

Behavioral and Social Factors Associated with Oral Diseases in American Patients with Cystic Fibrosis

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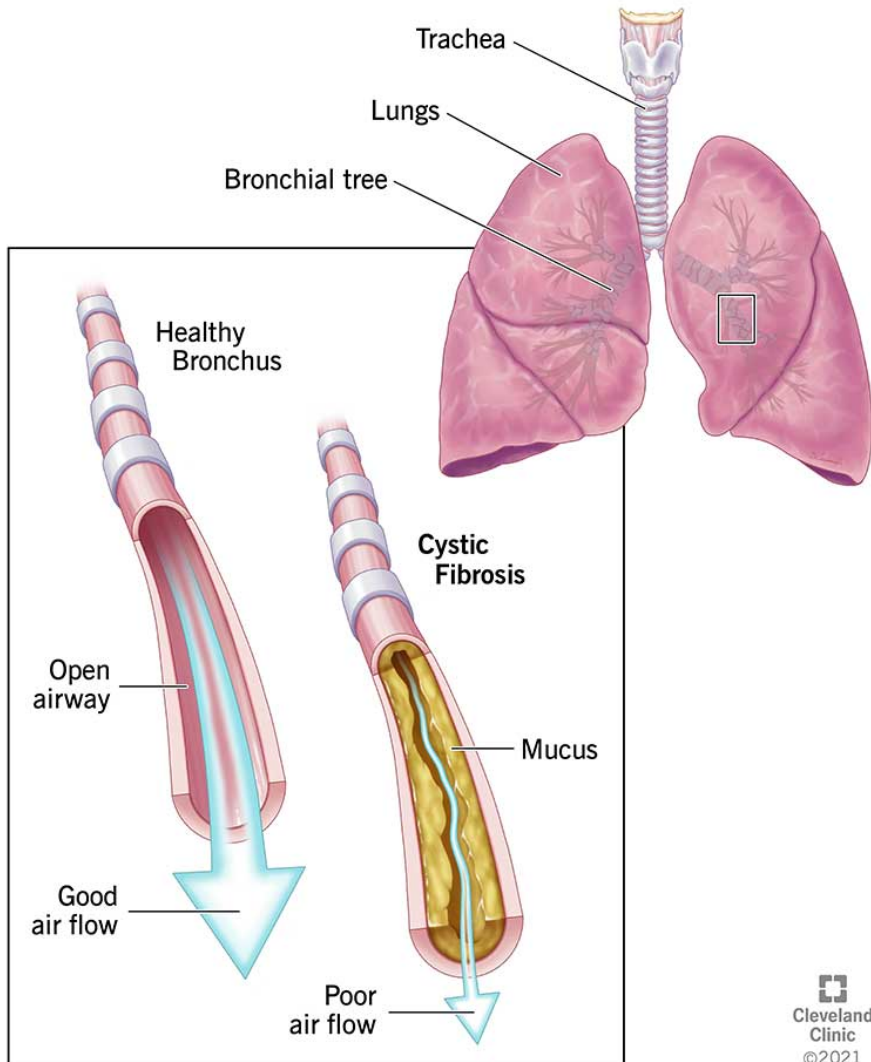




Conflict Of Interest Disclosure

The research team has no actual or potential conflict of interest to report.

Oral Health and Cystic Fibrosis



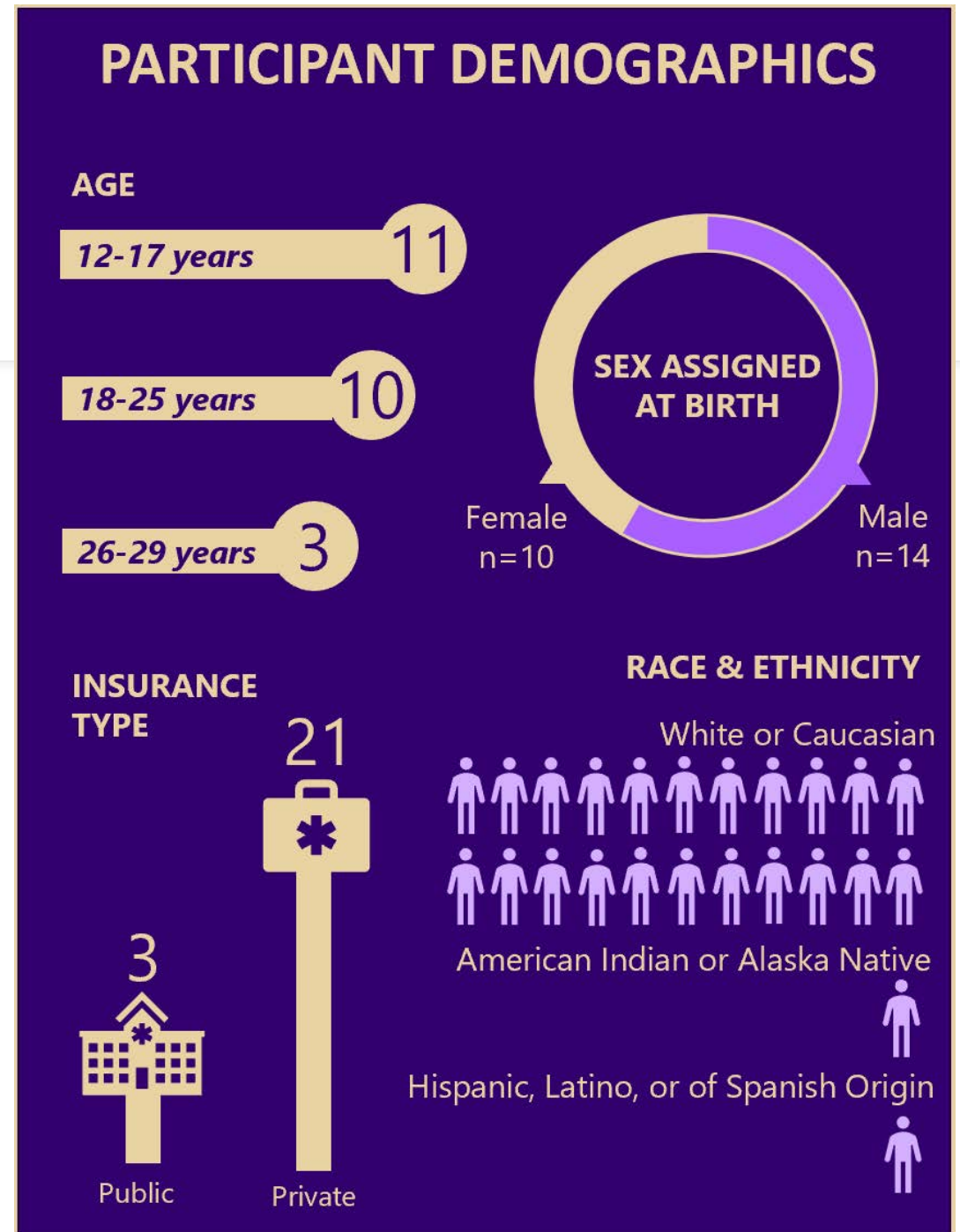
- Cystic fibrosis (CF) is the most common life-limiting autosomal recessive disease in Whites (1)
- CF affects nearly 40,000 children and adults in the U.S. (1)
- Long-standing view since 70's that individuals with CF are low risk for caries (6-12), despite high-risk profile:
 - frequent carbohydrate intake, high intraoral streptococcus mutans levels, altered saliva, and gastric reflux (3-5)
- Previous studies have shown oral bacteria may infect the lungs in individuals with CF (13)

Study Aim

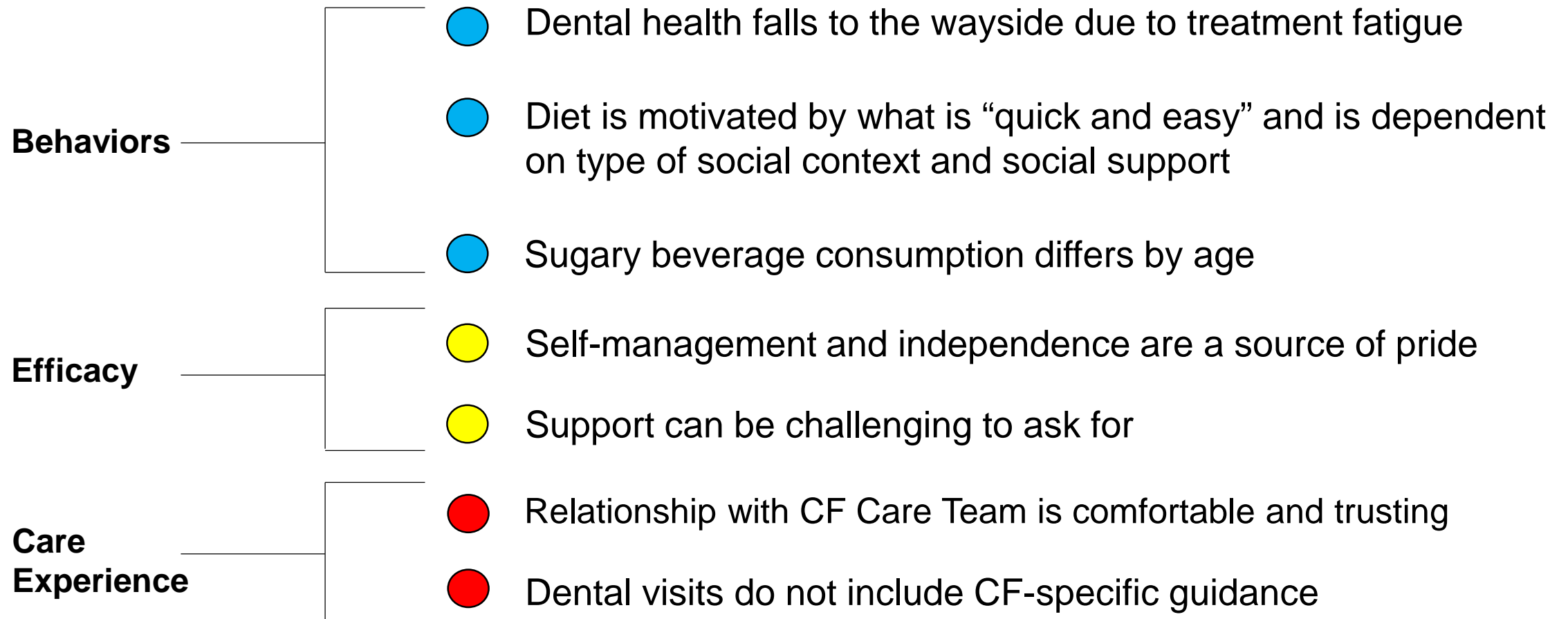
Examine behavioral and social factors associated with oral diseases in individuals with CF

Study Design & Demographics

- Semi-structured qualitative interviews from October to February 2022 with individuals 12 to 30 years old with CF
 - With parent/guardian for participants under 18
- Participants recruited from three CF Care Centers
 - Seattle Childrens, University of Alabama at Birmingham, and University of North Carolina
- Interview questions inquired about diet, experience with CF care teams, oral health behaviors, and support systems



Major Themes





Behavioral Themes

Dental health falls to the wayside

Adult Participants (n=13)

- About half (6) adult participants brushed only once a day
- About half (6) inconsistently or rarely floss
- Most (8) have had cavities

All Participants

- Inconsistent dental care
- Forgetfulness
- Electric toothbrushes improve habits

Child Participants (n=11)

- About half (6) brush only once a day, or rarely brush
- Majority (8) rarely or never floss
- Most (7) have never had cavities

“For three years I hadn't gone to the dentist, I hadn't found one in where I live. I knew I was going to have some cavities 'cause I had a little pain.” (adult)

“I brush them when I remember to, and that's usually only like once a day, if that.” (child)

Treatment fatigue is a barrier for dental health

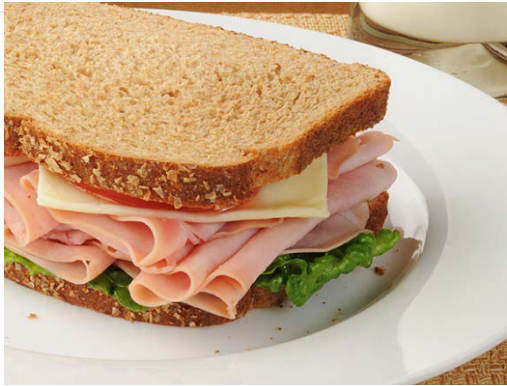
"I really don't want to go to the dentist. I don't want to do more stuff. I'm at capacity for daily treatments, and that's where we're at with my own dental health." (adult)

"I did not brush my teeth at all before I got treated because it was really hard. And now I don't want the habit of it 'cause I'm tired all the time." (child)

"I can only go [to dentist] on certain days with work. I gotta get that scheduled so I can not be in pain." (adult)

- Inconsistent dental visits: low energy levels, COVID-19, lack of time to schedule and attend appointments
- Encouragement and reminders from family members are helpful
- Electric toothbrushes improved dental behaviors by saving mental energy

Diet is motivated by what is “quick & easy”



- Breakfast is light, sometimes skipped
- Lunch is leftovers, “something quick”
- Dinner is "main" meal of the day
- Commonly reported foods: sandwiches, pasta, chicken, vegetables, and restaurant food

“Her lunch is at 10:30 in the morning, it is hard for her to eat that early again. When I pick her up, she is really hungry, and that's when you see the fast food” (parent)

“Because of my work, it tends to be something quick and simple from one of the restaurants around us.” (adult)



Diet is dependent on social context & support

Social Context

- Location availability, price, and produce shelf-life
- Time, cooking ability, and energy levels

“Healthier foods can just be so much more expensive, especially as a student.” (adult)

“Usually, we make a food calendar at the beginning of the week. We all get together and list what we want to eat, and then we'll go out and buy the ingredients.” (child)

“Frozen pizza or yeah, like fish sticks or fries or whatever. I've been trying to change that though.” (child)

Support

- Level of structure surrounding meal-time impacts dietary choices
- Dietary recommendations from providers are memorable and influential

Sugary beverage consumption differs by age

- Child participants drink water, milk; sip Gatorade/soda throughout day

"We made the switch to Gatorade Zero because my blood sugar was starting to get really high." (child)

- Most adult participants drink coffee and energy drinks in morning, water throughout day, milk or soda at mealtimes, and boost occasionally

"I've cut it back from twelve a day to six cans a day. Working on it." (adult)





Efficacy Themes

Self-management & independence is a source of pride

Proud of Independence

- Most are proud of consistency w/ medications, treatments, not letting CF stop them
- Most feel their CF is well managed, support system's help is sufficient

"My mom and dad and sister deserve a break from helping me with everything. So, I've been trying to take on more of that responsibility myself." (child)

"I am very glad that I'm able to still be able to go to school and be able to handle having CF and the issues that arise from it." (adult)

Types of Social Support

- Many give medication reminders, encouragement
- Highly independent to large support networks
- Gendered caregiving

"I would say my wife would be the first person I would talk to about [CF]. And the second, probably my mom since she was obviously the caregiver growing up." (adult)

Support can be challenging to ask for

"I'm really stubborn, I don't think I would ask anyone. I'd probably roll in a gurney before I do." (adult)

Comfort Sharing About CF

- Some child participants very private
- Most adults are comfortable discussing CF with boss at work
- Some adult participants increasingly comfortable discussing their CF with friends

Emotional Support

- Many desire emotional support
- Some are comfortable asking for support
- Many have experienced being bullied

"It'd be really nice if [sister] could sit with me while I did my breathing treatment. I have had to struggle with that. Just being alone in there and motivated to do it." (child)

"I've gotten responses anywhere between, 'oh, I have no idea what that is' or the extreme of 'well, if you're gonna die, then why are you even trying to finish high school?'" (adult)



Care Experience Themes

Relationship with Care Team is Comfortable and Trusting

Comfortable & Trusting Relationship

- Most are comfortable & trusting with care team
- Recommendations are remembered for years
- Most are recommended high-calorie, high-fat, high-salt

"Before we even get into the medical stuff, she's always talking to me on a personal level." (adult)

*"A frustrating part has been that the **CF diet has always been just pushing calories and not paying attention to where those come from.** A lot of the handouts that we get in clinic are suggestions for nutritional supplements that are often very high in sugar and not whole food. **I'm not interested in feeding him those when he's pre-diabetic.**" (parent)*

Care Experience Challenges

- COVID delayed transition to adult care
- Most never talk about dental health
- Many concerned about pre-diabetes

Dental visits do not include CF-specific guidance

- Most have never discussed how CF impacts oral health with their dentist
- Some unsure if their dentist knows they have CF

“I’m not sure if he even knows I have cystic fibrosis.” (child)

*“My doctor light-handedly mentioned to at least brush your teeth after albuterol when I was 13. **That's over a decade ago, and that just kind of stuck with me, whether or not it's still true.**” (adult)*

Implications



- Inclusion of dental providers on CF Care Team
 - Incorporate oral health recommendations
- Ongoing research to identify patient centered intervention
 - Improve patient bandwidth with support systems
 - Education on importance of dental health in CF

Discussion

- History of cavities and inconsistent dental visits
- Participants reported moderate to high sugary beverage consumption
- Social factors that influenced behaviors:
 - Energy levels, treatment fatigue
 - Access: finances, location, time
 - Differing levels of social support
 - Provider recommendations



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