

# Strengthening care teams to improve adherence in cystic fibrosis: a qualitative practice assessment and quality improvement initiative

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**Background:** Treatment regimens for patients with cystic fibrosis (CF) are complex, time consuming, and burdensome, and adherence to CF treatment is suboptimal. CF care teams play a critical role in supporting patients' chronic self-management skills, but there is no uniform method for assessing patients' adherence to treatment or standard interventions to help patients improve when necessary.

**Methods:** Between May 2015 and March 2016, care team members from 10 CF centers in the USA participated in a practice assessment and quality improvement (QI) initiative. The intervention included a baseline practice assessment survey, personalized continuing medical education (CME)-certified Webconferences with expert study faculty, targeted reinforcement of key practice points, and follow-up online survey and telephone interviews to evaluate the benefits and limitations of the intervention.

**Results:** Responses to the baseline practice assessment survey were received from 50 multidisciplinary care team members representing 10 CF centers. Primary barriers to adherence-related aspects of care in their clinics were motivating patients and caregivers to improve adherence and obtaining accurate information about adherence from patients. At the conclusion of the initiative, participants reported improvements in communication within their care team, implementation of new approaches to asking about adherence, and a renewed commitment to asking patients and caregivers about adherence at each clinic visit.

**Conclusion:** Structured QI interventions that bring multidisciplinary care teams together to reflect on clinic processes and elicit objective insights from outside faculty have the potential to improve practice patterns related to the assessment and improvement of patient adherence in CF.

**Keywords:** nonadherence, treatment burden, communication, team-based care

## Introduction

Patients with cystic fibrosis (CF) and their caregivers face the constant challenge of fitting complex treatment routines – estimated on average to consume nearly 2 hours each day – into schedules that are already often crowded with school, family, work, and other commitments.<sup>1</sup> Yet, adherence to potentially burdensome CF care plans is critical, as nonadherence is linked to poor health outcomes such as increased health care utilization, increased pulmonary exacerbations, lower lung function, and prolonged hospital stays.<sup>2–4</sup> However, treatment adherence is generally suboptimal. For example, a large retrospective analysis of a national claims database that examined the adherence to pulmonary medications over a 12-month period for >3,000 children, adolescents, and adults with CF calculated that the average composite medication possession ratio was 48%.<sup>2</sup>

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Furthermore, a study employing electronic monitoring of prescribed nebulizer therapy among patients with CF demonstrated a median adherence rate of only 36%.<sup>5</sup>

The significance of the challenges complicating treatment adherence in CF, as well as the importance of overcoming them, is underscored by the Cystic Fibrosis Foundation's (CFF) 5-year strategic plan; 1 of the 6 key objectives is specifically focused on improving adherence to prescribed therapies through "enhanced data collection and information sharing" across all stakeholders in the CF community.<sup>6</sup>

Members of the multidisciplinary CF care team play a critical role in helping patients and their families successfully adhere to complex treatment regimens.<sup>7,8</sup> Monitoring adherence is challenging, as patient/caregiver self-reports and care team subjective assessments are often inaccurate, and other means of monitoring, including daily diaries or electronic monitors, add to the treatment burden and are not practical.<sup>5,9</sup> However, because suboptimal adherence is associated with poor outcomes in CF, and there is no "silver bullet" intervention that can be uniformly applied in all situations, it is incumbent upon care team members to be equipped with the knowledge and skills necessary to proactively explore individuals' potential barriers to optimal adherence and uncover patients' personal and health-related goals. Once armed with an in-depth understanding of patients' challenges and preferences, CF care team members can facilitate collaborative, creative problem solving with patients and families that aligns specific barriers and goals with an individualized approach to help support improved disease management.

We designed a quality improvement (QI) initiative that explored the processes used by CF care team members to assess patients' treatment adherence, as well as identified improvement plans for multidisciplinary teams to implement in practice. The initiative sought to explore the CF care team members' attitudes, behaviors, and barriers related to the responsibility of working with patients and families to evaluate and improve treatment adherence, as well as communication with colleagues about how to approach challenging cases. It provided them with a structured, formal opportunity to discuss as a team various process improvements that could be implemented into clinic workflows to address suboptimal treatment adherence and how the effects of these process changes could be subsequently measured over time. The ultimate goal of the project was to determine if such an intervention would make teams more likely to regularly address adherence in clinic and provide additional support for patients' day-to-day disease self-management skills.

## Methods

### Initiative components

The research project was implemented in 4 phases between May 2015 and June 2016 and was approved by the Chesapeake Institutional Review Board (IRB). All participants in this study provided written informed consent.

#### Phase 1: recruitment and baseline assessment

A multidisciplinary panel of study faculty was selected to direct content development and facilitate the Webconferences based on professional expertise as CF care providers and/or experience in adherence research. Information describing the QI study was distributed by telephone, email, and mail to the national network of >110 CFF-accredited care centers in the USA. Ten programs were selected for the initiative based on interest and availability. Participation required the involvement of 3–5 multidisciplinary care team members from each site, including at least 1 physician or advanced practice provider involved in making treatment decisions.

A practice assessment survey, developed in conjunction with the study faculty, was distributed electronically to individual CF care team members from each participating group. Participants received a nominal stipend in return for their time. The practice assessment survey was designed to facilitate reflection on current processes and front-line challenges and served to identify potential areas for improvement related to the evaluation of, and optimal interventions for, individual patients' adherence barriers. A de-identified aggregate assessment summary report that detailed each care team's responses was provided in advance to study faculty in phase 2 of the initiative.

#### Phase 2: practice reflection and commitment to change

Ten, 60-minute, continuing medical education (CME)-certified Webconferences – 1 for each participating CF care team – were conducted by one of the study faculty experienced in CF care. All Webconferences began with a brief, standardized evidence-based didactic presentation. The majority of the hour was customized to address individual care teams' practice assessment results from phase 1, followed by faculty-led discussion regarding participants' practice-specific challenges and recommendations for process improvements. The goal of the Webconferences was to allow participants the opportunity to discuss their team's care processes and communication related to assessing and addressing adherence issues with patients with CF and their

families. At the conclusion of each Webconference, the faculty prompted participants to identify at least one area of their practice that they would seek to improve over the coming 4 months (“commitment to change”).

### Phase 3: targeted reinforcement and follow-up

Following the Webconference, each CF care team received a monthly targeted electronic resource (4 total) to reinforce the area(s) identified for process improvements in their clinic setting, serve as a reminder of the key educational messages in phase 2, and provide ongoing motivation to implement incremental changes in their clinic’s processes related to assessing and improving patients’ treatment adherence. These resources were developed based on responses to the baseline practice assessment survey in phase 1 and common themes from discussions between participating multidisciplinary CF care teams and study faculty in phase 2. The focus of each resource was as follows:

- A personalized summary of each participating CF care team’s discussion with study faculty, including a reminder of their specific commitment to change strategy.
- A patient education resource to explain the various treatments used in CF and why adherence is important for good outcomes.
- Two care team-directed resources, one addressing barriers and facilitators to adherence in CF and the other outlining effective tools and strategies for assessing adherence.

At the conclusion of this 4-month period, all participating care team members were emailed a link to a shortened version of the online practice assessment survey and an invitation to participate in a more in-depth follow-up telephone interview to discuss the impact of the initiative on their care team as a whole. These invites were sent out to individuals a minimum of 3 times to include feedback from as many participants as possible. Respondents received a nominal stipend in return for their participation in these follow-up opportunities, though their participation was not mandatory. Data gathered from a subset of individuals from each institution provided valuable qualitative insights into successes with, and barriers to, the implementation of identified process improvement(s), as well as continued educational needs.

### Data analysis

Due to the small sample size (10 CF care teams with 3–4 multidisciplinary care team members per site) and exploratory nature of this initiative, no formal statistical analysis was completed. Data were assessed for trends in changes in

attitudes and practice behaviors, and the results described herein are descriptive.

## Results

Ten care teams from CF centers in California, Illinois, New York, Oklahoma, and Pennsylvania participated in the initiative. Four of the teams provide care to pediatric patients, 5 teams provide care to adult patients, and 1 team cares for both children and adults with CF. The online baseline practice assessment survey had 50 respondents, representing several different roles on the CF care team (Table 1).

The majority of respondents agreed with the statement that adherence to prescribed CF treatment is important for all patients (86%). Overall, when asked how frequently they ask their patients about adherence, 68% of respondents indicated they do so at each visit, while 26% indicated they ask only when time permits, 4% ask when they suspect a decrease in adherence, and 2% do not ask at all. A higher percentage of respondents who believe that adherence is important for all patients ask at each visit compared with respondents who believe adherence is important for most or some patients (72% versus 43%, respectively).

When asked to identify who in the clinic is responsible for asking about adherence, baseline responses varied across different team members (Table 2). Physicians, respiratory therapists, social workers, and nutritionists or registered dietitians were most frequently cited as being responsible for this task. In contrast, only 50% of respondents indicated that nurses are responsible for asking about adherence. There was also a general lack of consensus about which care team members are responsible for counseling patients on strategies to improve adherence and follow-up. In fact, only one care team was consistent in defining who in their clinic was responsible for adherence-related tasks. Another team uniformly agreed that nurses, the respiratory therapist, and

**Table 1** CF care team roles of practice assessment survey respondents

Role on CF care team	Respondents, n (%)	
	Baseline (N=50)	Follow-up (N=18)
Physician	12 (24)	2 (11)
Clinic coordinator	9 (18)	3 (17)
Social worker	7 (14)	4 (22)
Respiratory therapist	7 (14)	1 (6)
Advanced practice providers	5 (10)	2 (11)
Nutritionist/registered dietitian	5 (10)	4 (22)
Clinic nurse	4 (8)	2 (11)
Others	1 (2)	0 (0)

**Abbreviation:** CF, cystic fibrosis.

**Table 2** Perceived CF care team responsibilities

Task	Respondents indicating the task as a responsibility of a specific team member, n (%); N=50					
	Clinic coordinator	Physician	Nurse	Social worker	Respiratory therapist	Nutritionist/ registered dietician
Asking patients about adherence	34 (68)	45 (90)	25 (50)	42 (84)	42 (84)	41 (82)
Counseling patients on strategies to improve adherence	33 (66)	39 (78)	20 (40)	42 (84)	33 (66)	36 (72)
Following up with patients about adherence	32 (64)	29 (58)	20 (40)	38 (76)	22 (44)	35 (70)

**Abbreviation:** CF, cystic fibrosis.

the social worker are responsible for all tasks, but opinions differed related to the responsibilities of the nutritionist, clinic coordinator, and physician.

Approximately one-third of the care personnel ranked motivating patients and caregivers to improve adherence (34%) and obtaining accurate information about adherence (32%) as “very challenging”. Indeed, specific questions related to these 2 topics were frequently provided when respondents were asked to provide a brief description of challenges they would like to discuss during the Webconference with study faculty. For example, of the 23 free-text responses to this question, 11 of them focused on how they can get more reliable information about adherence from patients and families and 7 responses asked about suggestions for how to better motivate patients and families to working toward fitting more prescribed treatments in each day. These topics, together with plans to create lists defining responsibilities of care providers going in to see patients, communicate before clinic meetings to discuss past issues, and regroup after clinic to discuss new issues and plans for follow-up, were common themes for the “commitment to change” strategies that were developed with study faculty at the end of each Webconference (Table 3).

At the conclusion of the project, multiple participants reported that the intervention positively affected their team’s approach to addressing adherence challenges with patients

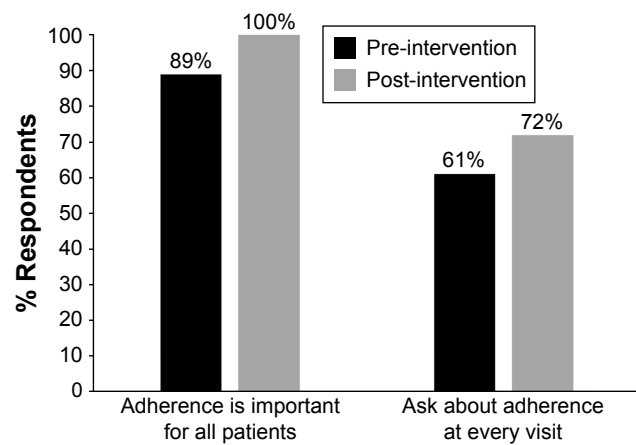
and families. Eighteen participants with varying roles from 7 of the 10 CF care teams (between 1 and 4 respondents from each center) completed both the pre- and post-intervention practice assessment survey (Table 1). A matched comparison of responses to 2 key survey questions revealed that there was a trend toward an increase in the belief that adherence to CF treatments is important for all patients, as well as a shift to more frequently asking patients and/or caregivers about adherence at every visit (Figure 1).

In addition, open-ended questions posed in the follow-up survey and telephone interviews provided more details on the benefits of participation; responses fell into 3 general categories: 1) improvements in communication within their care team, 2) introduction to new approaches to asking questions about adherence, and 3) a reminder of the importance of asking about adherence. For example, discussions with study faculty on the Webconference resulted in one team communicating more with one another about how they can address challenges together, rather than individually. Another team reported that the conversation with external faculty increased their willingness to “meet patients where they are” and take patients’ interests and goals into account when discussing how to increase their adherence. Similarly, the discussion prompted another team to be more accepting of collaborating with patients to develop small, achievable incremental goals related to improving adherence to CF

**Table 3** Sample “commitment to change” strategies developed during the Webconferences

“Document intervention plans developed with patients and the results of follow-up conversations for patients’ and clinic’s benefit.”	“Identify issues that are a specific priority for individual patients so questions and interventions can be tailored to each patient.”
“Discuss adherence differently with patients. Instead of asking how many times they are able to fit a specific treatment in during a week, ask instead, ‘What challenges are you having with [X]?’ or ‘What keeps you from [Y]?’”	“Develop a simple survey to assess patients’ current adherence level; these results can establish a baseline for individual patients, allow the CF team to track changes over time, and help gauge the effectiveness of different adherence interventions.”
“Ask patients to complete a simple list of open-ended questions upon check-in to gain insights on recent concerns; make this list available to all care team members (eg, place in a folder that is posted on the exam room door) so that all care team members can review it before entering the room.”	“Identify the logistical details of what is keeping someone from following their care plan to inform strategies that anchor patients’ CF therapies to an established part of their daily routine.”

**Abbreviation:** CF, cystic fibrosis.



**Figure 1** Matched pre- to post-intervention survey responses (N=18).

treatments rather than an “all-or-nothing” approach. Finally, yet another team reported that their participation reinforced the point that the prevalence of suboptimal adherence among patients with CF is high, and the discussions elevated the importance of regularly asking questions of patients and families during routine clinic visits.

## Discussion

This research project provided CF care teams with a structured opportunity to reflect on and discuss adherence with their colleagues and to develop small QI initiatives under the guidance of faculty from outside of their institutions. There tended to be consensus across care team members on processes for and barriers to evaluating adherence based on results from the baseline practice assessment survey, but questions about which care team members were responsible for various adherence-related tasks revealed some uncertainty. Care team members frequently were unclear about who was asking patients and caregivers about adherence, counseling them on strategies to improve, and following up at subsequent clinic visits.

Surveys and interviews with participants at the conclusion of the research project revealed that the Webconferences led to improvements in communication within teams, introduced them to new tools to use with patients to elicit better information about adherence, and elevated the importance of routinely asking about adherence to ensure potential barriers are identified and addressed early. While direct benefits of these discussions on patient care and outcomes are difficult to measure, qualitative responses suggest that the conversations are well positioned to enrich the patient–care team relationship. Because discussions involving multiple care team members within a CF clinic may be difficult to organize

ad hoc in a busy clinical practice, these facilitated discussions provided for a defined and organized period separate from the clinic. Indeed, in spite of the fact that coordinating such time with multiple members of care teams and with outside faculty may be a significant barrier to more widespread implementation of this kind of intervention, participants found that this formal format with protected time was a valuable experience that served as a reminder of the importance of improving practice patterns.

We also observed a trend toward an increase in the perceived importance of adherence to patients’ health outcomes and an increase in the number of care team members who report that they ask about adherence at every visit. Though the absolute increase in these percentages was small, they have the potential to translate into positive outcomes for their patients. When a conversation about adherence is a routine aspect of every clinic encounter, it can mitigate patients’ perceptions of being judged by care team members during times of poorer health. It also helps each care team member get to know the patient better, identify changes in a patient’s usual routines that might affect adherence, and understand what works for the patient before an adherence problem develops. Once patients’ specific barriers to adherence are uncovered, care teams and patients can tackle the problems together with multifaceted approaches that may include education and training, behavioral modification, problem solving, motivational enhancement, social support, and behavioral and health feedback. Indeed, supporting patients, building trust, and facilitating shared decision making – elements that have been shown to improve adherence outcomes in a variety of chronic conditions – should be fundamental components of CF care teams’ approaches to communicating with their patients.<sup>10</sup>

These study results demonstrate concrete actions that can be taken to improve team coordination and attention to patient adherence. Specifically, including an outside faculty in team meetings can promote involvement by all team members and facilitate team reflection, communication, and cooperation when considering strategies to address patient care challenges and improve care delivery. In addition, follow-up is important for maintaining these advances in teamwork, but ongoing involvement needs to include the entire team and not represent just a few individuals. While all care team members have time constraints, the design of this project seemed to stimulate participation, at least initially, by the whole team, showing how directed discussions may be essential to change current practice patterns.

The findings of this project were limited by the self-reported nature of the practice assessment survey data, the



qualitative insights from the Webconferences and follow-up interviews, and the fact that participation in the follow-up survey was not mandatory and limited. Therefore, the study findings are not reflective of all participants' perceptions, nor are they generalizable to CF care teams nationwide. In addition, because this was a pilot study and participants were identified based on expressed interest in the project, it is possible that the selection bias was toward programs that were already motivated to reflect on their processes for addressing adherence. Finally, the ultimate evaluation of a process for evaluating and improving adherence is the assessment of patient outcomes; however, this type of measurement was well beyond the scope of the current initiative.

Feedback on the initiative from participating CF care team members was generally positive, and follow-up participant interviews provided 3 themes for how this intervention could have been improved. There was a desire for case-based examples in the Webconferences to foster discussion and provide a framework to work through the strengths and weaknesses of different processes and strategies based on a given scenario. Furthermore, if busy programs are going to dedicate time to QI efforts with outside faculty, future initiatives should ensure that the curriculum includes specific examples that can prompt development of customized action plans in order to create value for the participants. Finally, videoconferencing may also be useful in this type of intervention to foster interaction and engagement. In addition to the improvements suggested in the follow-up interviews, the authors also note that future interventions using this design may be more effective if they incorporate additional opportunities for participating care teams to interact with study faculty to increase teams' engagement and promote sustainability in QI efforts.

## Conclusion

Formal care team discussions that provide structured opportunities to reflect as a group on current processes of care related to treatment adherence and to obtain objective feedback from individuals who practice outside of their clinic have the potential to positively impact practice patterns. This project reinforced the importance of practical, patient-centered approaches for addressing adherence in the CF clinic. The findings demonstrate that small, time-limited QI projects directed at improving clinic processes can facilitate proactive communication with patients at each visit to address barriers in an open, nonjudgmental way; increase patient/care team

member collaboration to establish and document realistic, meaningful, and achievable goals; and ensure follow-up on progress and barriers to progress. This kind of initiative also fosters team-based planning and communication to develop a cohesive strategy to address patients' challenging barriers to adherence and keep them motivated to improve.

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## Disclosure

AJ Gardner is an employee of Med-IQ, and AL Gray, S Self, and JS Wagener all received honoraria for participating as study faculty. The authors report no other conflicts of interest in this work.

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