

Original Article

Experience of care from the perspective of individuals with cystic fibrosis and families: Results from 70 CF Foundation accredited programs in the USA



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Abstract

Introduction: In 2012 and 2013, 30 adult and 40 pediatric CF Foundation-accredited programs across the United States recruited patients and families to complete an experience of care survey. This paper reports the positive attributes and the opportunities for improvement in CF care from the perspective of individuals with CF and families.

Methods: Patients and families completed the survey by web, interactive voice response, or with the help of a telecommunication professional. Funnel plot was used to determine positive attributes and improvement opportunities. Chi-square tests and 95% confidence intervals were used to determine differences between group and logistic regression models were used to determine factors associated with the experience of “best” care.

Results: 2090 adults with CF or parents of children with CF, 29% of the 7113 potential respondents, completed a survey. Both the adult and pediatric survey respondents reported the same 5 positive attributes of experience of care: courtesy and respect shown, easy to understand explanations, involved in decision-making, their questions were answered, and enough time with providers. Potential areas for improvement included assessing mental health and improving inpatient hospital staff’s knowledge of CF. In general, results from the pediatric survey were significantly better than the adult survey. Variables predictive of “best” care experience from both adult and pediatric respondents were treatments always working and two self-care factors of finding information and working out solutions.

Conclusion: The CF Foundation developed an experience of care survey to systematically collect and learn directly from individuals with CF and families about their impressions and observations of CF health care delivery. Respondents reported positive and respectful experiences and improvement opportunities were identified, which can help programs target specific areas to enhance the care experience.

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Keywords: Patient experience of care; Quality improvement; Survey

1. Introduction

A well-documented method to help health care systems determine areas for improvement is to understand the perspective of patients and families by way of surveys, such as the Clinician & Group Consumer Assessment of Healthcare Providers and Systems survey (CG-CAPHS) [1]. The US Cystic Fibrosis (CF) Foundation supported the development and validation of a patient

and family experience of care survey, which consists of 50 questions, mostly direct reports of care experience and disease management over the last 12 months [2].

Typically people living with CF, an inherited life-shortening, chronic disease, obtain preventive and chronic care on a quarterly basis and acute care as needed usually at an accredited CF center. The CF Foundation accredits CF care centers that meet criteria such as a multidisciplinary team, age-appropriate care, and access to specialists. The majority of care centers are based at academic medical centers and comprised of pediatric and adult programs. After the CF Foundation has accredited CF centers, they are visited at least once every 5 years for an assessment of all facets of a care center including personnel, facilities, departmental and

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institutional support, chart audit, and center-level outcomes from the patient registry. This peer review process is to support the best possible care for individuals with CF and is part of the CF Foundation's long history of supporting improvement work at the frontlines of care through a patient registry [3], professional development [3,4], benchmarking [5], improvement collaboratives [3], and encouraging partnerships between patients and families and care teams [6,7]. These strategies have enabled CF care centers to engage in leading improvement work to produce better system performance and patient outcomes [7–21]. The patient and family member experience of care survey was envisioned as another means of facilitating quality improvement by learning directly from patients and families about their impressions and observations about their CF care.

The aim of this quality improvement activity was to identify the positive attributes and improvement opportunities in CF care and to understand any unique differences between adult and pediatric respondents. Such information could help CF centers develop strategies to improve patient and family experience of care. We report on the most up-to-date and complete assessment of CF care experience in the US.

2. Methods

The description of the patient and family experience of care survey has been previously published [2]. For further information of the specific data collection protocol and survey refer to the online Methods & Results Supplement. The accredited CF care centers mostly consist of a pediatric program and an adult program. Some CF centers oversee smaller affiliate programs, which meet clinical criteria, but not teaching and research criteria to become a full care center. CF programs were invited to participate in the survey in conjunction with CF Foundation reaccreditation site visit. Thirty of 50 adult programs and 40 of 69 pediatric programs agreed to participate and assisted in recruiting 7113 individuals with CF or a parent with a child with CF to complete an experience of care survey. Survey data was collected between September 2012 and December 2013.

2.1. Analysis

Chi-square test was used to compare the respondents' demographic characteristics to the patient population at the participating programs using data obtained from the CF Foundation Patient Registry (CFFPR). Due to the large patient populations a probability value less than 0.01 was used to define a significant difference.

A survey question's responses were dichotomized to distinguish the responses of the positive categories from all other responses to obtain the percentage of positive responses (blank and not applicable were not included in denominator). A funnel plot was used to determine survey question results significantly above or below the overall result (3-sigma control limits indicates outliers). To determine differences between the adult and pediatric surveys, 95% confidence intervals (CI) were used.

A multivariable logistic model was used to determine variables predictive of best experience of care (overall care by the health care team was assigned "1" if respondent chose 10 from a scale of 0 to 10). Variables having a probability of less than 0.10 from the bivariate logistic analyses (see Methods & Results supplement file) and a variance inflation factor less than 2.5 (2.5 or greater represents a variable having too many correlations with other variables in the model and can impact the results of the model) were entered into the model using a web-based logistic regression building tool (<http://www.jeffreysmorrison.net/default.aspx>). Variables used to adjust the model were overall health, mental health, 4 or more visits, CF related diabetes (CFRD), and hospital stay. Variables that had missing responses or not applicable were excluded from the model. Two models were built for each version of the survey, which offered an opportunity for validation and a reduced likelihood of spurious associations.

3. Results

A total of 70 programs participated, 30 adult and 40 pediatric and 7113 individuals or families were invited to participate in the survey representing 26% of the 27,000 consented to participate in the CFFPR [22]. 839 adults, 28% of invitees, completed the adult survey and 1251 parents, 30% of invitees, completed a pediatric survey. The refusal rate for the adult survey was 14% (430 patients) and the pediatric survey was 13% (535 families). Four percent of the patient contact information was incorrect for both the surveys (117 adult patients and 170 families).

3.1. Demographic characteristics

Table 1 shows the patient demographic characteristics of the respondents and comparable data from the CFFPR. Adult survey respondents were similar to those in the CFFPR relative to race and CFRD. Differences between the survey respondents and the CFFPR were as follows: adult survey had more female respondents, lower proportion of Hispanic respondents, slightly older, more educated, more clinic visits, less Medicaid or Medicare insurance and shorter length of time receiving services at their care program. The pediatric survey respondents were similar to those in the CFFPR relative to gender, race, age younger than 17 years, and CFRD. The differences were: pediatric survey respondents were a lower proportion of Hispanic respondents, had more private insurance, less Medicaid or Medicare insurance, more clinic visits, and had shorter length of time receiving care at the program. Not listed in the table, the parents' demographic characteristics were 95% were Caucasian and 48% had a college degree or advanced degree.

3.2. Survey results

Table 2 shows the survey results with the 95% confidence interval. The percentage of positive response choice ranged from 22% to 96%; however, not all questions have the same response choices so comparison across questions should be done with

Table 1
Respondents' demographic characteristics from the adult and pediatric surveys and the distributions for the participating programs using the 2012 Cystic Fibrosis Foundation patient registry (CFFPR)^a.

	Adult		Pediatric	
	Survey n = 841	CFFPR n = 2518	Survey n = 1255	CFFPR n = 5230
Female ^b	54% (374)	48% (1202)	51% (545)	49% (2567)
White	97% (654)	96% (2428)	95% (967)	94% (4925)
Hispanic or Latino ^{b,c}	3% (19)	5% (131)	5% (52)	8% (392)
CFRD	34% (233)	35% (884)	9% (100)	11% (592)
Age				
2 years or less			13% (156)	12% (629)
3 to 5 years			14% (174)	13% (657)
6 to 9 years ^c			21% (253)	17% (883)
10 to 13 years			19% (231)	18% (954)
14 to 16 years			15% (187)	13% (701)
17 years and older ^c			17% (211)	27% (1406)
18–24 years	24% (161)	27% (692)		
25–34 years ^b	34% (226)	40% (1000)		
35–44 years	22% (150)	18% (464)		
45–54 years	12% (82)	10% (249)		
55–64 years ^b	6% (39)	3% (84)		
≥65 years ^b	2% (16)	1% (26)		
Education				
High school diploma or less ^b	18% (123)	29% (666)		
Some college or 2-y degree	35% (237)	31% (693)		
College or advanced degree ^b	47% (316)	40% (903)		
Insurance				
Private insurance ^c	59% (367)	55% (1348)	65% (608)	50% (2610)
Medicaid or Medicare ^{b,c}	32% (199)	41% (1008)	27% (256)	42% (2188)
Other ^b	9% (54)	3% (69)	8% (71)	6% (326)
Visits to program in last year				
≤2 ^{b,c}	21% (146)	31% (788)	10% (106)	16% (811)
3 ^c	16% (110)	20% (493)	11% (115)	16% (841)
4 ^{b,c}	34% (229)	20% (496)	39% (406)	25% (1309)
5–9 ^c	24% (161)	27% (674)	33% (347)	39% (2039)
≥10 ^{b,c}	5% (36)	3% (67)	7% (76)	4% (230)
Receiving care at program				
<2 years ^{b,c}	12% (85)	5% (131)	15% (156)	7% (374)
2–5 years	18% (126)	16% (403)	29% (299)	26% (1378)
6–10 years	19% (133)	18% (452)	26% (275)	26% (1343)
>10 years ^{b,c}	50% (349)	61% (1532)	30% (315)	41% (2135)

Abbreviations: CF, cystic fibrosis; y, year; CFRD, CF related diabetes; CFFPR, CF Foundation patient registry.

^a Percentages do not include missing responses.

^b For adult significant difference of distributions between the survey and CFFPR using a χ^2 test.

^c For pediatric significant difference of distributions between the survey and CFFPR using a χ^2 test.

caution. There were 22 questions with the same response scale from “Always” to “Never”, which were compared using a funnel plot. For both surveys, 5 questions were significantly above the rest and all were from the health care team domain (treated with courtesy and respect, explained things in a way that was easy to understand, team spent enough time, team answered questions or addressed concerns, and involved in decisions about care as much as wanted). The adult and pediatric surveys had areas of improvement opportunity in common with 4 questions significantly below the rest (appointment started within 15 min, asked about mental health, able to maintain body weight, and hospital staff knowledgeable about CF care). An additional question from each survey had significantly less positive respondents: the question if airway clearance therapy (ACT) worked on the adult

survey, and the question if nutritional plan worked on the pediatric survey.

3.3. Comparison of adult and pediatric survey results

Table 2 shows that 17 out of the 32 questions on the pediatric survey had significantly more positive respondents using the 95% CI compared to the adult survey. Notable results were the expected report of worse overall health and mental health status by the adult respondents. Of note, health care utilization by adults was lower than that of pediatric respondents: less visits and less access to multidisciplinary care team members.

Table 2
Positive response results for both the adult and pediatric surveys^a.

	Adult		Pediatric	
	Percent (95% CI)	Numerator (denominator)	Percent (95% CI)	Numerator (denominator)
<i>Experiences with timely CF care (% Always & Almost always)</i>				
Got a response from the health care team the same day	80% (78% to 83%)	664 (825)	83% (81% to 85%)	1030 (1235)
Appointment scheduled at a time that worked well	84% (81% to 86%)	680 (813)	83% (81% to 85%)	1021 (1228)
Got an appointment when needed care right away	84% (81% to 86%)	588 (702)	89% (86% to 90%)	890 (1005)
Appointment started within 15 min of scheduled time ^{c,d,e}	59% ↓≠ (56% to 63%)	476 (804)	68% ↓ (65% to 70%)	819 (1206)
Got medicine refills as soon as wanted	86% (84% to 89%)	681 (789)	89% (87% to 91%)	1059 (1191)
<i>Experiences with CF health care team (% Always & Almost always)</i>				
Treat with courtesy and respect ^b	94% ↑ (93% to 96%)	755 (800)	96% ↑ (94% to 97%)	1165 (1219)
Explained things in a way that was easy to understand ^b	93% ↑ (91% to 95%)	736 (790)	95% ↑ (93% to 96%)	1148 (1210)
Team spent enough time ^{b,e}	89% ↑≠ (87% to 91%)	634 (712)	94% ↑ (92% to 95%)	1124 (1198)
Asked about mental or emotional health ^{c,d}	57% ↓ (54% to 61%)	440 (771)	56% ↓ (53% to 59%)	641 (1151)
Team seem informed and up-to-date about the care received ^c	87%≠ (84% to 89%)	674 (776)	91% (90% to 93%)	1099 (1202)
Team answered questions or addressed concerns ^{b,e}	90% ↑≠ (88% to 92%)	705 (781)	94% ↑ (93% to 96%)	1124 (1191)
Involved in decisions about care as much as wanted ^b	91% ↑ (89% to 93%)	703 (770)	94% ↑ (93% to 95%)	1123 (1192)
Rating the overall care from the health care team (% 10 = Best)	47% (43% to 50%)	351 (749)	53% (50% to 56%)	593 (1115)
<i>Experiences with self-care (% Always & Almost always)</i>				
Confident in finding information about CF and care options	84% (81% to 87%)	582 (690)	87% (85% to 89%)	956 (1098)
Able to manage CF ^c	82%≠ (79% to 85%)	594 (724)	92% (90% to 93%)	1035 (1131)
Confident in home medical treatments ^c	83%≠ (80% to 86%)	599 (720)	93% (91% to 94%)	1037 (1121)
Confident in working out solutions when CF problems came up ^c	83%≠ (80% to 85%)	590 (714)	89% (87% to 91%)	983 (1107)
Able to handle CF care on own at home	86% (84% to 89%)	629 (729)	91% (89% to 93%)	1026 (1124)
Able to maintain your body weight ^{c,d}	62% ↓ (58% to 66%)	445 (717)	63% ↓ (60% to 66%)	693 (1095)
<i>Health care resources used in the last year (% Yes)</i>				
Dietitian involved in providing care ^c	86%≠ (84% to 89%)	651 (754)	95% (94% to 96%)	1097 (1155)
Respiratory therapist involved in providing care ^c	79%≠ (76% to 82%)	614 (776)	92% (90% to 93%)	1110 (1207)
Social worker involved in providing care ^c	75%≠ (72% to 78%)	585 (782)	87% (85% to 88%)	1051 (1213)
Use of the Emergency Department for a CF related concern (% 1 or more)	33% (29% to 36%)	234 (715)	32% (29% to 35%)	349 (1098)
Hospital stays for a CF-related concern (% 1 or more) ^c	46%≠ (43% to 50%)	330 (713)	38% (35% to 41%)	421 (1100)
4 or more visits the CF center ^c	62%≠ (59% to 66%)	426 (682)	79% (76% to 81%)	829 (1050)
<i>Health status and treatment worked (% Always & Almost always)</i>				
Overall health (% Excellent & Very good) ^c	35%≠ (32% to 39%)	242 (685)	68% (65% to 71%)	719 (1058)

Table 2 (continued)

	Adult		Pediatric	
	Percent (95% CI)	Numerator (denominator)	Percent (95% CI)	Numerator (denominator)
Overall mental or emotional health (% Excellent & Very good) ^c	55% [≠] (52% to 59%)	380 (686)	72% (69% to 74%)	766 (1069)
Had a lung infection (% No) ^c	22% [≠] (19% to 25%)	144 (666)	38% (35% to 41%)	388 (1020)
ACT worked ^{c,e}	68% ^{↓≠} (65% to 72%)	431 (631)	84% (81% to 86%)	841 (1006)
Lung medicines worked ^c	76% [≠] (73% to 79%)	501 (659)	85% (82% to 87%)	858 (1014)
Nutrition plan worked ^d	76% (73% to 80%)	492 (644)	79% [↓] (76% to 81%)	823 (1045)
<i>Hospital care (% Always & Almost always)</i>				
Hospital staff knowledgeable about CF care ^{c,d}	63% [↓] (58% to 68%)	217 (343)	71% [↓] (67% to 75%)	305 (428)

Abbreviations: CI, confidence interval; CF, cystic fibrosis; ACT, Airway clearance therapy.

^a Percentages do not include missing or not applicable.

^b Questions with a significantly more positive respondents: A comparison of 22 questions with the same response scale from “Always” to “Never”—both the adult and pediatric surveys had the same results using funnel plots (symbol ↑).

^c Questions with a significantly less positive respondents: A comparison of 22 questions with the same response scale from “Always” to “Never” for the adult survey using funnel plots (symbol ↓).

^d Questions with a significantly less positive respondents: A comparison of 22 questions with the same response scale from “Always” to “Never” for the pediatric survey using funnel plots (symbol ↓).

^e Questions significantly different between the adult and pediatric surveys using 95% confidence interval (symbol ≠, adult and pediatric results were not similar).

3.4. Variables predictive of best experience of care

Results of bivariate analyses of pediatric and adult surveys are shown in the Methods and Results Supplement. Table 3 shows the results of the multivariable models for both the adult and pediatric surveys, which produced very similar results. Variables predictive of best care included: 45 years of age or older (adult model only), receiving care for 6 years or more at the center, “Always” confident in finding information, “Always” confident in working out solutions when CF problems arise, and one or more treatments “Always” worked. The models adjusted for overall health, mental health, 4 or more visits, CFRD, and hospital stay produced similar results, and thus only the unadjusted model results are shown in the table. The results suggest respondents’ having confidence in

finding information, working out solutions, and treatments that “Always” worked, rated their overall experience with the health care team as “best” care.

4. Discussion

4.1. Positive attributes and improvement opportunities

The purpose of this paper was to share experience of care results from individuals with CF and parents with a child with CF from 70 CF programs across the US. The same positive attributes were identified on both surveys and involved the experience of care with the health care team—patient/family—provider communication (courtesy and respect, explanations, answer questions, and patient/family involved in decisions) and provider spends enough time with the patient/family. These aspects of care were also identified in a systematic review of 36 studies of patient perceptions of health care quality, in which communication was the top identified quality dimension [23]. Another positive finding is that the CF care experience appears to be better than general care in the areas that we were able to compare the survey results with CG-CAPHS (in Methods and Results supplement file).

We also identified improvement opportunities that may be applicable to many CF centers across the US. Most CF centers have participated in a quality improvement collaborative (i.e., Learning and Leadership collaborative [3]) and thus have been exposed to the Model of Improvement, which is a combination of assessing the evidence and blending it with knowledge of the

Table 3
Unadjusted multivariable logistic regression results of variables predictive of best possible care from the health care team.

Variable	Adult (n = 555)		Pediatric (n = 912)	
	OR	p-Value	OR	p-Value
Age 45 years or older	2.5	<0.001	–	–
Receiving care at center 6 years or more	1.6	0.037	1.4	0.025
Always Confident in finding information about CF and care options	2.9	<0.001	4.4	<0.001
Always Confident in working out solutions	3.4	<0.001	2.6	<0.001
One or more treatment Always worked	2.1	<0.001	1.8	<0.001

Abbreviations: OR, odds ratio; CF, cystic fibrosis.

particular context to execute interventions to measurably improve an aspect of care or service [24]. While adults with CF and parents of children with CF have been engaged in this work, improving the experience of care has not been a major theme of the improvement work to date. Tools and resources (such as those of the Institute for Patient- and Family-Centered Care, Institute of Healthcare Improvement, The Beryl Institute) have been developed to help health care teams improve this aspect of care. Additional resources specific to CF may also need to be developed.

An opportunity for improvement was shown when comparing the results between the 2 surveys. Adult respondents reported worse overall health compared to the pediatric survey and is part of the CF disease progression in which lung health typically deteriorates over time as shown in the CF Foundation patient registry 2012 annual data report [22]. Adult respondents also reported worse overall mental health, less confidence with finding information and home medical treatments, and treatments not working as well. Despite what appears to be a greater need for health care, adults reported less contact with providers that may be able to provide useful information (dietitian, respiratory therapist and social worker) and did not visit the clinic as often as the pediatric respondents. Adult CF programs have been developed more recently than pediatric programs due to the demographic shift in the patient population; thus these programs may have resource limitations or other challenges that create these results. However, access to CF providers is a concern given the projections of a growing number of adults with CF as a result of improvement in survival [25].

Much of the delivery of health care in CF focuses on treating physical problems; however screening and treating mental health issues are just as important for individuals living with a chronic condition [26]. Asking about mental health was one of the lowest scoring questions on both surveys and 15% of the adults and 10% on pediatric survey rated their mental health as poor or fair. There is strong evidence that individuals with CF have a much higher prevalence rate of depression compared to the general population and Quitner et al. suggest screening for and treatment of depression [26]. The European CF Society and the CF Foundation have partnered to develop clinical practice guidelines on the prevention, screening, and intervention for depression and anxiety in individuals with CF, which we anticipate will focus greater attention on this important aspect of care [27].

Lastly, hospital CF care seemed to be an area of concern with respondents and our findings were similar to a study in the Netherlands for hospitalized patients with CF, in which infection control procedures and being treated as an individual were crucial aspects of their experience of care [28]. Improved information exchange between the outpatient and inpatient staff may lead to improved experience of hospital care.

4.2. Predictors of overall experience with the health care team

Through the use of a multivariable logistic model, we were able to isolate two self-care factors—confidence of finding

information and working out solutions—associated with respondents rating the health care team as the best. Additionally, the report of treatment(s) working was also associated with the best care experience. McDonald et al. did a cross-sectional study on nutritional knowledge and confidence levels of parents of children with CF. They found that confidence scores were lower for nutritional aspects of care as compared to pulmonary aspects of care [29]. There are numerous new skills parents and caregivers need to learn and having the confidence in difficult situations is not innate—it is developed and shaped by a variety of factors [30]. Ways to improve confidence include planning, preparing and learning [30]. Growth and development early in life are critical to the course of CF and building a parent's confidence may be one of the many factors needed [29]. Behavioral interventions and nutritional education have been shown to improve nutritional status in children with CF [31–34] and may in part relate to building confidence of the parents.

Redesigning care delivery to provide an experience of care that promotes confidence is a challenge. There are instruments to identify problem areas [29] and to understand the level of patient activation [35]. Another instrument for consideration is the Clinician Support for Patient Activation Measure to assess clinicians' beliefs about the importance of patient self-management, in which clinicians support patients following their advice but do not fully support patients being independent, information-seeking caretakers of their health [36]. Although results may not be generalizable to the CF care team members, the multivariable logistic results suggest that enabling "patients to take independent actions and make independent judgments" [36] may be important in achieving "best" experience of care. The health care team can develop interventions to co-create this confidence and support individuals with their independent judgments and actions [36] needed in managing a complex disease.

4.3. Limitations

A response rate of 30% was adequate for a national perspective in the United States although falls short of obtaining everyone's perspective. Two of the known reasons for lack of response were incorrect contact information and refusal; thus there may have been a lack of awareness of the importance of needing an individual's perspective. A validation study of a patient experience questionnaire with 56 German CF centers, Stahl et al. reported a 74% response rate which they attributed to recruiting participants personally through the CF center staff and sending reminders through an external institute [37]. Although there may be cultural difference driving this result, this underscores the importance of engaging CF programs that have relationships with patients and families to promote participation in the survey.

There were some differences in demographic characteristics between the respondents completing the surveys and the CFFPR, which could have introduced a systematic bias in the results. Compared to the CFFPR the adult survey respondents had a higher percentage of females, individuals 55 years or older, college educated and receiving care for 10 years or more and a

lower percentage of Hispanics and individuals with Medicaid or Medicare. Using 95% CI we determined whether the demographic characteristics could have impacted the 5 positive attributes and 5 improvement opportunities. The only notable result was with the college educated respondents in which 49% (95% CI 43% to 54%) chose always or almost always for the survey question of whether the health care team asked about mental health. This result was significantly lower than 63% (95% CI 58% to 68%) for those respondents with less education. Thus, the overall mental health result of 57% may be slightly lower due to the higher proportion of college-educated respondents. However, mental health care remains a significant improvement opportunity since these 5 results ranged from 57% (the mental health question) to 68% (the ACT working question). For the pediatric survey, there were a higher percentage of respondents receiving care for 10 years or more and a lower percentage of Hispanics and individuals with Medicaid or Medicare compared to the CFFPR. The only notable result was for the improvement opportunity of nutritional plan working in which respondents with Medicaid or Medicare had a significant higher percentage of always or almost always, 85% (95% CI 81% to 90%), compared to those with private insurance, 75% (95% CI 71% to 79%).

With 839 adults completing the adult survey and 1251 caregivers completing a pediatric survey there was very good precision in the results. However, with large numbers of respondents, results, such as differences among the questions and differences between adult and pediatric survey, were most likely significantly different due to large samples. It was essential to not over interpret small differences and it is unknown what level of difference would be considered relevant. Therefore, we encourage consideration of only large differences as the more relevant findings. The relatively large number of respondents did provide us the opportunity to determine variables predictive of the experience of best care.

5. Conclusion

This paper reported the positive attributes and improvement opportunities of the care experience from the voice of individuals with CF and families. Overall people with CF and families reported positive respectful experiences with the health care team. Improvement opportunities were identified such as mental health care and hospital care.

Experience of care draws our attention to individualized care and services that meets people's needs and it will be critical as this work continues to share and learn how CF programs meets or exceeds patients and families expectations.

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Appendix A. Supplementary Methods & Results

Supplementary data to this article can be found online at <http://dx.doi.org/10.1016/j.jcf.2014.12.011>.

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