

Patient and Provider Perspectives on Communication About Body Image With Adolescents and Young Adults With Cystic Fibrosis

Sarah W. Helms,¹ PhD, Lillian M. Christon,² PhD,
Elisabeth P. Dellon,³ MD, MPH, and Mitchell J. Prinstein,¹ PhD

¹Department of Psychology, The University of North Carolina, ²Department Psychiatry, The Medical University of South Carolina, and ³Division of Pediatric Pulmonology, Department of Pediatrics, The University of North Carolina

All correspondence concerning this article should be addressed to Sarah W. Helms, Department of Psychology, University of North Carolina at Chapel Hill, Davie Hall, Campus Box 3270, Chapel Hill, NC 27599, USA. E-mail: sarhelms@live.unc.edu

Received June 21, 2016; revisions received January 23, 2017; accepted February 5, 2017

Abstract

Objective This mixed-methods study examined perspectives of adolescents and young adults (AYAs) with cystic fibrosis (CF) and health care providers on body image communication.

Methods Interviews and questionnaires were completed by 20 AYAs and 28 providers.

Results Although 85% of patients reported they had never had a body image conversation with a health care provider, 74% of providers reported discussing this topic with patients. Patients and providers described body image as an important issue, which should be discussed comfortably and supportively. However, patients often preferred to discuss body image as a distinct topic, separate from physical health, whereas providers preferred integrating body image conversations within weight- and health-based discussions. **Conclusions** Body image is an important topic for AYAs with CF that often goes unaddressed or addressed in ways that are less preferred by patients. Providers should reduce barriers to effective communication about this important topic, particularly through increased awareness of AYA preferences.

Key words: adolescents; cystic fibrosis; qualitative methods.

Cystic fibrosis (CF) is a life-limiting genetic condition in which a thick buildup of mucus occurs in the lungs, pancreas, and other organs, necessitating significant intervention to prevent respiratory and nutritional complications across the lifespan (Cystic Fibrosis Foundation, 2015). Individuals with CF have higher baseline caloric requirements to support their increased metabolic needs related to pulmonary infections and reduced lung function, pancreatic insufficiency, and maldigestion and malabsorption of nutrients (Ramsey, Farrell, & Pencharz, 1992). Given these higher caloric needs and poorer efficiency at processing nutrients, individuals with CF historically

were simply viewed as predestined to be smaller in stature and weight than their peers; however, recent research has documented the direct link between poor nutritional status and decreased life expectancy in CF, making the maintenance of appropriate body mass index (BMI) now an essential component of patient care (Anthony, Paxton, Catto-Smith, & Phelan, 1999; Stallings et al., 2008). In light of this link between BMI and mortality, the Cystic Fibrosis Foundation created treatment guidelines emphasizing the goal of striving for optimal nutritional status, defined as BMI at or above the 50th percentile (Stallings et al., 2008; Zemel, Jawad, FitzSimmons, & Stallings, 2000).

Adolescent and young adult (AYA) patients with CF thus face a unique challenge, insofar as they have a much easier time maintaining low body weight than their typically developing peers, and indeed often experience significant stress associated with maintaining or gaining weight (as encouraged by their care providers; [Savage & Callery, 2007](#); [Stark & Powers, 2005](#)). Thus, paying special attention to the role of body image and disordered eating behaviors among AYAs with CF is especially important ([Anthony et al., 1999](#); [Bryon, Shearer, & Davies, 2008](#); [Pumariega, Pursell, Spock, & Jones, 1986](#); [Stallings et al., 2008](#)). This goal also is highlighted in a recent meta-analysis, which noted the increased risk for body image concerns among individuals with CF as compared with both healthy peers and peers with other chronic illnesses ([Pinquart, 2013](#)).

Although body image concerns and disordered eating behaviors can occur in childhood, these concerns increase markedly during adolescence and young adulthood, particularly in light of Western cultural ideals that emphasize thinness for females and muscularity for males ([Powell & Hendricks, 1999](#); [Ricciardelli, & McCabe, 2001](#); [Truby & Paxton, 2001](#); [Walcott, Pratt, & Patel, 2003](#)). Even among otherwise healthy AYAs, negative body image is associated with a variety of maladaptive outcomes, including anxiety, depressive symptoms, peer/social challenges, poorer health-related quality of life, and unhealthy eating behaviors ([Neumark-Sztainer, Paxton, Hannan, Haines, & Story, 2006](#); [Pinquart, 2013](#); [Smolak & Thompson, 2009](#); [Stice, Hayward, Cameron, Killen, & Taylor, 2000](#); [Weninger, Weiss, Wahn, & Staab, 2003](#)). Of particular importance for AYAs with CF, body image concerns are one of the most salient predictors of disordered eating behaviors, which in turn may negatively impact disease course and longevity ([Thompson, Coovert, & Stormer, 1999](#); [Tierney, 2012](#)).

Cultural messages regarding ideal body size and shape may be equally problematic for both males and females, despite their differential methods of impact across gender (i.e., influencing AYA males to desire to be larger or more muscular, while discouraging AYA females from weight gain; [Cohane & Pope, 2001](#); [McCabe & Ricciardelli, 2004](#); [Walters, 2001](#); [Willis, Miller, & Wyn, 2001](#)). Prior research on AYAs with CF revealed that males tended to be less satisfied with their perceived BMI, whereas females were more likely to be happy with their perceived thinness ([Abbott et al., 2000, 2007](#)). Unfortunately, this body dissatisfaction among males may contribute to psychosocial challenges when culturally valued body types are unattainable, whereas the satisfaction with thinness among females may contribute to poorer long-term survival rates when females are less motivated to maintain adequate BMIs ([Abbott et al., 2000, 2007](#); [Tierney, 2012](#)). Across genders, AYAs with CF also report an increased pressure from others to eat,

which may be associated with lower self-esteem and body satisfaction ([Abbott et al., 2000](#)). Furthermore, body image may impact health care behaviors. For example, AYAs with CF who perceive themselves as underweight are more likely to take oral and enteral food supplements to improve their health and nutritional status, whereas AYAs with distorted body image, who do not perceive themselves as underweight, are less likely to do so ([Walters, 2001](#)). This is of even greater importance in the transition from adolescence to young adulthood, as these AYA patients take on more responsibility for their own care and parents may become less involved in these types of health care decisions ([Tuchman, Schwartz, Sawicki, & Britto, 2010](#); [Zack et al., 2003](#)).

Importantly, AYAs with CF report wanting to talk with their providers about both psychosocial and preventative care issues ([Zack et al., 2003](#)). As such, body image represents a critical topic for CF health care providers to address with their patients. Previous work has addressed more generally how chronically ill AYAs prefer to communicate with their doctors, and factors have been identified that typically impact patients' perspectives of patient-provider communication, including communication skills, quality of relationships, perceived physician lack of interest, and type of information being discussed ([Boyle, Farukhi, & Nosky, 2001](#); [Beresford & Sloper, 2003](#); [Swedlund, Schumacher, Young, & Cox, 2012](#)). Although body image is a relevant and important topic to discuss with AYAs with CF ([Abbott et al., 2000](#); [Walters et al., 2001](#)), there is little research on how this communication occurs in clinical practice, and whether there are preferable ways for this communication about body image to occur.

In this study, we focus on better understanding the clinical needs of AYAs with CF in regards to communicating with providers about body image, a topic of critical importance for this developmental period and this chronic illness. This study used a mixed-methods approach to explore current practices in communication about body image, from both patient and provider perspectives. Patients and providers were asked about frequency of their own communication experiences around body image using a qualitative interview approach. Given the lack of research on the best methods for body image communication in this population, our ultimate aim was to understand what the various components of a successful communication around body image between a patient and a provider would entail. Ultimately, we believe that these data can inform recommendations for CF care teams regarding communicating about body image with AYA patients.

Methods

Participants and Procedures

We elicited participation from both patients and providers for source triangulation, to search for convergence

and divergence across these two critical perspectives on communication in clinic settings (Creswell & Miller, 2000). Participants were therefore both AYAs with CF ($n = 20$) and a range of health care providers specializing in providing care for AYA CF patients ($n = 28$).

Participants included 20 AYA patients with CF ($n = 10$ female, 50%), aged 15–21 years ($M = 17.5$ years) at the time of the study. These patients were recruited from a larger study on physical and psychosocial health at a Cystic Fibrosis Foundation-accredited care center in a university medical center setting (Helms, Dellon, & Prinstein, 2015). Patients initially were recruited for the larger study from the pediatric care center; however, some had transferred their care to the adult care center at the same university medical center by the time this portion of the study was completed, 3 years after initial recruitment. Eligibility for initial recruitment into the larger study included (a) confirmed diagnosis of CF, (b) scheduled for a routine (nonurgent) clinic appointment, (c) fluent in English, (d) not cognitively or emotionally impaired (e.g., owing to developmental disability), and (e) aged 12–18 years old. All adolescents meeting these criteria ($n = 75$) during the 2-month recruitment period were identified. Of these, 26 were unable to be approached (e.g., owing to missing their scheduled appointments or attending clinic without a parent to provide written consent); the remaining 49 patients were approached and 43 provided consent to participate. Those who declined ($n = 6$) cited time constraints, lack of interest, and other research obligations as reasons for refusal.

Of the 43 patients who participated in the initial phase of the larger study, three patients had transferred care to another center and one patient had received a lung transplant and was not being served by the CF care team at follow-up. The remaining 39 patients were considered eligible for the current study, and the patients who were seen in clinic during a 3.5-month follow-up period ($n = 23$) were approached regarding participation during their regular CF clinic visits. Three patients declined to participate, yielding the final sample of 20 AYAs with CF. All patients were interviewed regarding body image at routine clinic visits, when they were not experiencing acute health concerns.

At baseline of the larger study, patients presented with a range of disease severity ($M_{\text{BMI}} = 19.36$, $SD = 2.74$, range = 14.9–26.1; $M_{\text{FEV}_1(\%)} = 76.22$, $SD = 22.53$, range = 17–119%); however, over half ($n = 25$) fell within guidelines for “acceptable” to “optimal” nutrition status, measured by BMI at or above the 25th percentile, and two-thirds ($n = 27$) fell within the classification for normal to mildly impaired lung function (forced expiratory volume in 1s, $\text{FEV}_1 \geq 70\%$ predicted; CFF, 2015). These health indicators remained fairly stable, on average, by the current

follow-up timepoint, approximately 3 years after baseline ($M_{\text{BMI}} = 19.38$, $SD = 2.54$, range = 14.4–23.9; $M_{\text{FEV}_1(\%)} = 70.40$, $SD = 20.49$, range = 29–103%). The majority of patients self-identified as White or Caucasian ($n = 19$), and one patient self-identified as mixed race. Based on chart review, 20% of patients had been identified as homozygous $\Delta F508$, 5% as heterozygous $\Delta F508$, 15% had other mutations, and the remaining patients had ambiguous or unknown genetic profiles. As a proxy for socioeconomic status, insurance status and parental education were assessed. The majority of patients (75%) had private insurance (HMO/PPO), with fewer patients using Medicaid (20%) or military/Tricare insurance (5%). The majority of parents/caregivers who participated at the larger baseline assessment self-reported that they had college degrees or advanced degrees (55%); 35% reported high school or a GED as their highest educational attainment.

Participants also included providers ($n = 28$; 64% female) from the same CF care center (both pediatric and adult CF care programs), who responded to closed- and open-ended online questions regarding body image and CF. All providers were recruited based on having specialized training and expertise in AYA CF care, including attending physicians ($n = 11$), pediatric or adult pulmonary medicine fellows ($n = 7$), nurses ($n = 4$), dietitians ($n = 3$), and other therapists (e.g., respiratory therapists, social workers, $n = 3$). On average, providers reported that 44% of the CF patients they routinely treated fell within the designated AYA age range (range = 10–100% of each provider's patient population).

Semi-structured interviews were conducted. All initial interview questions for patients and providers were developed via triangulation across extant literature on body image and AYAs with CF and among a multidisciplinary team of four researchers and clinicians with experience working with AYAs with CF. Patients and providers both answered one closed-ended question, asking about the frequency with which patients and providers have had conversations with each other about their body image or how they feel about their bodies. Open-ended questions asked about barriers and supports to routine discussion of body image in CF care, as well as eliciting perspectives on how and by whom these conversations about body image should be conducted. For provider interviews, as responses were provided in an online format for efficiency, no iterative changes were made to the questions and all providers responded to the same questions. For patient interviews, a semi-structured interview with open-ended questions was conducted following an interview guide. Follow-up questions were asked to clarify, and/or to provide additional information when appropriate. To document the questions

asked in the semi-structured interviews, all interviews were transcribed (Cohen & Crabtree, 2006).

All procedures were approved by the university's institutional review board. Informed consent and/or assent were obtained from all patients; patients aged <18 years provided written assent and caregivers provided written consent, whereas patients aged ≥ 18 years provided their own written consent. All patients received a \$10 gift card for participation in the current phase of research. Interviews were conducted between December 2013 and February 2014 in private clinic rooms in the CF center, and usually lasted approximately 30 min. Caregivers and participants were separated during the semi-structured interviews to ensure privacy, and participants were explained the purpose of the interviews. Interviews were conducted by a licensed doctoral-level psychologist (Caucasian female) with experience in interviewing and qualitative methodology. This interviewer, who has past experience working clinically with CF patients, was unaffiliated with the CF care team where patients were recruited for this study. The interviewer had previous exposure to the participants from the first phase of the larger study. The interviews were audio recorded and transcribed verbatim by a trained research assistant and verified by the interviewer. In the interviews, patients were asked to describe their prior conversations with health care providers regarding body image, and when or how they thought that body image conversations should occur (if at all) within the CF clinic setting. A semi-structured interviewing approach was used wherein the same questions were asked of each participant, and then the interview prompted for follow-up responses or clarifications as indicated.

Health care providers were invited via email to participate in an online survey regarding body image and CF care. The online format was used for ease of completion for busy medical professionals. Informed consent was obtained online, before participation. Providers were asked how frequently they discuss body image with AYAs with CF, and when or how they thought that body image conversations should occur (if at all) within the CF clinic setting. Providers were given a free-response format to respond to questions. Follow-up questions were not possible owing to the nature of the online interviews.

Descriptive Data Analysis

Frequency was calculated for patient and provider responses to the closed-ended question about frequency of body-image discussions.

Qualitative Data Analysis

Interview transcripts underwent a qualitative thematic analysis (Braun & Clarke, 2006) in a number

of phases described herein using guidelines set out for qualitative research (Tong, Sainsbury, & Craig, 2007; Wu, Thompson, Aroian, McQuaid, & Deatruck, 2016). Qualitative coding occurred from May 2014 to January 2015, and was completed by a team of three doctoral-level psychologists with experience working clinically with patients with CF and advanced training in qualitative coding. In the first phase of coding, two coders reviewed the data separately to identify patterns and themes that were relevant to communication about body image between providers and patients with CF. Each coder completed memos on the themes identified in the data. Second, the two coders discussed the transcripts and the themes that were identified, and a finalized codebook was created including a definition of each theme and examples. Third, the responses were coded separately by the same two coders. Memoing and discussions were conducted for documentation and triangulation (Strauss & Corbin, 1998). Fourth, disagreements were discussed between the two coders, and consensus was achieved through these discussions (Hill et al., 2005; Lincoln & Guba, 1985; Strauss & Corbin, 1998) on the themes across patient and provider responses. Finally, after this initial stage of coding was completed, 20% of transcripts were randomly selected for reliability coding by a third individual for auditing purposes (also a psychologist), with 82% agreement. Instances of nonagreement were discussed and a final consensus was achieved. Throughout the data collection and coding process, procedures were undertaken to enhance the validity and trustworthiness of the data (Meyrick 2006) including obtaining perspectives from both patients and providers and being transparent about description of methods, recruitment, data collection, and our analysis plan. Transcription, verification, and thematic analysis also involved multiple steps following established guidelines (Braun & Clarke, 2006). Quotes for themes that were identified are provided to illustrate each code and to provide enough "raw data" for readers to make their own interpretations (Drisko, 2005, p. 592).

Results

Descriptive Data

Of the 20 patients interviewed, 85% ($n = 17$) reported *never* having a conversation with a health care provider about their body image or how they feel about their bodies. By contrast, only 26% of providers said they *never* have conversations with their patients about body image. Figure 1 shows the frequency with which patients and providers reported engaging in these types of conversations.

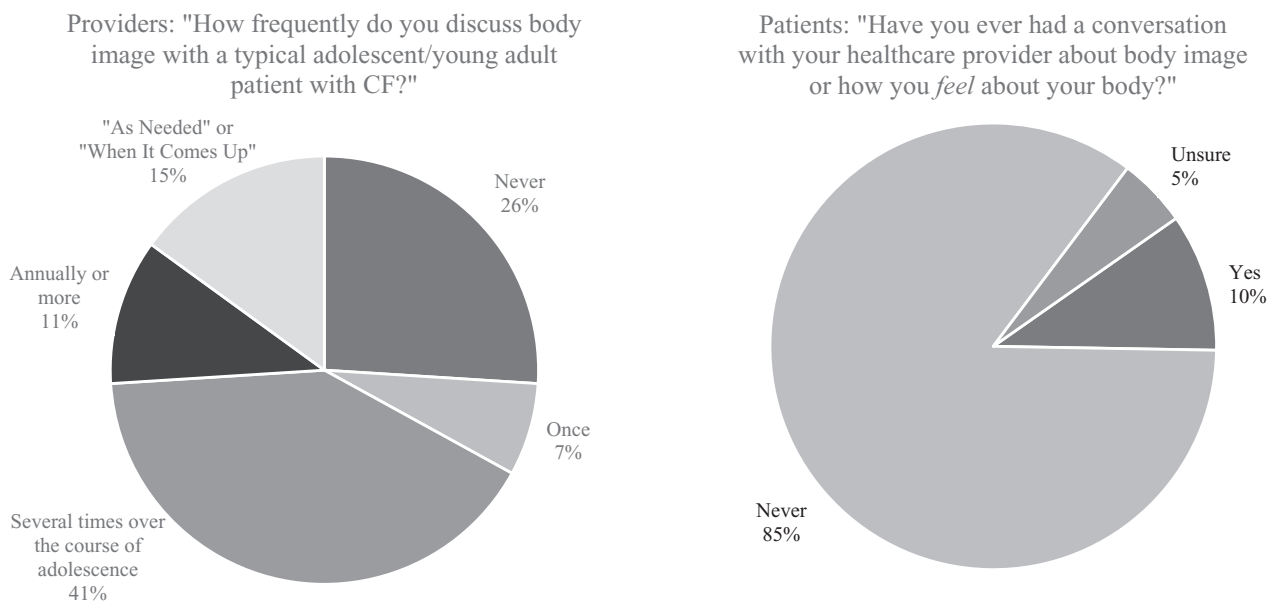


Figure 1. Health care provider and patient responses on frequency of body image discussions.

Patient Perspectives

Three themes were identified regarding when/how patients thought body image conversations should take place (1) as a routine part of care, (2) in a supportive and comfortable way, and (3) in a way that supports psychosocial health, separate from physical health indications. A fourth theme, regarding uncertainty and variability of approaches, highlights the challenges and nuances inherent in managing these types of communication.

Routine Part of Care

Patients described their desire for health care providers to include conversations about body image as part of the routine care received in clinic. One patient explained that having providers who routinely broach the topic could help patients to feel more comfortable, rather than expecting patients to bring up concerns on their own. Another patient emphasized the importance of addressing the mental and emotional aspects of body image periodically in conversations in clinic.

Bringing it up [routinely] so that the patient doesn't have to definitely would help a lot, because a lot of times people don't want to bring it up... Maybe [providers] could ask you questions and you can find out if the way you feel about your body isn't normal, and you could get help... [They could say] "A lot of people with your condition have skewed body images" or something like that. You could say, "Oh yeah. I think I might, like, have some of those problems." And they say, "Well maybe you can go talk to this person about it." (20-year-old female)

It may be a good idea to ask periodically how the person feels about themselves, you know, mentally and emotionally feel about what they're dealing with. And then you can tie body image into that. (21-year-old male)

Support and Comfort With Communication

Patients discussed the importance of feeling comfortable and supported by providers, which enables open, honest communication about sensitive topics, such as body image concerns. Patients described prior experiences (or desired experiences) with providers that highlighted engaged, empathic, authentic communication skills, and that demonstrated providers' investment in them, both as patients and as individuals.

My main thing is feeling comfortable with telling anybody anything, because I don't... I mean, me personally, I just don't talk about how I feel... There's a big trust issue. (15-year-old female)

You're hearing, but you're not listening. That's a big thing, especially with teenagers... really understanding... if you try to get me to talk, and if I feel like you're not listening, I'll shut down. (18-year-old female)

It would kind of depend on the doctor. How comfortable [patients] are actually talking... you usually can tell the interest they have in you. Like, my doctor talks. He even asks about my personal life... and you can actually tell that he cares. (19-year-old male)

Because many patients identified the importance of a strong interpersonal connection with the provider who is discussing body image, they sometimes varied in identifying which specific provider might be the most appropriate individual to initiate these discussions: some preferred the idea of discussing body image with their routine health care providers (particularly when those interpersonal connections were described as being strong), whereas other patients suggested they would feel more comfortable with a psychosocial specialist, devoted to this topic. Across these responses, patients expressed their individual perceptions about types of providers who would help them to feel most comfortable and

supported, as well as ways that those providers could uniquely approach the body image topic in supportive ways.

They're not really concerned with, like, your psychological problems—it's not really their job. . . I don't really think the doctors are concerned with how you feel about your body because they can't do anything about that. And they don't really know, they're not trained in how to, like, deal with it. They're doctors. For your lungs, body. (20-year-old female)

Someone who's like, only focused on that. . . I wouldn't want to talk to, you know, a doctor or a nurse really because they're more set on—you know—it's not a bad thing it's just their job, it's more set on the facts and the health. . . at the end of the day that's not their job, that's not their main focus. And I think that says a lot. (16-year-old female)

Well, the one person I don't advise is like the therapist type deal. The ones who's like, "Are you depressed?" or this and that. . . Therapists usually try to take it too far. It doesn't feel like you're just having a conversation. It feels like they're looking down, kind of, or just a whole different environment. (21-year-old male)

Supporting Psychosocial Health, Separate From Physical Health

Patients discussed the often-unclear boundaries between physical health concerns (e.g., weight, BMI) and psychosocial concerns (e.g., body image, *feelings* about, or *reactions* to, these health concerns). Patients discussed their preference for body image to be discussed *separately* from the topics of physical health and weight, for a variety of reasons. Some individuals highlighted the difficulty in discussing their feelings about body image with providers who were addressing the topic within the context of their medical goals for weight gain. This challenge was often exacerbated among patients who felt that their own health or weight goals differed from the goals of the medical team (e.g., feeling satisfied with themselves at a lower BMI than their medical team recommended, conflicting opinions about g-tubes, or other interventions). Particularly when patient and provider goals do not align, patients discussed feeling uncomfortable talking openly or honestly about their body image within the context of health- and weight-related medical conversations.

Just kind of be casual about it. Don't really push, like, "You need to gain weight. . . You would be healthier if you were this." Not pushing the negatives. . . because we try [to gain weight]. We try very hard, and sometimes we just can't. I don't think they believe us at all. (16-year-old female)

It kind of sucks because every time you come in, they weigh you, and they're like. . . "Gain more weight or you'll get another g-tube." . . . You're eating a lot of food, but they're still telling you that you're not eating enough. It's, like, always the case. . . They don't really care [about my frustration], they just want your weight up. . . I always try to please them [even though I don't want to gain weight]. . . I'm fine with the way I am, but I'm just always trying to please them because they're in charge. (17-year-old female)

They want me 150 to 170 [pounds]. . . I don't feel comfortable being over 150. I kind of feel fat. . . They just say, "You need to eat more. . ." but at the same time, it's not really a big problem with the weight. . . It's just, I'm not at their ideal, but I'm at my ideal.

(21-year-old male)

Uncertainty and Variability of Approaches

Finally, participants discussed their own uncertainty about when or how health care providers should discuss topics related to body image, and/or expressed the need for flexibility in handling these concerns. For example, patients stated that body image can be a "touchy subject" and as a result, care providers need to "definitely ask the right way," but without having a clear vision of what the "right" way might be. Others stated that "everybody's different" or that the conversations "can go both ways—[patients] could bring it up, or maybe the doctor." Lack of experience with having these types of conversations led some patients to share that they "don't really know [how to have body image conversations] because I've never had anybody really ask me about it." Patients highlighted the diversity of AYAs with CF and the need for conversations to be approached differently across individuals, but acknowledged that their lack of experience in having these types of conversations routinely in clinic contributed to their uncertainty about how best to structure the dialogue.

Teenagers all have different ideas on what their body image is. . . no matter what kind of questions you ask, it'll always be different and each teenager will give you their own kind of opinion on it. (15-year-old female)

Provider Perspectives

Similar to themes from patient interviews, providers also discussed the importance of (1) making body image conversations part of routine clinic care, and (2) doing so in a supportive and comfortable way. However, unlike patients, providers discussed their positive perceptions of (3) engaging in body image conversations via their connection to health (specifically weight/growth) concerns. Finally, providers also discussed their uncertainty and variability in handling these concerns.

Routine Part of Care

Providers shared the belief that body image concerns should be discussed as a routine part of clinical care. Providers acknowledged the competing demands for time within already busy clinic visits, but generally supported the importance of integrating body image conversations more regularly, perhaps as part of an annual screening, with more frequent follow-ups as needed. Providers noted that a primary benefit of incorporating these assessments routinely would be to normalize the experience for patients.

During clinic appointments as a part of the social work assessment. Ideally, it would be something incorporated into the assessments and normalized. . . let everyone know that we now discuss body image with everyone. Also, I think more than one person from the team could be addressing body image. . . especially since one person will not be able to adequately reach everyone. (Psychosocial Provider)

[Body image should be discussed] as part of a year assessment with the nurse. Perhaps having a check-list of items to go through regarding body image to help them broach the topic and make a normal part of their visit once a year. Follow-up yearly if no concerns, or at each visit if the patient has positive items on the check-list. (Physician)

Ideally a psychology/social worker, but typically it would be an attending physician. . . which is ok too—little availability of others. Should probably be a routine screening question during adolescence, which gets repeated occasionally over time. (Physician)

Need for Comfort

Providers discussed the importance of helping patients to feel comfortable, to facilitate open, honest communication about body image. Providers noted that for many adolescents, this requires both a strong interpersonal connection between patient and provider, as well as timing conversations under “circumstances which are comfortable for the patient,” specifically “when the parent is not around.”

I have found that patients talk more openly to the provider they feel most comfortable with regarding body image. It can be such a sensitive topic that the patient needs to feel connected to the provider. (Dietitian)

Linking Body Image Conversations and Health

Providers shared their perspective that body image conversations were most easily and/or most appropriately broached within the context of health-related topics, such as weight, growth, and nutrition. For example, one physician noted that these conversations should occur “when reviewing growth curves.” Another physician recommended that providers discussing body image should “include information on how nutritional state may affect overall health and lung health in particular.” A third physician explained, “For those who are underweight, it is easiest to ask how they think or feel about their current weight—is it desirable or would they like it to be different?”

Uncertainty and Variability of Approaches

Finally, providers acknowledged either uncertainty about how or when to bring up body image with patients, or they believed that these conversations should occur at differing, and sometimes vaguely identified, times. For example, physicians, respiratory/physical therapists, and dietitians all stated that these conversations should occur at the “right time,” “whenever needed,” “if the signs are there,” or when concerns

are “sensed.” Some physicians also stated that they were “unsure” or felt that they “really have no idea” how or when to discuss body image with patients. Lack of knowledge or familiarity with the topic of body image was identified as a barrier to providing more routine and in-depth discussions, as well as lack of personal comfort with the topic.

Discussion

Overview of Findings

Prior research has clearly documented the importance of body image among AYAs with CF, often impacting not only psychosocial functioning, but also the long-term health and survival of patients who are unable or unwilling to maintain adequate BMI (Tierney, 2012). In this sample, both patients and providers acknowledged that body image is an important topic; however, conversations about body image are infrequent and generally *not* part of routine care. Based on these results, providers often are aware of the need for discussion about body image, yet are uncertain about how or when to initiate these conversations. Both patients and providers report some variability in who is the most appropriate person to initiate these conversations—often unique to the individual and his/her relationship with specific providers. Findings indicated a number of barriers and recommendations for having these conversations. Consistent with previous work examining factors affecting the openness and effectiveness of communication between patients and providers (Beresford & Sloper, 2003), communication skills were noted as being of critical importance for having conversations about body image with AYA patients.

Patients and providers disagreed about the overlap between body image and physical health conversations: Providers prefer to introduce the topic of body image when discussing weight, growth, BMI, and other health status indicators. By contrast, patients view body image and health as distinct and sometimes opposing goals, particularly when weight-gain goals are not being achieved or when patients and providers have differing opinions. Understanding patients’ personal and health-related goals is particularly relevant during adolescence and young adulthood, owing to the importance of goal pursuit, individuation, autonomy, and increasing responsibility for self-care characteristic of these developmental periods (Ernst, Johnson, & Stark, 2010; Schwartz & Drotar, 2006). Particularly among AYAs, who may favor short-term rewards rather than long-term gains (Reyna & Farley, 2006), acknowledging and working through potential areas of goal competition or goal conflict is essential. For example, females who value thinness may inadvertently sabotage long-term health and survival, owing

Table I. Recommendations for CF Providers Working With AYA Patients Regarding Communication About Body Image

- Body image should be discussed as a routine part of CF clinic care.
- Communication approaches should be individualized and tailored to maximize patient comfort and openness in talking about body image:
 - Treatment teams should consider who is the most appropriate provider for having body image discussions with each patient, noting that this decision may vary based on patient preferences and may change over time.
 - The provider having the conversation about body image should have an interpersonal connection and good rapport with the AYA patient.
 - The patient's preferences should be assessed regarding when and how body image will be discussed: Patients often prefer to have discussions about body image *separately* from topics of physical health and weight, particularly when providers' goals about patients' weight/BMI are not being met.
- Providers should have adequate knowledge about/comfort with the multifaceted topic of body image and health, and they should acknowledge challenges in reconciling competing goals with regard to body image and health, particularly for patients with notably discrepant goals (e.g., differences in provider vs. patient goals; patient's own internally competing goals for health, appearance, size, etc.)
 - Providers may identify the duality of patients' goals regarding physical functioning versus physical appearance, seeking to clarify areas of complementarity or contradiction.
 - Providers may explore rational/cognitive elements of patients' body perceptions ("What do you *think* about..."), emotional reactions or body-related attitudes ("How do you *feel* about..."), satisfaction ("How *satisfied* are you with..."), the importance or value patients place on various aspects of physical functioning and appearance ("How *important* is it to you that..."), as well as motivation to change ("What would it be like to think about changing...") and barriers/supports to change ("What might make it easier/harder to...").
- Discussions about body image are likely most fruitful when had with the AYA patient alone (without family members present), unless patient preference dictates otherwise

to this type of body image-related goal conflict (Abbott et al., 2000, 2007; Tierney, 2012). Clinical models for intervention may benefit from a focus on acceptance (i.e., the ability to tolerate negative emotional reactions to CF disease-related factors while still working toward goals), clarifying goals, increasing self-efficacy, and understanding ambivalence toward opposing goals or change (Ernst et al., 2010).

Recommendations for CF Providers

As described by both patients and providers, communication about body image cannot proceed under a "one size fits all" approach: identifying which provider is most appropriate given institutional and interpersonal considerations is essential, along with a variety of methods for identifying and meeting patient preferences. Given many patients' preferences for addressing body image separately from physical health, pediatric psychologists, social workers, and other mental health professionals offer the unique ability to spearhead the introduction of the topic of body image decoupled from the physical health components of care, and then facilitate communication with other CF health care providers as indicated based on individual patient needs. However, some patients noted a preference for this communication to occur with their routine CF care team pulmonologists or other care providers; in these cases, psychosocial providers may offer assistance in collaborating with other team members on relevant skills and knowledge for effectively meeting patient needs.

Table I provides a summary of recommendations for CF care providers regarding body image conversations. These recommendations reflect a distillation of the patient and provider perspectives from this study. It should be noted that there is a need for future research on best practices for patient-provider communication, as it relates to patient outcomes, as well as the best and most effective way of training providers on these recommendations. The recommendations discussed herein should thus be considered an initial guide, to be refined based on future research.

First, CF care teams should have regular discussions regarding body image with all AYA patients. Teams should have plans about which provider will initiate these discussions and how they will be followed up over time, with varying frequency based on identified needs. Previous work has indicated that this may be patient specific, and AYAs with chronic illnesses prefer to have important conversations with providers they are most familiar with and who they have known the longest; female patients also have shown a preference for having health care conversations with female doctors (Beresford & Sloper, 2003). Second, because of the sensitivity and challenges inherent in discussing body image, it is important to have providers broach this topic with skill, comfort, emotional understanding, and flexibility. Providers must be prepared to follow patients' leads when having these conversations. Taking a person- or patient-centered approach, rather than a disease- or condition-centered approach may be helpful to patients to open up further in these conversations (Beresford & Sloper, 2003). As noted above,

providers may prefer to bring up these discussions as part of their review of weight- and health-related topics; however, this may not be patients' preferences. Indeed, a key aspect of these conversations may involve open communication about discrepancies between providers' weight- or health-related goals and other competing goals or motivations for the patient or family. While family involvement may be beneficial, it may be helpful to have initial conversations with the AYA patient alone to maximize comfort and openness.

Providers with limited experience or comfort in discussing body image may benefit from additional training on conceptual models of body image or review of empirical literature on the topic. For example, providers should be comfortable in discussing the duality of physical functioning and health versus physical appearance, including ways that goals for each domain may complement or contradict one another. Providers should understand the complexity of the construct of body image, including (1) rational/cognitive components of one's own body perceptions, (2) attitudes/emotional reactions to current body perceptions and future goals, (3) satisfaction with one's body, (4) personal values or importance placed on one's body, and (5) motivation for change (Powell & Hendricks, 1999; Wenninger et al., 2003).

Taking a nonjudgmental and inquisitive approach in discussions of body image may also be beneficial, as AYA CF patients may not feel comfortable having conversations that they perceive as possibly leading them to reveal health behaviors that may be considered problematic by health professionals (e.g., dieting, maladaptive eating behaviors; Beresford & Sloper, 2003). If discussions of body image lead to discussions of health behaviors, providers are encouraged to use motivational interviewing techniques with AYAs with CF (see Gold & Kokotailo, 2007 for an excellent primer).

Limitations and Future Directions

The current study offers several unique strengths and contributions to the literature on body image among AYAs with CF; however, findings should be interpreted in light of limitations. First, this study represents a preliminary examination of patient and provider perspectives within a limited sample size. Future work should examine these issues within larger, more representative populations. Furthermore, given the small sample size and qualitative design, responses were not examined separately by gender, BMI/health status, provider discipline, or other demographic factors that may help to further contextualize the findings. Given prior research demonstrating unique gender-related concerns regarding body image, future research on this topic may be particularly relevant (Abbott et al., 2000, 2007). Additionally,

given the relative health of many participants in the current sample, future research may help to clarify the convergence or divergence of perspectives on body image communication among AYAs with more advanced lung disease and/or low weight/BMI. Second, provider responses were provided online, with free-response-style questions. This approach maximized the convenience (and response rate) among providers who otherwise may not have taken the time to conduct a lengthy, face-to-face interview; however, this approach also limited the ability to query unclear responses or elaborate on topics with the richness of a full qualitative methodology. As noted by Hill et al. (2005), researcher biases may be present in the design and interpretation of qualitative studies, though we attempted to minimize this bias by purposefully recruiting from a CF center within which none of the researchers conducting qualitative interviews or coding was directly involved in patient care.

Future work should examine both patient and provider perspectives on the implementation of body image conversations within clinic settings, and examine the effect of such conversations on important outcomes, including psychosocial functioning and physical health. For instance, an interesting next step might be to study the effect of interventions training providers on patient-provider communication around body image on important patient outcomes. This and other efforts to empirically test and refine the evidence-base for the included recommendations, is an important direction of future research. Patient satisfaction ratings of their interactions with providers pre- and postprovider training may also be helpful to examine. Ultimately, the field would benefit from future prospective studies in the area of patient-provider communication.

Acknowledgement

The authors wish to thank Shannon Hourigan, PhD, for her invaluable assistance with data coding for reliability analyses associated with this project.

Conflicts of interest: None declared.

References

- Abbott, J., Conway, S., Etherington, C., Fitzjohn, J., Gee, L., Morton, A. ... Webb, A. K. (2000). Perceived body image and eating behavior in young adults with cystic fibrosis and their healthy peers. *Journal of Behavioral Medicine*, 23, 501–517.
- Abbott, J., Morton, A. M., Musson, H., Conway, S. P., Etherington, C., Gee, L. ... Webb, A. K. (2007). Nutritional status, perceived body image and eating behaviours in adults with cystic fibrosis. *Clinical Nutrition*, 26, 91–99.

- Anthony, H., Paxton, S., Catto-Smith, A., & Phelan, P. (1999). Physiological and psychosocial contributors to malnutrition in children with cystic fibrosis: Review. *Clinical Nutrition, 18*, 327–335.
- Beresford, B. A., & Sloper, P. (2003). Chronically ill adolescents' experiences of communicating with doctors: A qualitative study. *Journal of Adolescent Health, 33*, 172–179.
- Boyle, M. P., Farukhi, Z., & Nosky, M. L. (2001). Strategies for improving transition to adult cystic fibrosis care, based on patient and parent views. *Pediatric Pulmonology, 32*, 428–436.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77–101.
- Bryon, M., Shearer, J., & Davies, H. (2008). Eating disorders and disturbance in children and adolescents with cystic fibrosis. *Children's Health Care, 37*, 67–77.
- Cohane, G. H., & Pope, H. G. (2001). Body image in boys: A review of the literature. *International Journal of Eating Disorders, 29*, 373–379.
- Cohen, D., & Crabtree, B. (2006, July). *Qualitative research guidelines project*. Retrieved from <http://www.qualres.org/HomeSemi-3629.html>.
- Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into Practice, 39*, 124–130.
- Cystic Fibrosis Foundation. (2015). Cystic fibrosis foundation patient registry, 2014 *annual data report*. Bethesda, MD: Cystic Fibrosis Foundation.
- Drisko, J. W. (2005). Writing up qualitative research. *Families in Society, 86*, 589–593.
- Ernst, M. M., Johnson, M. C., & Stark, L. J. (2010). Developmental and psychosocial issues in cystic fibrosis. *Child and Adolescent Psychiatric Clinics of North America, 19*, 263–283.
- Gold, M. A., & Kokotailo, P. K. (2007). Motivational interviewing strategies to facilitate adolescent behavior change. *Adolescent Health Update, 20*, 1–10.
- Helms, S. W., Dellon, E. P., & Prinstein, M. J. (2015). Friendship quality and health-related outcomes among adolescents with cystic fibrosis. *Journal of Pediatric Psychology, 40*, 349–358.
- Hill, C. E., Knox, S., Thompson, B. J., Williams, E. N., Hess, S. A., & Ladany, N. (2005). Consensual qualitative research: An update. *Journal of Counseling Psychology, 52*, 196–205.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park: Sage Publications.
- McCabe, M. P., & Ricciardelli, L. A. (2004). Body image dissatisfaction among males across the lifespan: A review of past literature. *Journal of Psychosomatic Research, 56*, 675–685.
- Meyrick, J. (2006). What is good qualitative research? A first step towards a comprehensive approach to judging rigour/quality. *Journal of Health Psychology, 11*, 799–808.
- Neumark-Sztainer, D., Paxton, S. J., Hannan, P. J., Haines, J., & Story, M. (2006). Does body satisfaction matter? Five-year longitudinal associations between body satisfaction and health behaviors in adolescent females and males. *Journal of Adolescent Health, 39*, 244–251.
- Pinquart, M. (2013). Body image of children and adolescents with chronic illness: A meta-analytic comparison with healthy peers. *Body Image, 10*, 141–148.
- Powell, M. R., & Hendricks, B. (1999). Body schema, gender, and other correlates in nonclinical populations. *Genetic, Social, and General Psychology Monographs, 125*, 333–412.
- Pumariaga, A. J., Pursell, J., Spock, A., & Jones, J. D. (1986). Eating disorders in adolescents with cystic fibrosis. *Journal of the American Academy of Child Psychiatry, 25*, 269–275.
- Ramsey, B. W., Farrell, P. M., & Pencharz, P. (1992). Nutritional assessment and management in cystic fibrosis: A consensus report. The Consensus Committee. *The American Journal of Clinical Nutrition, 55*, 108–116.
- Reyna, V. F., & Farley, F. (2006). Risk and rationality in adolescent decision making: Implications for theory, practice, and public policy. *Psychological Science in the Public Interest, 7*, 1–44.
- Ricciardelli, L. A., & McCabe, M. P. (2001). Children's body image concerns and eating disturbance: A review of the literature. *Clinical Psychology Review, 21*, 325–344.
- Savage, E., & Callery, P. (2007). Clinic consultations with children and parents on the dietary management of cystic fibrosis. *Social Science and Medicine, 64*, 363–374.
- Schwartz, L. A., & Drotar, D. (2006). Defining the nature and impact of goals in children and adolescents with a chronic health condition: A review of research and a theoretical framework. *Journal of Clinical Psychology in Medical Settings, 13*, 393–405.
- Smolak, L., & Thompson, J. K. (2009). *Body image, eating disorders, and obesity in youth: Assessment, prevention, and treatment* (2nd ed.). Washington, DC: American Psychological Association.
- Stallings, V. A., Stark, L. J., Robinson, K. A., Feranchak, A. P., & Quinton, H.; Clinical Practice Guidelines on Growth and Nutrition Subcommittee; Ad Hoc Working Group. (2008). Evidence-based practice recommendations for nutrition-related management of children and adults with cystic fibrosis and pancreatic insufficiency: Results of a systematic review. *Journal of the American Dietetic Association, 108*, 832–839.
- Stark, L. J., & Powers, S. W. (2005). Behavioral aspects of nutrition in children with cystic fibrosis. *Current Opinion in Pulmonary Medicine, 11*, 539–542.
- Stice, E., Hayward, C., Cameron, R. P., Killen, J. D., & Taylor, C. B. (2000). Body-image and eating disturbances predict onset of depression among female adolescents: A longitudinal study. *Journal of Abnormal Psychology, 109*, 438–444.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Swedlund, M. P., Schumacher, J. B., Young, H. N., & Cox, E. D. (2012). Effect of communication style and physician-family relationships on satisfaction with pediatric chronic disease care. *Health Communication, 27*, 498–505.
- Thompson, J. K., Coovert, M. D., & Stormer, S. M. (1999). Body image, social comparison, and eating disturbance: A

- covariance structure modeling investigation. *International Journal of Eating Disorders*, 26, 43–51.
- Tierney, S. (2012). Body image and cystic fibrosis: A critical review. *Body Image*, 9, 12–19.
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Healthcare*, 19, 349–357.
- Truby, H., & Paxton, S. J. (2001). Body image and dieting behavior in cystic fibrosis. *Pediatrics*, 107, e92.
- Tuchman, L. K., Schwartz, L. A., Sawicki, G. S., & Britto, M. T. (2010). Cystic fibrosis and transition to adult medical care. *Pediatrics*, 125, 566–573.
- Walcott, D. D., Pratt, H. D., & Patel, D. R. (2003). Adolescents and eating disorders: Gender, racial, ethnic, sociocultural, and socioeconomic issues. *Journal of Adolescent Research*, 18, 223–243.
- Walters, S. (2001). Sex differences in weight perception and nutritional behaviour in adults with cystic fibrosis. *Journal of Human Nutrition and Dietetics*, 14, 83–91.
- Wenninger, K., Weiss, C., Wahn, U., & Staab, D. (2003). Body image in cystic fibrosis—Development of a brief diagnostic scale. *Journal of Behavioral Medicine*, 26, 81–94.
- Willis, E., Miller, R., & Wyn, J. (2001). Gendered embodiment and survival for young people with cystic fibrosis. *Social Science and Medicine*, 53, 1163–1174.
- Wu, Y. P., Thompson, D., Aroian, K. J., McQuaid, E. L., & Deatrck, J. A. (2016). Commentary: Writing and evaluating qualitative research reports. *Journal of Pediatric Psychology*, 41, 493–505.
- Zack, J., Jacobs, C. P., Keenan, P. M., Harney, K., Woods, E. R., Colin, A. A., & Emans, S. J. (2003). Perspectives of patients with cystic fibrosis on preventive counseling and transition to adult care. *Pediatric Pulmonology*, 36, 376–383.
- Zemel, B. S., Jawad, A. F., FitzSimmons, S., & Stallings, V. A. (2000). Longitudinal relationship among growth, nutritional status, and pulmonary function in children with cystic fibrosis: Analysis of the Cystic Fibrosis Foundation National CF Patient Registry. *The Journal of Pediatrics*, 137, 374–380.