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I'm going to tell you a little about myself: Illness centrality, self-image and identity in cystic fibrosis

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I'm going to tell you a little about myself: Illness centrality, self-image and identity in cystic fibrosis

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Abstract

This study assessed the illness centrality of adolescents with CF and the specific ways that CF may affect adolescents' identities, through the qualitative analysis of video narratives. Adolescents with CF were loaned video cameras and asked to "show us your life outside the hospital" and to "teach your healthcare team about your CF." Four major themes were identified related to illness centrality: CF is Central, CF is Compartmentalized, CF is Integrated into Self Image, CF is Denied. Integration and compartmentalization often co-existed. Four themes emerged related to the role of CF in self-image and identity: (1) Valence (positive or negative); (2) Control (no control or some control); (3) Difference/Normalcy (different, normal, normal except for CF); (4) Acceptance/adaptation (acknowledgement of CF, reworking life to accommodate CF). Adolescents did not have just one feeling about CF but felt differently at different times. Younger and/or healthier adolescents were less likely to focus on CF as central to their self-image. When not dealing directly with treatments or clinic visits, these adolescents had identities comprised largely of "typical" adolescent interests such as school, friends, hobbies, and family. CF played a more prominent role in the identities of older and sicker adolescents. Adolescents also found ways to adapt or alter their lives and their CF-related activities to make them feel more like "normal" adolescents. Implications for treatment are provided.

Keywords

Self-image, identity, centrality, adolescents, cystic fibrosis, experience, video

Note

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Introduction

The purpose of this study was to determine from the video narratives of adolescents with cystic fibrosis (CF) how central CF may be to an adolescent's self-image and the specific ways in which CF may affect an adolescent's identity. CF is a chronic, life-shortening illness affecting primarily the respiratory and gastrointestinal systems. The median predicted survival age in CF is now nearly 40 years due to improvements in medications and treatments.¹ However, these treatments are burdensome and time-consuming,^{2,3} contributing to decreased quality of life⁴ and poor adherence.⁵ Understanding an adolescent's internal experience, including the components of his or her

identity, can support a stronger, more trusting patient-provider relationship, leading to increased patient adherence and improved outcomes.⁶⁻⁸

Illness Centrality

Illness centrality refers to the degree to which people define themselves in terms of their illness.⁹⁻¹² Most often, illness centrality is viewed as having adverse psychological consequences. Hegelson and Novak found that when females with diabetes viewed their illness negatively, centrality was related to poor psychological well-being.⁹ Luyckx et al concluded that illness centrality was negatively associated with emotional stability and self-esteem in adults with

diabetes.¹³ Other researchers have determined that illness centrality has a negative impact on self-esteem¹⁴ and well-being,¹⁰ and is associated with non-adherence.¹⁵ Admi, the only researcher to assess centrality in CF found that illness did not play a central role in the lives of affected adolescents and young adults.¹⁶

Self-image and Identity

Self-image is defined as “how a person sees himself”¹⁷ and identity as “how people think of themselves, the unique sense of personhood held by each person in their own right.”¹⁸ In this article, the terms self-image and identity are used interchangeably.

There is limited research on self-image in CF or other pediatric conditions. Landon et al¹⁹ found that males, but not females, with CF had self-images concordant with emotionally disturbed adolescents. Conversely, Sawyer found that females, but not males, with CF were less well-adjusted than their healthy peers.²⁰ Piquart assessed body image (one component of self-image) in CF patients and found that children and adolescents with CF had poorer body images than their healthy peers.²¹

Ferro and Boyle conducted a meta-analysis of quantitative studies comparing the self-concepts of children with and without chronic illness.²² They determined that youth with chronic illness had compromised self-concepts as compared to healthy control patients. The included studies evaluated participant responses to specific questions, but did not conduct open-ended patient-centered explorations of how their illness affects the self-images of young people with CF.

This study was part of a larger research project exploring various dimensions of the lives of adolescent CF patients. Earlier analyses suggested that for many young people self-image was based on typical adolescent issues (e.g., school, friends) and did not focus on CF. Consequently, we identified the following research questions: (1) How central is CF to the identity of an adolescent with CF?; and (2) How does having CF affect an adolescent's self-image or identity?

Methods

Subjects/Recruitment

The participants were youth with CF between the ages of 12 and 18 years who attended the University of Florida CF Center. Participants were loaned video cameras and asked to “show us your life outside the hospital” and to “teach your healthcare team about your

CF,” allowing adolescents to decide how much attention to pay each of these topics. Participants had full control over the information they chose to share with the research team by returning only the visual data they wanted to have analyzed. We used judgment sampling, enrolling exemplars of the adolescent population at our clinic, in order to assess a diversity of views. Participants recorded approximately 111 hours of participant-generated illness narratives.

Data Analysis

This study used grounded theory, which has been specifically recommended for research with the chronically ill²³. Rather than relying on *a priori* theories for perceiving and categorizing narrative material, we allowed themes to emerge from the material and proposed theoretical constructs based on these themes.

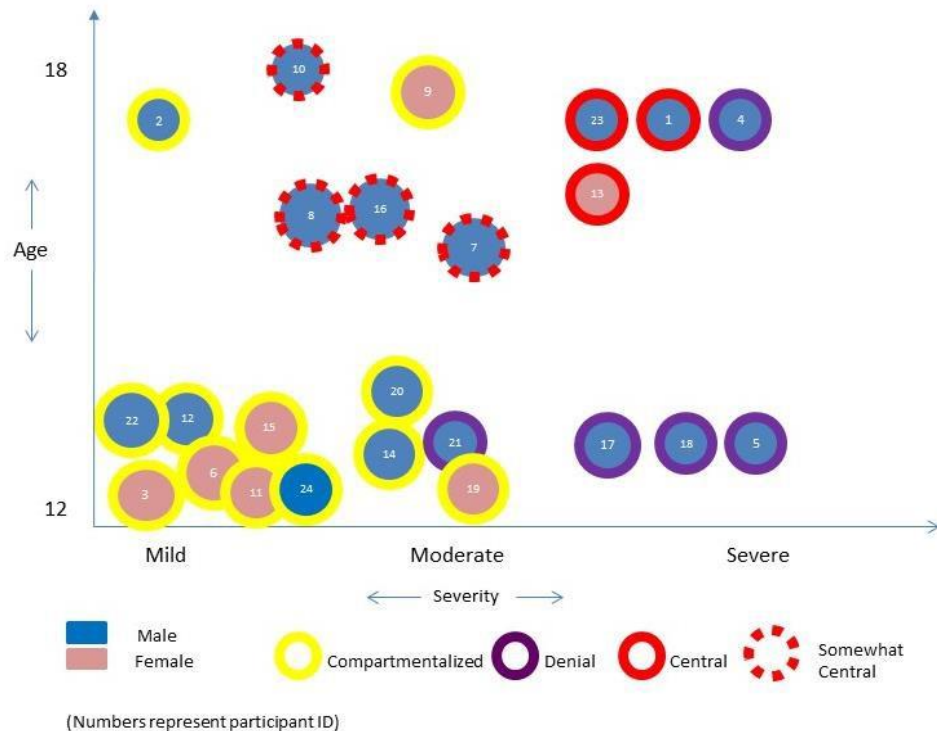
Data analysis included the steps of “logging” and “coding.” Loggers rigorously transcribed the videos verbatim using Transana software, including their own subjective observations and feelings. Videos and transcripts were thoroughly reviewed by the research team who identified preliminary themes. These themes became the initial coding categories into which transcripts (participants' narratives and loggers' comments) were coded. Separate coding categories were developed for each research question.

Team members met regularly to discuss code definitions and modifications, researcher bias and deviant samples. Memos documented researchers' thoughts, decisions, and reasoning. We worked iteratively between text and codes until we reached saturation and finalized themes. In order to assess reliability, two research assistants independently coded 13 tapes yielding an interrater reliability of 88% for themes related to illness centrality and of 91% for CF-self-image themes. We triangulated our findings on centrality by comparing the percentage of CF-related talk in the transcripts of older vs. younger adolescents and those of sicker vs. healthier adolescents. Percentage of CF-related talk was calculated separately for adolescents demonstrating denial.

Results

Participants comprised nine females and 15 males between the ages of 12 and 18. Fourteen participants were in early adolescence (12-14 years old) and ten were in later adolescence (15-18). Seventeen participants had mild/moderate lung disease (FEV1 >50% predicted) and seven had severe lung disease (FEV1 <50% predicted). (Figure 1).

Figure 1. Age, disease severity, and illness centrality of participants



Illness Centrality

Four major themes were identified related to illness centrality:

CF is Central

This code was used if the participant indicated, or the logger or coder observed, that CF was a significant part of how the adolescent saw him or herself. CF was central for three adolescents and partially central for four. CF appeared more central in a sicker and/or older subgroup of adolescents with CF. Cameron (Names of participants have been changed to protect confidentiality), a 16 year-old with mild obstruction, stated,

I'd say a big chunk of me is cystic fibrosis because it just affects everything you do. It's like you move all the time and you are active all the time no matter what you do, you are always breathing and that is the main thing it affects, so it's affecting every physical part of my life. Physically it affects every part of my life, it affects my breathing, it affects my eating, it affects those kinds of things... I think about my health every day just where I'm going with it and seeing if I'm getting better or worse.

Alex, 16 and severely ill, stated, "Well I think about my health every day, I can't think about a time that I don't. Everything I do is bent on what is good for the treatment of my health"; he then outlined multiple ways that CF impacted him. He filmed his bedroom, arranged to accommodate his illness, with encouraging posters on the wall. He highlighted a bookshelf holding all his medications that was easily accessible from either his bed or the central part of his room and demonstrated a rolling chair that allowed him to easily move his airway clearance vest. Eric, an 18 year-old, used his hour of video to focus exclusively on comprehensive management of his recent transplant. Melissa, 18 with severe disease, spent her days in one place in the living room due to CF-related fatigue and talked almost exclusively about CF.

CF is Compartmentalized

This code was used if, after openly discussing CF and CF treatments, participants focused almost exclusively on non-CF related adolescent activities such as school, friends, family events, activities, hobbies and sports. This "compartmentalized" approach was present in 12 participants and seemed to occur most often in younger, less seriously ill, participants.

For example, Alysa, a compliant 12 year-old with normal lung function, focused on her room, clothes, schoolwork and friends. A logger commented “*I think Alysa is showing us what makes up her personality - the things that describe who she is and what she likes.*” Another mused, “*I think it's great that she doesn't even think of herself and her health first. This shows that her illness really is not impacting her in way that inhibits her from enjoying life like a normal healthy 12 year-old.*” Yet another commented, “*It's interesting how normal Alysa is acting. It doesn't even seem like she has a chronic illness. From her interaction with [her friend] and her family, you can see Alysa is enjoying her vacation and does not let her illness stop her from living a normal life.*”

Another logger commented on a segment of a tape made by Wendy, a 16-year-old with moderate lung disease, “*I like seeing that Wendy has so many good friends...from what it sounds like, she has the same teenage mindset as everyone else her age. Having CF didn't make her grow up too fast according to this part of the video especially. She's a funny, carefree young woman.*”

CF is Integrated into Self Image

Integration was coded when adolescents alluded briefly to CF, or showed momentary symptoms (e.g. fatigue or coughing) and then kept going with other activities. In these moments, the adolescent acknowledged CF, but CF was not the adolescent's primary focus. The twelve participants who compartmentalized also showed integration. This pattern is demonstrated in the following dialogue between Shaun, a 14 year-old with mild lung disease, and his friend Davis, while skateboarding:

Shaun coughs a lot

Shaun: I have got to clear my lungs a bit. That's CF for ya. It's kinda suckish. This tree fell down, it looks cool

Davis: Hey!

Shaun: What?

Davis: It don't fall no more. I tell you if you double strap these *(interrupted by Shaun)*

Shaun: Okay shut up, I need to talk to the camera. This is like our first time making videos for real, so we're gonna start making a bunch of skate videos *(he then goes on to film the two boys skateboarding).*

Jewel, a 13 year-old with mild lung disease, said to the camera “Good morning, I just woke up and got my treatment and now I'm getting dressed...well I'm off to school and I will be back at 2:15, 2:30 maybe. I don't know. Um, be back soon. And just letting you know, this is what I'm wearing. (Camera is turned so you can see her outfit.) I got a pink collared shirt on with a pink tank top and my blue skinny jeans. But um, see you guys soon.”

Veronica said, “Okay... I'm done with my Pulmozyme (A

medication to thin mucus), now let me show you what I have for dessert. Blueberry pie with whipped cream and it's right by me and I love it. So Thanksgiving was really fun. My cheer competition went well, but as you can see I have a little bruise like right against my eye right here. You really can't tell, but it kind of hurts a little. Anyway, so my cheer competition went well but like umm... my friend's bow in her hair, it fell out.

CF is Denied

Denial was coded when participants rarely or never mentioned or showed anything related to CF. Five participants, 4 of whom were severely ill, were coded as using denial. While CF was apparent from their low weight, fatigue or frequent coughing, these participants excluded CF entirely from their views of themselves, or the views of themselves that they showed to others. Unlike other participants, those coded as being in denial did not introduce themselves in the first video as having CF. Four of these participants simply launched into recording activities. The fifth started with, “Hello my name's Matt. I am 16. It is July 6th 2010. It's my first day of taping. And it's going to be a brief day. I'll show you where I live and how is my family and stuff here and there from my daily life.”

The percentage of CF-related talk was higher in older adolescents (32%) than younger adolescents (13%), and in sicker adolescents (73%) than in healthier adolescents (14%). Despite the fact that the majority of adolescents in denial were quite ill, they spent only 6% of their tapes on CF-related material.

The impact of CF on self-image and identity

Four themes emerged related to the role of CF in self-image and identity: (1) Valence (positive or negative); (2) Control (no control or some control); (3) Difference/Normalcy (different, normal, normal except for CF); (4) Acceptance/adaptation (acknowledgement of CF, reworking life to accommodate CF). Each of these themes is described in more detail below.

Valence (Negative/Positive)

Negative or positive valence was coded if adolescents, loggers or coders identified an adverse or beneficial impact on an adolescent's self-image.

Negative: Comments such as “It's kind of a pain,” “It's annoying,” “I kind of hate it” “I'd rather not have it” or “I don't really like it” were common. Ara, a 17 year-old with moderate disease, ranted, “No one gives a shit. No one cares.” Alex went on a short tirade: “It sucks, it really sucks. Nobody likes having illnesses. Nobody. Nobody can look you in the face and say ‘yeah its awesome, I love it.’ I almost cursed just then...”

Positive: Sometimes adolescents expressed a sense of

pride in their knowledge of CF and their consistent adherence. Several participants emphasized their exercise routines. Ben, describing a day when he attended marching band with a PICC (Peripherally Inserted Central Catheter) line still in, said, "and I think, like people are generally impressed by that, because, you know, I had a PICC line in... but I was healthy. I was physically really able." Other participants noted that having CF had given them capabilities that they would not otherwise have had. Cameron observed, "I wouldn't mind if there wasn't [a cure for CF] because this routine that I have to go through every day helps me get into motion with things and helps me out with life, so it isn't really that bad." Alex commented, "The illness gives me, I develop skills I probably wouldn't have like when, like, for example, I talk with adults a lot easier than most kids my age." And at another point he continued, "I have to say though, that what I have learned having the illness, I think I'm a better person because of it. As that might sound strange, I feel like I wouldn't learn or be as knowledgeable as I am now."

Amount of Control (None/Some)

"No control" was coded when participants verbalized ineffectiveness at influencing their health. "Some control" was coded if participants verbalized or implied that their choices and behaviors could influence their health.

No Control: Ara said, "[Life] doesn't hold back and go, oh I'm gonna give you 5 minutes so you feel better. Every morning I wake up either puking my guts out or not feeling good or just nauseous...and there's no stopping it, it just comes and it takes over you." Alex said bitterly, "My challenges have been huge, they add up, but there's nothing I can do! I'm stuck. I could sit here and complain constantly and just become annoying on this camera but that's not gonna change anything. It's not gonna make the slightest difference in the fact that I have it, or the fact that the illness will care. It's not gonna stop killing me or whatever it's doing. You know it's not gonna care. It's gonna keep going."

Some Control: Other participants, and the same participants at other times, felt that they did have some control over their health. Alysa commented, "I think my health is very good. I've done all my treatments. I was diagnosed with cystic fibrosis when I was 6 months old. So after that I've just done my therapy, hypertonic (A solution of sodium, chloride and water that is inhaled through a nebulizer, as a mist, in order to thin secretions), TOBI (Inhaled Tobramycin®, an antibiotic), all my pills, everything. I've done it. Never missed one day of doing my therapy, not one day...so, my health is very good." Alex stated, "...I mean that the illnesses will worsen, or I'll develop more, and I can control them and I can impede their progress upon me

by taking medications and doing stuff that my doctors prescribe. It's still a small amount of control. In the big long run, it's still not really doing the biggest difference. It might slow it down, but it will not stop it...but, I have control to an extent."

Difference/Normalcy

Adolescents' views and loggers'/coders' observations were coded into three categories: "I'm normal," "I'm normal except for having CF," "I'm different, I'm not normal due to CF." A fourth expression related to normalcy, "finding a new normal", was categorized under "adaptation."

Normal: Loggers frequently commented on participant "normalcy." For example, a logger commented about Alysa, "I have noticed in Alysa's video's that although she has CF she does not let her illness affect her physically or emotionally because she is very active in sports and seems to have many friends...[It] seems as if she loves name-brand clothing like most adolescents. Alysa seems to really like books. She also really seems like a "normal" kid who just had a great Christmas with her family and got a lot of great presents. She doesn't seem to mention CF too much about getting in the way of her normal routine and happiness." Observing Veronica, a logger commented, "I like how she and her friend play together with make-up and makeovers. It's very typical games for girls her age and it's nice to see she does all the same things many other girls do...it's great that they're playing like this together it shows some normalcy for Veronica's life."

In another example, Jayden made no reference at all to CF as she mused aloud about her life:

"What's been on my mind today is wondering if I'll ever be with my, be living with my mom, at her house. I enjoy riding my horses, playing with my aunt, my dogs, my cats. What really annoys me is when my animals don't listen and whenever I have to watch the news or different stuff like that. Or my brothers really annoy me and when my animals don't listen, really annoys me."

Normal except for CF: Some of the adolescents viewed themselves as "normal except for having CF". Ara stated, "I'm pretty much a normal person except for the cystic fibrosis. I don't feel different than most people except my lungs shut down...or my pancreas gives out. But otherwise I feel normal." Often these participants wanted to prove to others that they were normal. Ben said proudly that he was "more normal than a healthy person," and then discussed bicycling 20 or more miles per day.

Cameron expressed the need to prove that he had the same abilities as others: "I don't like it [CF] because

people underestimate me for it which is something I feel that nobody should be underestimated, that's just unfair for everyone and people take natural disabilities and think this person can't do that or this or none of that." In one of Alex's tapes a logger wrote "*I wonder if Alex feels any resentment when people tell him he can't do something, I think part of the reason he is such a natural leader or so headstrong is that he is trying to prove to others he can do it.*" Ara commented, "I'm pretty much a normal person except for the cystic fibrosis. I don't like people to know about it. I want people to like me for who I am and what I can do and not just because I have a disease. Because that's just not cool."

Not normal: Sometimes participants expressed feeling different from others. Veronica said, "I feel like I'm the only person who has it and other people like don't know that I have it so I'm just gonna try and like keep it a secret... whenever my friends are out there, I feel like they don't understand. Like Jaime, Elyse, Eddie, and all those people. I wish they'd understand because um, I wish they'd like, when I have them over at my house, I feel kinda embarrassed. Well not really embarrassed, but like, it's just kinda awkward to show them all my stuff when they don't have that stuff too." Alex stated, "Other people go around thinking 'Oh you're such a trooper.' That might be true but it's like I wish I didn't have to be. I just want to be normal, whatever that means."

Acceptance/adaptation

This was coded if adolescents acknowledged and demonstrated acceptance of their condition, adapted their situations to accommodate CF, or re-defined normalcy to fit their situations.

Tom, who was very ill, stated, "I get to hang out normally, as normally as I can I should say or just to get through the day." Marcus nodded emphatically when his mother asked if CF was normal to him because it was all he knew.

Most adolescents stated or demonstrated that in some way they had adapted to CF in a way that allowed them to accept it and to feel more normal.

Acceptance/adaptation was apparent when treatments were described or shown to be routine. Dan remarked, "I had it [CF] pretty much since I was little so it's just pretty much second nature. [My friends] are all used to it, they really don't care. I don't know it's kinda everyday." Alex, clearly verbalizing his acceptance, said, "I'm pretty comfortable with my illness... I'm not one of those people who gets upset if you make fun of it or make jokes about it." A friend of Wendy's said to her, "I think you deal with it tremendously well. That you have come to the reality that this is just who you are and you are gonna live your life to the fullest with it

or without it and that's just who you are and who you are gonna be."

Adaptation was also shown when activities such as videogames or other technology were described by adolescents as helping them pass the time while doing treatments. Some adolescents decorated their airway clearance vests or had friends/family members sit with them as a way of making the process more enjoyable. Dallis, a 12 year-old boy with normal lung function, used a nebulizer for inhaled antibiotics. He said to the camera, "I kinda like doin' this because it makes me feel like a dragon. Watch! (takes 3 puffs and blows some out) I just blew out smoke, like a dragon. Really neat!" Adolescents often had accommodations (fewer chores, a shortened school day) that allowed them to adapt their daily lives to their illnesses.

Acceptance and adaptation were also evident in participants' maturity, evidenced through humor and making meaning of the illness, frequently admired by loggers. When putting on his airway clearance vest, Alex proclaimed, "Prepare for war!" Waving an Acapella[®], a hand-held airway clearance device that provides resistance when blown into, moving thick mucus so that it can be coughed up, he announced with a laugh, "I get them when I leave the hospital. It's almost like a gift, comes free with every hospitalization!" Alex reflected that although he was not religious, he felt that he had been "given" CF because he "was the only person who could handle it." In the transcript, the logger wrote, "*Alex's statement would make it seem that he is in full acceptance of his illnesses.*"

Discussion

Summary of Findings

Younger and/or healthier adolescents were less likely to focus on CF as central to their self image, as evidenced by the low centrality and frequent sense of "normalcy" in these adolescents' lives. When not dealing directly with treatments or clinic visits, these adolescents had identities comprised largely of "typical" adolescent interests such as school, friends, hobbies, and family. A cough or question about CF might yield a brief verbal acknowledgement of the condition, but the adolescent easily returned to non-CF topics. For these participants, "compartmentalization" and "integration" were complementary. Participants focused on CF during treatments or CF-specific discussions; CF was only lightly integrated into their identities the rest of the time. Such compartmentalization supported adolescents' wishes to feel and appear "normal."¹

Consistent with previous findings,¹⁶ CF played a more prominent role in the identities of older and sicker adolescents. Sicker adolescents were more limited by

their illness and, as a result, CF was more central in their lives and less easily compartmentalized. A few, typically sicker, adolescents were in denial and did not acknowledge CF at all. Paradoxically, CF symptoms of the 4 ill adolescents demonstrating denial were seen as central to researchers viewing the visual data.

When CF affected adolescents' identities, it did so through positive and negative self-attributions, greater and lesser senses of control over the illness, and variants on feeling normal or different. Participants did not have just one feeling about CF; regarding each of these dimensions, adolescents felt differently at different times. They found ways to adapt or alter their lives and their CF-related activities to make them feel more like "normal" adolescents. These findings were consistent with Charmaz's¹² observation that people often "ignore, minimize, struggle against, reconcile to and embrace chronic illness at different times."

Our findings that CF can have a negative impact on identity, that adolescents fear not feeling normal, and that adaptation is important in CF are consistent with findings from previous studies.^{24,25} At the same time, we found that many adolescents with CF appeared to feel normal much of the time and that, for these young people, CF had a limited impact on their identities. Some adolescents identified positive effects of CF on their self-images. The narratives of these adolescents were consistent with Arthur Franks' "quest narrative"²⁶ in which a patient gives meaning to illness and with the conclusions drawn by other investigators that there is value in finding ways to adapt to chronic illness.^{12,27}

We also found areas of difference with previous research. Adams²⁸ categorized asthma subjects into "acceptors" on the one hand and "deniers/distancers" on the other. We found that adolescents could distance from (compartmentalize) their CF while also accepting it, and that deniers were an entirely different category. Showers et al.²⁹ identified compartmentalization and integration as two contrasting ways of managing negatively viewed aspects of the self. In our study, compartmentalization and integration were complementary ways of adaptively incorporating illness into the identities of adolescents with CF.

Implications for Treatment

Recent attention has been focused on the elevated rates of depression and anxiety in people with CF.³⁰ Positive self-concept, an essential component of mental health, is related to adherence and better physical health outcomes, while negative self-concept has been linked with depression, anxiety and worse physical health outcomes.^{23,31,32} Clinicians should appreciate the complexity of adolescents' feelings related to CF^{12,16} and interact in ways that enhance adolescents' self-esteem --

demonstrating empathy so that the patient feels understood and supporting the positive, non-CF elements of an adolescent's self-image. Based on our findings, key recommendations for clinicians caring for adolescents with CF include:

1. Understand that adolescents do not experience CF in one singular way. CF may affect self-image in both positive and negative directions. Providers should empathize with an adolescent's expressed experience during a particular clinic visit, while also bearing in mind that this is part of a larger, complex illness experience.
2. Empathize with adolescents' feelings about control or powerlessness. Reinforce adolescents' control over their illness when they speak of it, but acknowledge the limits of control when this is expressed.
3. Remember that compartmentalization of CF is not denial. Adolescents who compartmentalize may not wish to discuss their CF, but can attend to their treatments. Adolescents who deny CF ignore treatments.
4. Support the positive aspects of identity that the adolescent endorses. For patients who compartmentalize, support their enjoyment of and pride in normal adolescent activities. Link the completion of treatments with being able to more fully participate in typical teen activities. If the adolescent expresses pride in adhering to their treatment, affirm this.
5. Bolster adolescents' sense of normalcy by supporting adaptations to CF. Remember that feeling like their peers is of paramount importance to adolescents.
6. When consistent clinician empathy has supported adolescents to feel more resilient, ask them what positives have come from their experience with CF. Bear in mind, however, that when a patient is feeling disheartened about his or her CF, a focus on positives may be experienced as un-empathetic.

Limitations

By defining "identity" broadly, this study may not have adequately differentiated between actual and wished-for identity. Aware of the video camera's "gaze", adolescents in this study may have presented more positive self-images than they actually felt. Taylor and Brown³¹ noted that youth with chronic illness may

systematically overestimate their self-concept as a self-protective mechanism. We espoused Charmaz's¹² belief that "identity implicitly takes into account the way people wish to define themselves."

This study may not have captured visceral, preconscious, nonverbal elements of adolescents' experiencing CF as part of themselves. Conversely, it is also possible that because the project asked participants to teach providers about their CF, they may have focused more on CF than they otherwise would have.

Finally, these findings are not generalizable to adults with CF, whose personalities are more fully developed and who likely have more advanced lung disease.

Future Research

Qualitative research is used to generate hypotheses. It would be useful for future quantitative studies to formally measure the relationship among illness centrality, illness severity, and age and to evaluate associations between illness centrality and wellbeing or adherence. Researchers could also test the hypotheses that younger adolescents experience less internal sense of ownership of CF and that ownership and integration of CF into an adolescent's identity increase with age. Future research may also wish to assess the efficacy of structured interventions to support and validate adolescents on the four CF-related themes we identified as well as exploring ways to address adolescents' denial.

Conclusion

The centrality of CF to affected adolescents' identities varies over time and across individuals. How an individual patient experiences and makes meaning of living with CF has a profound effect on his or her adherence to medical treatment, physical, and psychological wellbeing. Adolescents with CF have identities based on aspects of themselves unrelated to CF as well as varying acceptance and integration of their chronic condition in their self-images. Providers should identify and respond to the components of self-image most salient for a given adolescent, empathizing with the difficulties and reinforcing the strengths.

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