

Trends in Coping Methods in Adolescents with Cystic Fibrosis

Charlotte Streetzel, Susan Chauncey Horky, LCSW
University of Florida Pediatric Pulmonary Center



UF University of Florida

CENTER for UNDERGRADUATE RESEARCH | EXPLORE DISCOVER CREATE

Many thanks to the Herbert Bearman Foundation for their generous support of this project

PURPOSE

The purpose of this qualitative study was to identify and understand the coping mechanisms used by adolescents with cystic fibrosis (CF), through an innovative project using participant-made videos. How do these youth deal with living with this disease? This was part of a larger project aimed at appreciating the “life outside the hospital” of teens with cystic fibrosis. In addition to research, the videos from this project were used for education training and to enhance clinical care.

BACKGROUND/NEED

- CF is a chronic, progressive, life-shortening illness affecting primarily the lungs and digestive system. Progression of lung disease can be slowed by airway clearance treatments and nebulized medications that take from 1-3 hours daily.
- Research has proven that adherence to treatment increases longevity and health outcomes.
- A crucial method of increasing patient adherence to treatment recommendations is by establishing a strong patient-provider relationship.
- Providers see people with CF for only a small portion of their lives, and not in their natural surroundings.
- Knowledge of the ways that teens successfully (or unsuccessfully) cope with CF will better prepare providers to aid these youth. Familiarity with patients’ experiences is necessary for building strong relationships, an essential precursor to patient care.

METHODS

- Participants were 22 teens with CF (ages 12-18) who attend the University of Florida CF Center (7 males, 15 females have to date completed 99 one hour tapes).
- If interested, teen and parent signed consent and were loaned camcorder and tripod. Teens were asked to “show us your life outside the hospital” and to talk to the camcorder like a diary. Aside from a few ideas, teens were encouraged to tape whatever they liked.
- Undergraduate research assistants were assigned to call/visit, encourage and help participants.
- All videos were read and transcribed verbatim using Transana software. Research assistants were encouraged to include any immediate reactions and emotional responses to the events in the tapes, along with descriptions that explicate factual events.
- These transcripts were read then analyzed using a systematic generation of theory from systematic research; a set of rigorous research procedures leading to the emergence of conceptual categories.

TRENDS

Three main trends of coping were identified.

Maturity

“Jessica looks at life differently than other people because she is mature due to CF.” - friend of 12 year old participant

- Research assistants coded “Maturity” at least once for over 75% of the participants.
- “Maturity” was demonstrated in different ways but frequently involved discussions and behaviors that suggested a participant seemed “older than his/her age.”
- Subcategories of Maturity included coding for behaviors that demonstrated highly developed views in academic subjects, a heightened appreciation for art or nature, and utilizing humor in lieu of feeling ill or while conversing about a serious health issue

Object and/or activity reliance

“It’s a good verse from the Bible and we really think it means a lot... The Bible is just a great thing to carry up through your life.”

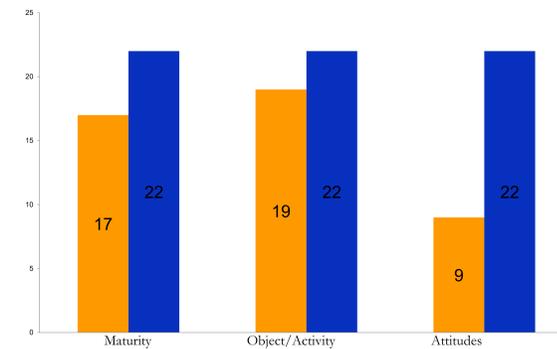
- Research assistants coded this category when participants discussed or participated in activities that were viewed as attention averting, stress-relieving, or productive (or not) in living with CF.
- This mechanism appeared more often than both displaying “Maturity” and developing specific coping “Attitudes”.
- Included subcategories are technology, having a pet, being involved in charities, being religious (or not), and having posters in the bedroom.

Attitudes/Perspectives

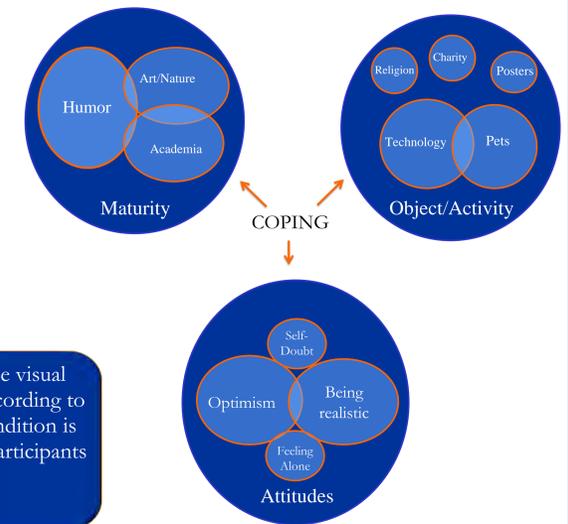
“Curing [CF] is a little far fetched but to make it less of a burden for people would be nice.”

- Subcategories within this theme include views towards life with CF that were repeatedly identified in our group of participants.
- The subcategories that were coded include feeling optimistic, expressing self-doubt, feeling alone, and being realistic.
- Having a certain outlook on life plays a role in physical and mental well-being and it affects future decision-making that can either be productive or detrimental.

Main Categories of Coping



Subcategories



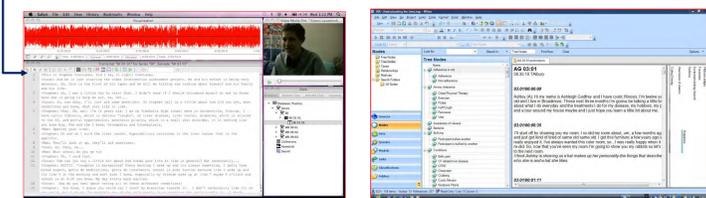
The number of participants in each main coping category are depicted in the visual above. The subcategories making up each theme are represented by size according to their relative coding frequencies in the diagram to the right. The human condition is highly variable and oftentimes individuals cycle through different affects. Participants fall into multiple categories and demonstrate forms of both productive and detrimental coping skills at different points in time.

Table 1: Understanding Life with Cystic Fibrosis

Theme	Example	Coping Tool	Further questions
Maturity	Heightened interest in academia: A transcriber states: “[C/L]s philosophies are so deep for a male his age. Everything he says makes a lot of sense though. It is great how much he thinks into things and analyzes everything.”	Transcribers noted several participants with passionate views towards nature, art and academic subjects. We speculate that living with a chronic illness evokes deeper reflection on one’s life, and the world in general.	Does having a chronic illness alter one’s perspective of the world? What about living with CF has facilitated deeper appreciation for art and nature, science and academics? Does thinking and finding meaning about the world help them get through the difficult parts of the illness? Is there a relationship between mature views and disease severity?
Objects/Activities	Having a Pet: An 18 year old girl discusses her dog Sadie, a Chihuahua, who helps her with CF by “lay[ing] on my chest when I have trouble”	As a coping technique these activities can be viewed as methods of diverting ones attention during a time of discomfort or during a treatment, or as a way to feel more in control of their illness.	Do those with CF spend more time using computers, television, or video games because of their illness? How does playing a video game allow them to escape their illness and temporarily assume a different identity? Does taking care of a pet aid in overcoming their lack of control over their own health? One participant videos his room stating: “[It is] where I spend a lot of time when I’m at home.” Does having posters on their walls in their rooms comfort them, divert their attention, or inspire them to push through CF?
Attitudes	Optimism: When discussing the possibility of a cure a 15 year old boy states: “I wouldn’t mind if there wasn’t because this routine I have to go through everyday helps me get into motion with things and helps me out with life so it isn’t really that bad.”	We speculate that development of these attitudes is consequence of living with the illness, however it ultimately affects the way they live their lives. Based on the subjective observations of our transcribers, there are countless examples of participants exhibiting certain perspectives towards life that might not be expected in an individual of their age or with their medical condition.	Are these perspectives helpful or detrimental in coming to terms with and handling the difficulties of their illness? For example, does being realistic about their illness, as opposed to being in denial, aid in mentally preparing them to live with CF forever? Research has shown that being optimistic while living with CF improves patient outcomes. How can the healthcare team aid in building these positive attitudes?

CONCLUSIONS

Teens with CF try to maintain a “normal” lifestyle. In many cases the disease is invisible and the participant might not feel “sick” while they actually are. Keeping up with their health becomes part of their routine and many describe it as “time consuming” and “embarrassing” and for this reason, burdensome. In understanding the role of other activities that aid them in making the daily commitment to their health, providers will have more knowledge of what living with the illness requires. Providers should attend to teens’ non-CF related interests and activities, to encourage working towards future goals, to enhance the patient-provider relationship and to increase treatment adherence.



With many, many thanks to the dedicated and caring research assistants who have helped with this project

This project is/was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS), under grant #172MC00002/University of Florida Pediatric Pulmonary Center/PE Wagner, for total grant amount of \$1,718,631. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government/Government.