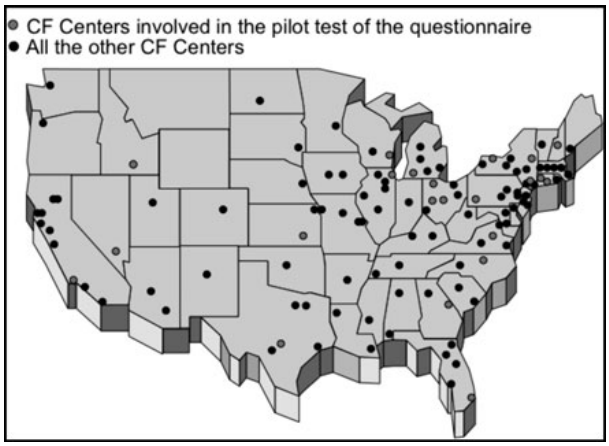

Figure 1. US map and location of CF centers and those that participated in the pilot study. CF indicates cystic fibrosis.

Analyses of pilot data

To determine whether survey questions could differentiate among CF care centers with 10 or more respondents, an analysis of means was used.[4] If a center's rate was in between the control limits, then the rate was no different than the overall rate. If a CF care center's rate crossed either the upper or lower control limit, then the rate was significantly different from the overall rate ($P < .01$).

Psychometric evaluation included average and standard deviation of the question responses, the percentage of responses at the lowest response (the floor), the percentage of responses at the highest response (the ceiling), the percentage of not answering the question (missing), and correlation of the responses of each question to the overall care experience question. To evaluate the ability to distinguish CF care centers and thereby aid in identifying both high-performing centers (for benchmarking) and centers with suboptimal patient and family care experience, we estimated a center-level standard deviation (Center SD) and center-level reliability with 45 respondents. The Center SD was calculated using variance components analysis, and the estimate considered good (ie, able to distinguish centers) if it was at least 5 points on a 0 to 100 scale. Thus, the Center SD was significantly greater than a center-level effect of a mean of zero ($P < .05$), and those between 3.5 and 5 points were marginally significant ($P < .20$). The center-level reliability was a Cronbach α for 45 respondents and was calculated by applying the Spearman-Brown prophecy formula to the variance components results (STATA, StataCorp, College Station, Texas). Cronbach α was used to test the 3 dimensions of care with acceptable values between 0.70 and 0.90.

RESULTS

Phase 1

A literature search was conducted in April 2010 and no published articles were found that specifically addressed patient with CF and family care experiences. There were questionnaires that

measured specific areas in CF care, such as health status, knowledge, attitudes, and behaviors, as well as several developed for patient satisfaction for both inpatient and outpatient settings.[5-8] An example of a widely used survey is the Hospital Consumer Assessment of Healthcare Providers and Systems for patients who had a hospital admission.[9]

The UK CF Trust and several US CF care centers shared surveys they use to obtain information on patients' care experiences. The survey from the CF Trust was the most comprehensive with respect to CF care, inquiring about satisfaction with health care professionals, facilities, infection control practices, and access to services and medications. Most of the surveys from US CF care centers were less than 15 questions and had questions relative to access, technical skills, courtesy of health care workers, and overall satisfaction. Other surveys were longer and covered these same areas as well as questions about experience with other services (mental health, social work, nutrition, etc), hospital care, information sharing, and disease management.

Finally, input from individuals with CF, family members, and health care professionals were obtained through a Web-based survey deployed via CF center directors serving on the CF Foundation Center Committee. Sixty-six individuals with CF and family members completed this survey, providing 215 suggested questions. These questions were grouped into common themes, including infection control, timeliness of care, disease management, up-to-date information, and answers to care questions. Seventy health care professionals provided 252 suggested questions. Top themes were similar to those of individuals with CF and families, but health care professionals also wanted feedback on what needed to be improved and what worked well. Table 1 lists the 5 top themes and some of the respondents' suggested questions.

The potential questions obtained from these sources were collated into 7 domains: demographics, biological health, functional health, care at the center, satisfaction, hospital, and costs. Within the domains there were 79 themes and a total of 471 possible questions.

The first draft of the survey contained 68 questions within 5 dimensions: experiences with the CF center, care plan, home care, hospital, and demographic characteristics. Questions were framed relative to the last 12 months, since the CF Foundation was interested in an annual data collection protocol and recommends patients visit their CF care center 4 times a year. Most of the questions were framed as reporting the frequency of an experience instead of rating the satisfaction of the experience. For example, "During your visits to the CF center in the last 12 months, how often did the clinical staff explain things in a way you could understand?" Response choices were *never*, *sometimes*, *usually,* and *always* (the final survey had response choices that also included *almost always* and *almost never*).

Phase 2

Five CF care centers recruited individuals with CF and family members to participate in a focus group to obtain input on the first draft of the questionnaire. Four focus groups and 2 personal interviews were held using a phone conference line with a total of 18 participants. Eleven of the participants were parents of a child (or children) with CF and the other 7 were adults with CF. They had 1 to 30 years of experience with CF. The focus groups and interviews lasted 60 to 90 minutes. Participants provided an abundance of helpful advice to improve the draft survey. As an example, Table 2 lists 2 questions on the survey and the feedback we received. Participants also shared other concerns, such as observations of disorganization of the process of care and receiving contradictory advice from different providers within a CF care center and from the patient's primary care provider. They were curious as to how information obtained in a future survey would be used and delighted to learn that they would have an opportunity to praise and provide suggestions for improvement via a survey.

Eight participants assessed the revised adult version of the survey and 22 participants assessed the revised child version via the Web-based questionnaire distributed by CF Foundation e-mail listservs. Supportive comments were shared, such as

Table 1

TOP 5 THEMES OBTAINED FROM PATIENTS, FAMILY MEMBERS, AND HEALTH CARE WORKERS ON WHAT QUESTIONS THEY WOULD LIKE TO SEE ON A CF CARE EXPERIENCE SURVEY

Patient and Family Member	Health Care Worker
What questions would you want to ask patients with CF or family members to learn about their experiences in receiving care at the CF center outpatient clinic?	
Infection control	*Would change*
"Do you feel your Center (exam room and waiting area) is a clean environment?"	"What can we do to improve?"
"Are you concerned with infection control?"	"If you could change 3 things about your CF care you are receiving, what would they be?"
"Do you think the level of infection prevention is high enough?"	"What area could we do better in?"
Timeliness	*Worked well*
"Did you feel you were promptly served?"	"What is the best aspect of coming to clinic?"
"Do you find that your clinic experience takes the appropriate amount of time?"	"What do you find most helpful about your clinic visits?"
"How long do you sit around and wait?"	"What is the best thing about your experience with us?"
Disease management	*Information needs*
"How does the CF Center help you prepare for transition to self-care?"	"Do you feel you get enough information from the team?"
"What symptoms need to be addressed right away and what can wait until clinic hours?"	"Are you given enough information about your disease and your treatments?"
"What is your exercise activity and how much can you do?"	"Do visits increase understanding of CF situations?"
Up to date	*Timeliness*
"Do you feel your CF team is knowledgeable about current treatments and clinical trials?"	"Is your wait time too long?"
"Do you feel you are given up-to-date information?"	"When you come to clinic, do you have enough time with the nurse? Doctor? Social worker? RT? Nutritionist?"
"Whether they received new information and became better educated during each visit."	"Did you receive timely care?"
Answered questions	*Understand information*
"Do you feel that your questions are answered to your satisfaction?"	"Do you understand the information given to you by the team? If no, how can we help you understand better?"
"The clinic keeps an open forum for parents, patients, specialist, and clinic nurses. The forum allows parents to communicate, ask questions, and get answers."	"Do you understand why the treatment plan was prescribed?"
"Do you feel your or your child's questions are answered thoroughly and at the level that is commensurate with your or your child's ability to understand them?"	"Do you feel that new treatments are explained in an easy to understand manner?"

Abbreviation: CF, cystic fibrosis.

Table 2

FOCUS GROUP RESPONSES TO DRAFT QUESTIONS ON THE PATIENT AND FAMILY CARE EXPERIENCE SURVEY

In the last 12 mo, not counting times you needed health care right away, how often did you get an appointment as soon as you wanted?
☐ Never
☐ Sometimes
☐ Usually
☐ Always
Participants' responses
Patients have scheduled appointments, so this question did not make sense to most participants: "It's been probably ten years since I've scheduled an appointment that have already been scheduled because they schedule my follow or check-ups when I leave so I've never had to schedule any."
"Is there a question in there about sick appointments because I have personally had some minor issues, not counting the regular two month appointments but when I had some concerns that something might be happening with my daughter I'll often hear well let's just wait and see and unless I kick and scream I'm not likely to get an appointment. I'm not talking urgent we're talking I would feel better, I would like someone to listen to her, is there a question that pertains to that situation?"
"I think that's an issue with adult patients with full time jobs, I think the fact is that your care has to come first and well if you can get out of your job that would be good but and have a full life as an adult patient is not having like somewhat indiscriminate halfway considerate schedule with appointments. To me its an unnecessary nuisance like why do I have to have appointments at 2:00 in the afternoon. So I think somehow maybe you could add that in someplace that's true for parents of kids it's a lot of burden on them and then if they have to constantly get out of work so I just think that if there's some question that could speak to that issue that would be good."
"Access to care with them has never been an issue. I know the patient education day [the doctor] brought that up—that some people do have an access issue but I didn't quite understand the issue he was making because in our experiences it has always been something very different and the access has always been fantastic."
In the last 12 mo at the CF center, how often were you encouraged to wash your hands or use antibacterial gels?
☐ Never
☐ Sometimes
☐ Usually
☐ Always
Participants' responses
"I was not encouraged to wash my hands; I don't remember actually ever being encouraged to wash my hands in Clinic. It definitely is an important question and also one thing I like to see is whether they've washed outside I don't know but all of our rooms have sinks in them and I like to see the professionals wash each time they come in the room."
"It should be on there because nobody's ever asked me if I washed my hands."
"I'm going to say never because at our Center when you check-in at the lobby you're given a mask and gloves so we put our gloves and mask on."
"The question might be better asking what procedures do you have for infection control and to find out what people are doing and have choices are you being asked to use anti-bacterial jells or you know, mask and glove, just several choices."

Abbreviation: CF, cystic fibrosis.

"Thank you so much for looking into the CF care experience and allowing me to have this opportunity to express my concerns," and "The survey captures a good majority of my CF care experience." The survey was shortened, eliminating redundant questions (same concept but worded differently), new questions were added to evaluate individual team members, and questions were rephrased for clarity. Figure 2 shows an example of the process of refining a care experience question.

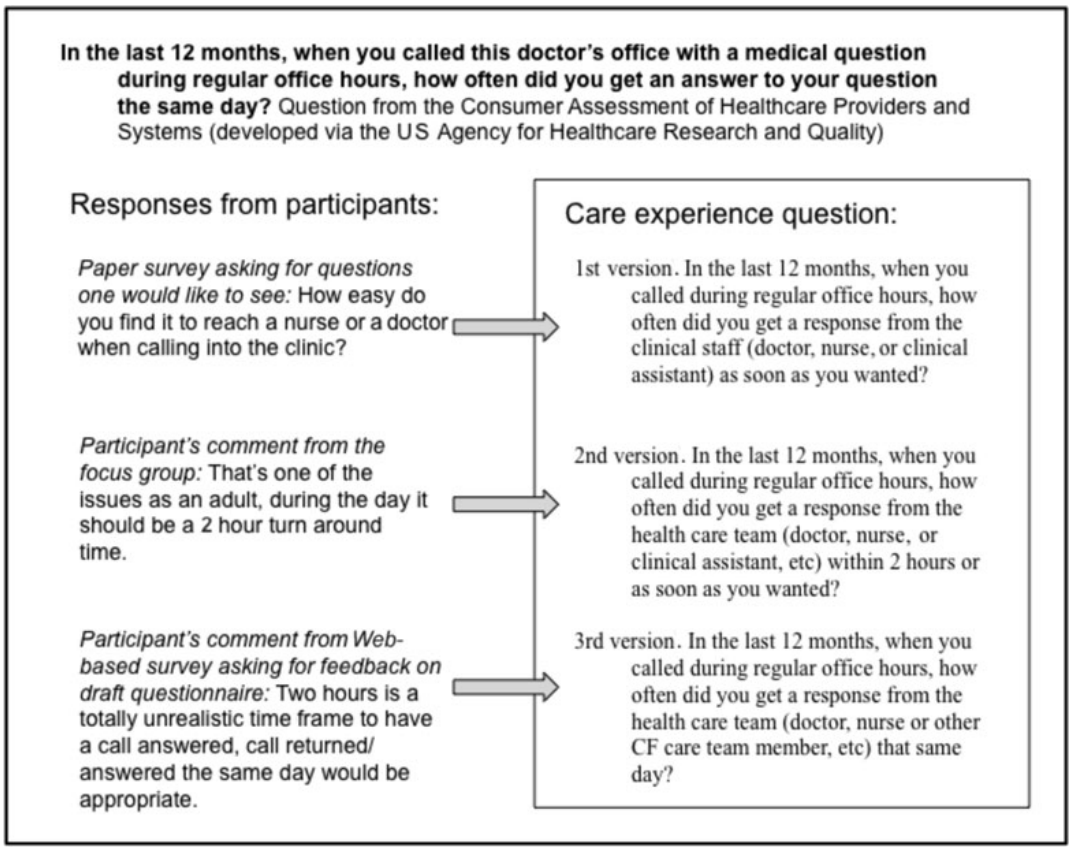

Figure 2. The process of refining a care experience question through the feedback from patient and family members. CF indicates cystic fibrosis.

Phase 3

A pilot test was conducted with 25 CF care centers (see Figure 1). Two hundred thirty-six respondents completed the adult survey and 249 respondents completed the pediatric survey. The response rate (completed survey divided by number of patients enrolled at the CF care centers) was 17% for the adult survey and 12% for the pediatric. The center response rate varied from 3% to 23%. Ninety-one percent of the respondents completed the Web-based surveys and 9% by phone.

Table 3 shows the demographic and health characteristics obtained from the completed surveys and the CF Foundation registry data for the patients seen at the centers who participated in the pilot study. The adult survey respondents had slightly more females than males. For the adult survey, 58% were 34 years of age or younger and for the pediatric survey, 63% were 6 years of age or older. The group of adult respondents was well educated with 52% having a college or postgraduate degree. The majority of the respondents (63% for adults and 74% for pediatrics) had private insurance. Half of the adult respondents and 44% of the pediatric respondents reported spending greater than $1000 for out-of-pocket CF medical care in the last 12 months. Forty percent of the adult and 78% of the pediatric respondents rated overall health as *excellent* or *very good*. Sixty-one percent of the adult and 80% of the pediatric respondents rated their emotional health as *excellent* or *very good*. Thirty percent of the adult and 8% of the pediatric respondents reported that they have CF-related diabetes and 9% of the adults reported their body mass index as underweight. Half of the adult and 10% of the pediatric respondents reported

Table 3

RESPONDENTS' DEMOGRAPHIC AND HEALTH CHARACTERISTICS FROM THE ADULT AND PEDIATRIC SURVEYS AND THE DISTRIBUTIONS FOR THE PARTICIPATING CENTER USING THE 2010 CYSTIC FIBROSIS FOUNDATION REGISTRY[a]

	Survey		CF Registry 2010	
	Adult, n = 236	**Pediatric, n = 249**	**Adult, n = 2681**	**Pediatric, n = 3054**
Female	59% (129)	51% (121)	49% (1306)	50% (1520)
White[b]	92% (196)	91% (215)	92% (2477)	87% (2665)
CF-related diabetes[b]	30% (67)	8% (19)	36% (931)	11% (333)
Age[b,c]				
<1 y		4% (9)		4% (110)
1-5 y		33% (78)		27% (839)
6-10 y		27% (63)		22% (663)
10-15 y		27% (63)		36% (1088)
16-17 y		9% (20)		12% (354)
18-24 y	22% (48)		42% (1114)	
25-34 y	36% (78)		34% (905)	
35-44 y	19% (40)		15% (398)	
45-54 y	13% (27)		7% (178)	
55-64 y	8% (18)		3% (69)	
≥65 y	2% (4)		1% (17)	
Education[b]				
Less than high school	3% (6)		7% (166)	
High school diploma or equivalent	15% (32)		21% (484)	
Some college or 2-y degree	30% (65)		36% (830)	
College graduate	26% (57)		32% (728)	
>4-y college degree	26% (57)		4% (86)	
Insurance[c]				
Private Insurance	63% (133)	74% (172)	66% (1729)	59% (1809)
Medicaid or Medicare	29% (62)	19% (44)	26% (676)	35% (1047)
Other	8% (17)	6% (15)	8% (276)	6% (198)
Out-of-pocket CF costs				
<$200	20% (41)	22% (48)		
Between $201 and $600	19% (39)	21% (46)		
Between $601 and $1000	11% (22)	13% (28)		
>$1000	50% (100)	44% (96)		
Visits to center in last year[b,c]				
≤2	14% (31)	5% (12)	27% (704)	11% (319)
3	19% (42)	9% (21)	17% (444)	14% (414)
4	27% (60)	30% (72)	18% (459)	24% (713)
5-9	31% (68)	46% (112)	32% (819)	47% (1413)
≥10	8% (18)	11% (26)	6% (151)	6% (168)
Receiving care at center				
<2 y	10% (22)	21% (51)		
2-5 y	21% (47)	27% (66)		
6-10 y	16% (36)	22% (54)		
>10 y	53% (118)	30% (72)		

(*continues*)

Table 3

RESPONDENTS' DEMOGRAPHIC AND HEALTH CHARACTERISTICS FROM THE ADULT AND PEDIATRIC SURVEYS AND THE DISTRIBUTIONS FOR THE PARTICIPATING CENTER USING THE 2010 CYSTIC FIBROSIS FOUNDATION REGISTRY[a] (*Continued*)

	Survey		CF Registry 2010	
	Adult, n = 236	**Pediatric, n = 249**	**Adult, n = 2681**	**Pediatric, n = 3054**
BMI				
Underweight (<18.5 kg/m^2)	9% (19)		10% (210)	
Normal weight (18.5 to <25 kg/m^2)	73% (160)		67% (1455)	
Overweight or obese (≥25 kg/m^2)	18% (40)		24% (519)	
FEV_1[c]				
25-45	25% (47)	7% (11)	24% (599)	3% (53)
46-63	26% (48)	3% (5)	23% (577)	6% (115)
64-82	26% (48)	12% (18)	26% (653)	16% (331)
83-100	17% (31)	37% (55)	21% (525)	39% (787)
101-120	7% (13)	39% (58)	7% (176)	36% (739)
Overall health				
Excellent	10% (23)	36% (87)		
Very good	30% (67)	42% (104)		
Good	40% (89)	17% (42)		
Fair	16% (36)	3% (8)		
Poor	4% (8)	2% (4)		
Emotional health				
Excellent	19% (42)	45% (110)		
Very good	42% (94)	35% (84)		
Good	24% (53)	14% (33)		
Fair	14% (31)	6% (14)		
Poor	2% (4)	1% (2)		

Abbreviations: CF, cystic fibrosis; BMI, body mass index; FEV_1, forced expiratory volume in the first second percent predicted.
[a]Percents do not include missing responses.
[b]For adult significant difference of distributions between the survey and CF registry using a contingency table χ^2 test.
[c]For pediatric significant difference of distributions between the survey and CF registry using a contingency table χ^2 test.

forced expiratory volume in the first second percent predicted (FEV_1) below 64%. Two-thirds of the adult and 86% of the pediatric respondents had 4 or more visits to their center in the last year. Sixty-nine percent of the adult respondents had been receiving care at the same CF care center for 6 or more years.

The adult respondents are similar in distribution to the patient population at the CF centers relative to gender, insurance, body mass index, and FEV_1. The pediatric respondents are similar relative to gender, race, CF-related diabetes, and education. Other characteristics showed significant differences in the distributions. For example, 14% of the adult respondents had 2 visits or less to a CF care center in the last year whereas the registry data report that 27% of adults at all care centers attend 2 or less visits annually. A similar pattern was seen in the pediatric survey (5% of survey respondents and 11% over all CF centers attended 2 or less visits annually). The registry of patient with CF had 2681 adult patients and 3054 pediatric patients from the pilot centers, so small differences could be significant.

Questions were grouped into 3 dimensions of care experience: access to care, health team care, and self-care. The dimension of access contained questions about timeliness of services, such as "Did the

appointment start within 15 minutes and received care as soon as needed?" Examples of the health team care questions were as follows: "Whether a team member asked about mental health?" "Whether they spent enough time with you?" and "Were you involved in the decisions about care?" The dimension of self-care contained questions about managing CF and level of confidence for various tasks. Figure 3 lists the 3 dimensions of care and the questions (abbreviated) with the positive responses (2 top

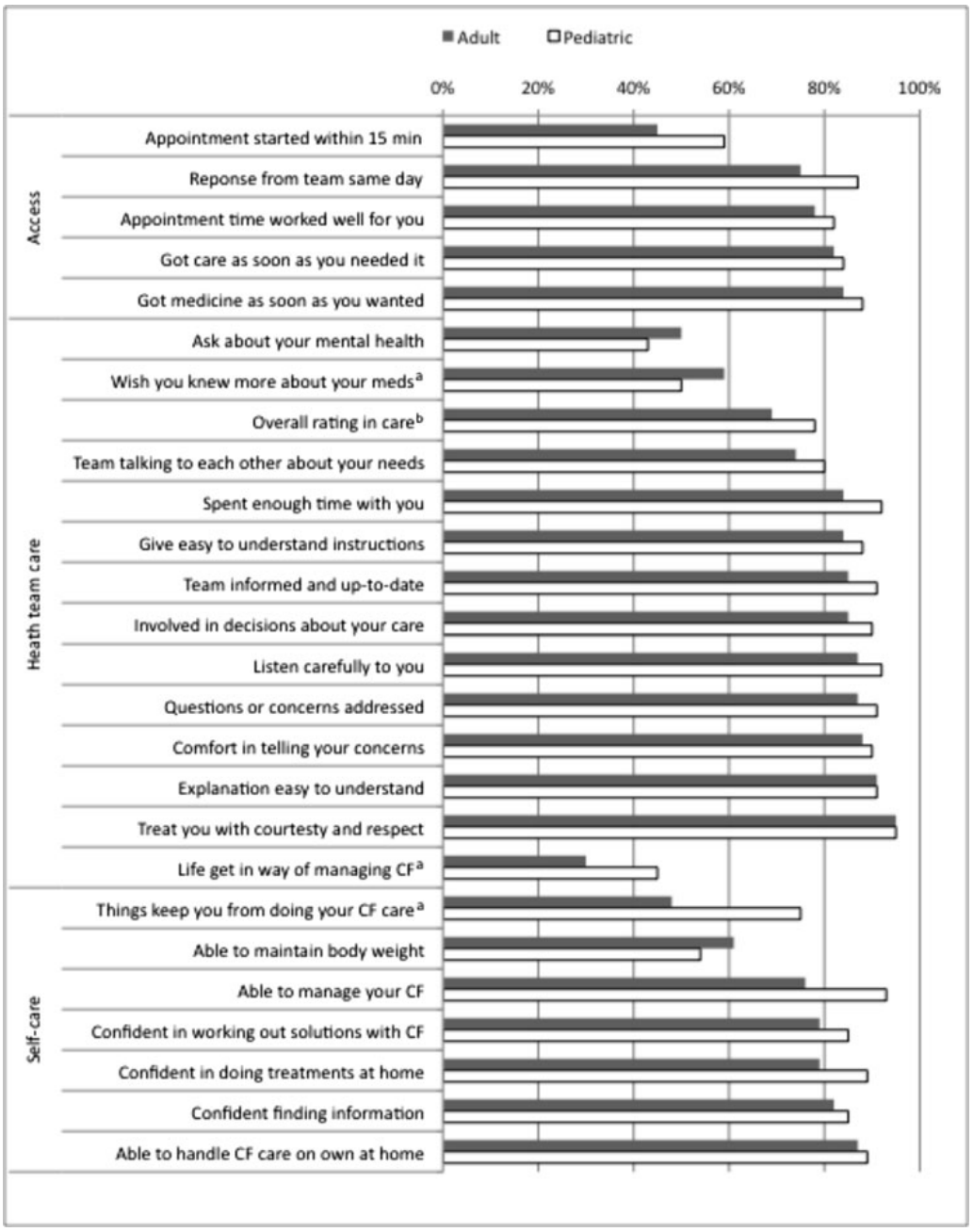

Figure 3. Percentage of positive responses (*always* or *almost always*) for questions listed by dimension of care experience for both adult and pediatric surveys. [a]Negatively worded question thus positive response was *never* or *almost never*. [b]Best = 10 and worst = 0; percent positive was 9 or 10. CF indicates cystic fibrosis.

response choices of *always* or *almost always*) from the adult and pediatric surveys. The top rated question was 95% of the respondents (both adult and pediatric) *always* or *almost always* thought that the health care team treated them with courtesy and respect. The following are adult survey results for questions not listed in Figure 3:

- Most respondents saw a doctor and nurse, whereas 13% of the respondents saw a physical therapist.
- Sixty percent of the respondents thought their airway clearance therapy and 75% thought their lung medicines *always* or *almost always* worked.
- Fifty-three percent of the respondents spent less than 2 hours per day on treatments.
- Eighty percent of the respondents reported that they had a lung infection within the last year.
- Twenty-six percent of the respondents had at least 1 emergency department visit and 43% of the respondents had at least 1 hospital admission.

Center comparison

For the adult survey, 10 of the 25 CF care centers had enough respondents to evaluate differences among the centers using analysis of means. Figure 4 displays each center's percentage of positive responses for the question, "How often did the care team treat you with courtesy and respect?" The overall rate for the 10 centers was 96%, with the range from 73% to 100% for 6 centers. The rate of 73% for Center 22 was below the lower control limit and thus considered a significant result. The other 9 center rates, from 92% to 100%, were within the control limits and may be considered within random variation.

Table 4 lists center comparison results for 7 questions from the adult survey that showed significant differences. These results suggest that CF care centers have different health care resources available to their patients (some CF care centers do not have consistent availability of a specific therapist), have different infection control practices, different health care team results, and a different use of therapies. The pediatric survey had 6 questions that had differences across 11 CF care centers: health care resources, infection control, medicine refills, and number of times child accessed center (results not shown).

Psychometric evaluation

Table 5 reports the 3 dimensions of care experience questions from the adult survey and the psychometric properties. The average for most questions was above 75 (score transformed from 0 to 100). The questions were answered by most of the respondents except for 2 questions: *care as soon as you needed it* (missing 19%) and *team talking to each other about you* (missing 14%). Most of the access and health team care questions had a medium correlation (between 0.30 and 0.80) with the overall rating of care question. The question reporting on *how often did the appointment time work well for you* had a correlation of 0.63 and thus accounted for 40% of the variance in the overall rating of care question. Most of the self-care questions had weak correlations with the overall rating of care question, which was the expected result. For example, the question of *how often do things keep you from doing your CF care* had a 0.03 correlation with the overall rating of care question and we would expect that care received at the center would most likely have insubstantial association with CF care issues at home. To evaluate the ability of a question to distinguish centers, the last 2 columns in Table 5 show the Center SD and the center-level reliability that would be observed with the SD estimated with 45 respondents per center. Five survey questions (*appointment started within 15 minutes*, *team talking to each other*, *ask about your mental health, able to manage CF*, and *able to handle CF*) had a Center SD above 5 points, and these questions also had good reliability ($\geq$0.70) along with 3 other questions (*listen carefully, spent enough time with you*, *and questions or concerns addressed*). There were 10 questions that had small Center SD estimates and low reliability (Center SD $<$2 or 0, which were represented as blanks in Table 5). The child survey psychometric evaluation had similar results (results not shown).

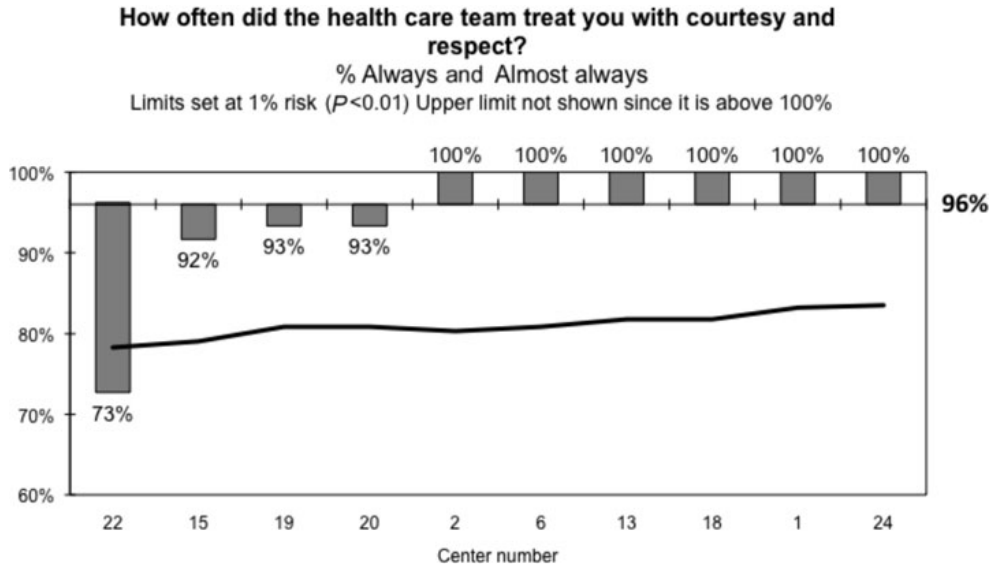

Figure 4. Analysis of means chart showing center comparison result for the respect and courtesy question on the adult survey. X-axis crossing y-axis at the overall rate of 96%. Black line is the lower control limit. Center 22 exhibited a rate (73%) below the lower limit, thus a significant result. Center number was randomly assigned.

Table 4

SIGNIFICANT CENTER COMPARISON RESULTS FROM THE ANALYSIS OF MEANS CHARTS FOR THE 10 ADULT CENTERS THAT HAD 11 OR MORE RESPONDENTS[a]

Survey Question	Center # (Respondents)	Center's Rate	Overall Rate
Seen RT (% yes)	Center 6 (15)	20%▼	62%
Seen SW (% yes)	Center 13 (17)	35%▼	78%
	Center 22 (11)	9%▼	
Health care team treats you with courtesy and respect (% always or almost always)	Center 22 (11)	73%▼	96%
Health care team listens carefully to you (% always or almost always)	Center 22 (11)	55%▼	87%
Infection control: I was asked to wash my hands or use hand gels (% yes)	Center 24 (22)	14%▼	51%
Infection control: I was asked to put on mask, gown, or gloves (% yes)	Center 2 (12)	29%▼	49%
	Center 22 (11)	0%▼	
	Center 24 (22)	91%▲	
Airway clearance treatments have worked (% always or almost always)	Center 6 (14)	14%▼	62%

Abbreviations: RT, respiratory therapist; SW, social worker.
[a]Symbol ▼ represents that center's rate was less than overall rate and symbol ▲ represents that the center's rate was greater than overall rate. Center number was randomly assigned.

Table 5

PSYCHOMETRIC PROPERTIES FOR THE CARE DIMENSIONS FOR THE ADULT SURVEY

	Mean (SD)	Floor %	Ceiling %	Missing %	Correlation With Overall Rating	Center SD	Center Reliability
Access							
Response from team same day	80 (21)	0	39	1	0.47	4.39	0.66
Appointment time worked well for you	85 (20)	0	52	1	0.63		
Got care as soon as you needed it	86 (19)	0	58	19	0.6	3.71	0.62
Appointment started within 15 min	64 (26)	3	17	0	0.41	6.81	0.75
Got medicine as soon as you wanted	86 (19)	0	56	3	0.48	2.67	0.46
Heath team care							
Treats you with courtesy and respect	95 (12)	0	82	0	0.65		
Listens carefully to you	90 (17)	0	69	0	0.68	4.30	0.74
Explanation easy to understand	91 (16)	0	67	0	0.6	3.02	0.62
Team talking to each other about your needs	78 (26)	3	45	14	0.35	6.38	0.73
Spend enough time with you	88 (19)	0	63	1	0.66	4.80	0.75
Ask about your mental health	65 (31)	8	24	2	0.31	9.37	0.80
Give easy to understand instructions	87 (19)	0	59	1	0.48	3.32	0.58
Team informed and up-to-date	88 (20)	1	62	3	0.65	3.03	0.51
Questions or concerns addressed	90 (18)	0	69	3	0.56	4.67	0.75
Overall rating in care	89 (14)	0	45	4	1	1.40	0.31
Comfort in telling your concerns	90 (17)	0	70	1	0.51	4.58	0.76
Wish you knew more about your medications[a]	72 (22)	3	19	2	0.28		
Involved in decisions about your care	88 (18)	0	61	3	0.48	1.55	0.25
Self-care							
Confident finding information	85 (19)	0	51	9	0.57		
Life get in way of managing CF[a]	62 (19)	2	7	4	0.06		
Able to manage your CF	80 (16)	0	27	5	0.1	5.32	0.84
Confident in working out solutions with CF	83 (17)	0	38	6	0.24		(*continues*)

Table 5

PSYCHOMETRIC PROPERTIES FOR THE CARE DIMENSIONS FOR THE ADULT SURVEY (*Continued*)

	Mean (SD)	Floor %	Ceiling %	Missing %	Correlation With Overall Rating	Center SD	Center Reliability
Able to handle CF care on own at home	87 (17)	1	51	5	0.05	5.81	0.84
Able to maintain body weight	75 (26)	2	37	7	0.09	4.22	0.54
Things keep you from doing your CF care[a]	70 (22)	2	19	7	0.03		
Confident in doing treatments at home	85 (18)	0	50	4	0.23		

Abbreviation: CF, cystic fibrosis.
[a]Negatively worded questions reverse-coded.

The final survey

Based on the center comparison and psychometric evaluation, some questions were eliminated. For example, 7 questions pertained to hospitalizations, which 97 of 225 respondents (43%) experienced; however, there were not enough respondents to allow center comparisons. The question of *how often were hospital staff knowledgeable about CF care* was a major concern mentioned by several focus group participants and remained in the final survey.

Some questions were eliminated because of low variation across CF care centers; such as, if respondents had a lung infection they, were then asked whether their lung function returned to previous levels. Most of the adult (83%) and pediatric (85%) respondents chose *definitely yes* or *somewhat yes*, and there were no significant differences among the CF care centers.

Based on the psychometric analysis, some questions were eliminated because they did not have adequate psychometric properties (eg, too many missing responses). For example, the question, "How often did you think the health care team members were talking to each other about your health care needs?" was eliminated because it did not have adequate psychometric properties, did not show differences across the CF care centers, and focus group participants thought that this question may confuse respondents.

From the 68 questions in the pilot test survey, then, a final survey was created containing 50 questions. (As an example, the final adult version can be seen in the appendix.) There are 33 care experience questions, 2 hospital questions, and 15 demographic questions. The survey takes approximately 10 to 15 minutes to complete. Cronbach α was used to determine the internal consistency or homogeneity of the questions, which aids in evaluating whether the questions are measuring the same concept. Cronbach α values for the 3 care dimensions of access, health team, and self-care were 0.74, 0.85, and 0.71, respectively, for the adult survey and 0.69, 0.79, and 0.68, respectively, for the pediatric survey (Cronbach $\alpha > 0.7$ indicates good internal consistency).

DISCUSSION

Patient experience was reported as a top priority from health care leaders across US hospitals.[10] The patient with CF and family experience of care survey can help care centers pinpoint areas for improvement efforts.

The survey was developed with input from health care professionals, individuals with CF, and family

members, who expressed support for the survey and shaped the content. It was clear, based on our ongoing contact with the CF community, that an off-the-shelf survey would not accurately reflect the experience of care received by patients with CF and their family members. Results suggest that the survey has substantial face and content validity. In addition, the results showed discriminant validity in which some questions could differentiate CF care centers.

Patients and families expressed strong opinions about some of the issues covered. For example, it should be noted that infection control was an important issue for most individuals with CF and family members (focus group and the surveys).[11] In a study conducted by Miroballi and colleagues[12] to understand CF patients' and family members' infection control knowledge, attitudes, and practices, 65% of the respondents were aware of the infection control guidelines.

Another important issue in CF care is treatment burden. A study by Sawicki and colleagues[13] reported that adult CF respondents from their survey spent an average of 108 minutes (with a standard deviation of 58 minutes) on daily CF treatments, which agrees with our finding that 47% of adult respondents reported that they spend more than 2 hours on treatments. Another area of interest in CF care is depression and anxiety, which are common among individuals with CF ranging from a quarter to almost one-half of adults with CF.[14] Although the care experience survey does not contain depression screening questions, 16% of the adult respondents rated overall mental or emotional health as *fair* or *poor*.

Finally, pulmonary exacerbations are associated with worsening of lung function.[15] The CF Foundation Patient Registry Annual Data Report states that 45% of adults had at least 1 pulmonary exacerbation in 2010 (defined as treatment in the hospital and/or at home with a course of intravenous antibiotics).[3] Our care experience survey had a broader definition of pulmonary exacerbation in which respondents were asked: *Did you have a lung infection (pulmonary exacerbation) or have any of these symptoms: shortness of breath, being really tired, coughing more?* Eighty percent of adults reported having a pulmonary exacerbation, in which 52% of these respondents had at least 1 hospital admission.

Limitations

One of the limitations of the survey was the low response rate. We identified several factors that may have adversely influenced response rate. The testing of the survey was done during the summer months and due to various commitments from the potential respondents the survey was not completed. The process of getting patient and family contact information from the CF care centers to QDM proved to be cumbersome and ultimately had to be altered so that the burden of recruitment was placed on the CF care centers. The switch in ownership of the recruitment process caused delays and the local recruiters may not have completely understood the purpose of piloting the patient experience survey. Finally, the individuals with CF and family members who received an invitation to complete a survey were provided a unique access code to use when completing the survey, which could have been lost or simply added to the burden of the survey. In addition, some potential respondents could have been worried that the survey was not truly anonymous and therefore chose not to participate. Because of the low response rate, not all the CF care centers that recruited patients could have their results compared with overall results, and these centers could not be included in the analysis of means.

Another limitation pertains to the pediatric survey. Most of the questions on patient experience ask how often you and your child observed a specific behavior. It is not known how the adult answering the survey for the family might have responded to questions for which the adult and the child had different observations or different opinions.

There were several areas that some participants wanted to include on the survey, such as lung transplant issues, an evaluation of home health care services, transition issues from pediatric to adult care, and transferring responsibility of CF care to the child/teenager (eg, making appointments, doing lung clearance, diet) which were not included. Thus, the

patient and family member experience of care survey does not cover all aspects of care that may be important.

Strengths

A strength of the development of the survey was that 25 CF care centers from across the United States recruited patients and family members, which promotes the generalizability of the results. The same is true for 5 diverse CF care centers that recruited patient and family members for focus groups. We heard from people from various parts of the country and also used e-mail listservs to garner feedback. Although we have no specific data on where these sources live, it did provide various inputs to construct a patient-centered survey.

We provided a report back to the 25 CF care centers on the pilot test results. We sent each CF care center a thank you letter, a technical report of the findings, a summary report of the findings (adult and pediatric summaries), and a center-level report. The center-level report showed whether each question was significantly different from the overall results and the technical report showed center comparison results. Within a week of receiving this packet of information, we asked health care professionals, individuals with CF, and family members for their feedback on the reports. Most of the feedback was positive; professionals who responded reported that they needed to work on infection control, hospital care, and to explain things better.

Plans call for the patient and family experience of care survey to be used with 30 CF care centers in 2012, as part of their reaccreditation process. In addition, the results from the surveys will be reviewed along with registry data from these CF care centers by the CF Foundation. Eventually, the goal is to collect this information annually for all CF care centers to track and improve the patient and family member experience of care.

CONCLUSION

Through CF Foundation leadership and in collaboration with CF centers and numerous individuals with CF and their families, we were able to develop a CF patient and family experience of care survey. The information derived from the survey will provide another dimension of quality to complement the process and medical outcomes reported from the patient registry. This work represents the CF community's ongoing commitment to improve and provide exemplary care for all individuals with CF.

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