

Trends in coping methods in adolescents with cystic fibrosis

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Cystic fibrosis is a genetic, life-shortening, chronic illness affecting the Caucasian population and which involves a burdensome schedule of daily treatments. Adherence to treatment plans has proven to slow disease progression and improve patient outcomes.¹ Establishing a strong patient-doctor relationship is crucial to increasing patient adherence, especially in adolescents. Healthcare professionals are better equipped to improve patient adherence when they have a deeper understanding of the lives of their patients, and when they are able to communicate in a relatable manner. This qualitative analysis looks at the coping mechanisms utilized by adolescents with cystic fibrosis, focusing on the details of their lives outside of the hospital, for the purpose of learning how individuals with CF and other chronic illnesses are able to maintain their quality of life while adhering to their treatments, or not. In our study we discovered several common trends of coping including displays of heightened maturity, reliance on an object or an activity, and the development of certain attitudes towards life.

INTRODUCTION

Cystic fibrosis (CF) is an autosomal recessive disorder that can be caused by over 1,800 mutations in the CFTR gene.² The genetic defect leads to an imbalance in the salt and water concentrations of epithelial cells, causing a build up of thick mucus, which drastically hinders the normal functioning of the lungs, the pancreas and the digestive tract.³ It is well known that the quality of life for individuals with CF is improving and there has been a large increase in life expectancy from that of the 1950's. Living with CF, however, involves a time consuming and physically demanding schedule of treatments, frequent hospitalizations and the consumption of massive amounts of medications on a daily basis. Treatment plans consume several hours of the patient's life each day. Although there are varying degrees of severity and the possibility of comorbidities with CF, an average day includes the use of a vibrating vest to aid with airway clearance, a nebulizer for the inhalation of antibiotics, multiple oral enzymes to aid with digestion, and an intensive nutrition plan focusing on high calorie intake.

Strict adherence to the recommended daily treatments has proven to increase longevity and quality of life for the patient.¹ Yet, with increasing numbers of prescribed medications in recent decades, adding to the physical and financial burden on the individual and their family, the nationwide adherence rate is only as high as 50%.⁴ Non-adherence to CF treatment is associated with significant decline in lung function, lower quality of life and increased healthcare costs.⁵ Evidence also indicates that strong patient-provider relationships are associated with improved health outcomes and patient satisfaction. The primary focus of this project, therefore, is to analyze the lives of a sample of adolescents living with cystic fibrosis, in an attempt to recognize patterns of coping strategies and to identify overlooked mechanisms in their

routines that may be contributing to the maintenance, or degradation, of their health. This information can be vital to future recommendations of healthcare professionals treating adolescents with CF and other chronic illnesses. A physician who has an accurate understanding of effective coping methods, while recognizing the signs of poor coping, will be better equipped to aid the patient in improving his or her health. As Rich states, "Patients' living situations, behaviors, and life experiences have a profound effect on their well-being and their ability to adhere to medical plans. Clinicians may be unable to intervene effectively if they do not understand how patients live with chronic health conditions in their daily physical, psychological, and social environments."⁶

Studies that focus on children with chronic diseases often make use of self-report surveys and clinical observations. It is not surprising, however, that the focus of these visits is on the patient's illness at that moment rather than their life experience with the illness. This project makes use of a novel qualitative method of studying the lives of teens known as Video Intervention/Prevention Assessment (VIA).⁷ This innovative approach allows the teens to film their daily lives outside of the health care setting. We loaned video camcorders to teens with CF and asked them to create visual narratives of their lives.⁶⁻⁷ In our qualitative analysis we focused on identifying themes that might indicate helpful, harmful or novel methods of coping with CF. We have identified several overarching themes including displays of heightened maturity, patterns of reliance on an object or activity, and developing particular attitudes towards CF and life in general. Within each theme we have identified sub-categories with more concrete examples of coping mechanisms, and we also note that in our participants we observe the variability of the human condition. Within one tape, and across several tapes, a participant may fall into multiple categories of

copings, and thus the categories we present here are not mutually exclusive.

Methods

The data for this project were collected from videotape transcripts that had been previously obtained through the University of Florida Video Intervention/Prevention Assessment (VIA) program for a research project on this group of adolescents. Participants were given video camcorders and were instructed to “teach us about your life outside of the hospital and what you would like your doctors to know about living with CF.”⁶ VIA is valuable because participants are free to film any part of their lives and are encouraged to speak openly about how they are feeling, things they enjoy and about what it is like to live with their condition. The technique is based on the premise that patients are experts on living with illness and that they have much to teach to providers, who are, in turn, the experts on the disease.⁶ This open-ended approach does not “lead” the participants in the way that a survey might, and it gives them full control over the content of the video.

VIA is a novel method of gaining insight to the patient’s lives that very few research studies have used. The perspective VIA offers is one that healthcare professionals could not get from limited contact with a patient in a clinical setting. The lack of understanding of life with a chronic illness is exemplified when one participant expresses her sentiments about her doctors: “they don’t understand what I do every morning because they don’t do it themselves.” Therefore, the insight gained through VIA will allow the healthcare team to gain a deeper understanding of what life with a chronic disease entails and may improve their interactions with patients.

Subjects/Recruitment

The participants were 22 youth with CF between the ages 12-18 years who attended the University of Florida CF Center. The PI, a clinical social worker and member of the CF team, explained the project to eligible teens/ parents and obtained informed consents and assents. Participants were loaned video cameras and asked to “teach your doctor about your life” by filming everyday events and by talking to the video camera as though it were a diary. Judgment Sampling was used in which exemplars (representatives of subgroups of the teen population such as age, gender, family structure, and socioeconomic status) were chosen, based on our knowledge of the population and of CF, in order to assess a diversity of views.⁶ More than 90 hours of participant generated illness narratives were generated.

Data Analysis

In this study, we utilized a Grounded Theory approach to analyze the transcripts. This approach is recommended for research on chronic illness. The Grounded Theory approach works by allowing themes and trends to emerge

from the material being investigated, as opposed to having theories developed a priori.

Video transcripts were created Transana software in which the research assistants logged the video content verbatim, while adding in their subjective responses to elements of the video and making further comments to explicate factual events. This study was part of a larger study that asked additional questions about the lives of teens with CF and identified additional themes. The preliminary coding process has been described in a previous publication and yielded 92% agreement on original codes.⁶

For the purpose of the current project, only codes related to coping with the illness were utilized. As reading of the transcripts progressed, initial codes were refined (combined or divided) or augmented to reflect higher order concepts. The authors discussed these codes to confirm internal coherence. This iterative process of developing codes, refining codes, re-reading transcripts and discussing ended once saturation occurred and no new themes arose. A comparison of coding between the two authors demonstrated 82% reliability.

RESULTS

Three general themes of coping have been identified, each having several subcategories. General themes include “Heightened maturity” (“Maturity”), a “Reliance on Objects or Activities” (“Objects/Activities”), and “Taking on Specific Attitudes or Outlooks Towards Life” (“Attitudes”). The distribution of participants in each of these general categories is depicted in **Figure 1**.

Behaviors that form the subcategories of *Maturity* include appreciation for art and nature, deeper interest in academia, and the use of humor. *Object/Activity Reliance* has been broken down into the use of technology, taking care of a pet, having posters in the bedroom, religion, and charity. The subcategories that comprise *Attitudes* include self-doubt, feeling alone, being optimistic, and being realistic.

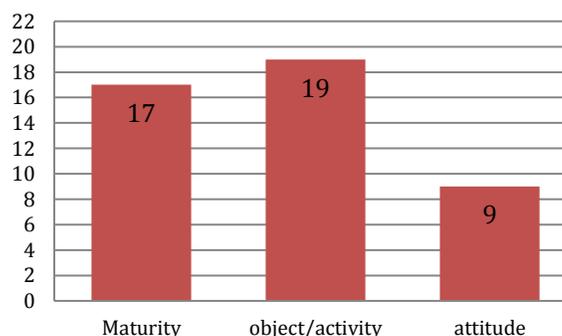


Figure 1: The Distribution of Participants among the Main Trends of Coping with Cystic Fibrosis

Maturity

Maturity in the context of this project refers to situations in which a participant remarks or behaves in a way that is deemed “older than expected.” Transcribers coded *Maturity* at least once for over 75% of the participants in the study, specifically when a participant displayed a profound appreciation for art or nature, a heightened interest in math, science or academia, and for cases when a participant brings humor into a discussion of serious health concerns or in lieu of feeling ill. **Figure 2** illustrates the number of participants that were coded in each subcategory out of the total number who demonstrated *Maturity*. In this project we report on specific examples within Art/Nature, Academia and Humor that demonstrate heightened maturity.

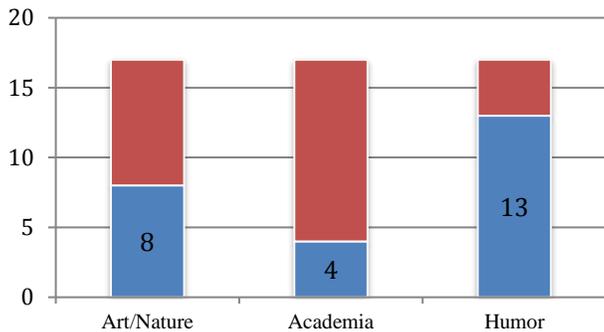


Figure 3: Representation of Participants across the Sub-Categories of Maturity

“Creating art is the highest level of human capability.” Heightened appreciation for art and nature is a subcategory for *Maturity* in order to recognize occasions when participants demonstrate interests in specific pieces of art or aspects of nature that seemed to be more advanced than that of an age-matched adolescent. Actions or thoughts that express a deeper level of interest or understanding towards art and nature are coded here based on the belief that the participant has a more developed insight on these areas of life.

Transcriber: “Chris’s philosophies are so deep for a male his age.” A heightened interest in science, math, or academia is a subcategory for *Maturity* because, similar to Art/Nature, several participants demonstrated a more profound interest in academia than an average adolescent might. This category includes instances of participants spending a notable amount of time discussing their interest or love for an academic subject and it is evident that a more in-depth reflection on these subjects has occurred. For example, one participant spends a large portion of his video discussing the theory on “ethical behavior” that he has developed and on which he is writing his own book.

“I have to take all the pills. No one is going to do it for me. No one is going to be like “hey, I’ll take it, thanks” (chuckles) I’ve had a few offers (laughs), its a whole other story.” Humor is identified as a subcategory of *Maturity* because although humor can be attributed to qualities

inherent in one’s personality, we noted that humor was used in the midst of serious discussions pertaining to health or life with CF. In these cases, humor lends itself as a verbal tool for coping with the harsh realities of living with a chronic disease.

Object/activity reliance

Reliance on an object or activity in this project is defined as referencing, videoing or participating in these activities for a notable amount of time or repeating it a number of times during the video. Over 85% of participants indicate some type of object or activity reliance in their daily lives. This mechanism appeared more often than both displaying *Maturity* and developing a specific coping *Attitudes*. As **Figure 3** illustrates, some participants fall into in multiple subcategories of reliance. Participation in these activities allows the participant to divert their attention, especially during a time of discomfort or during a treatment, and they may also contribute to feeling greater control over their illness.

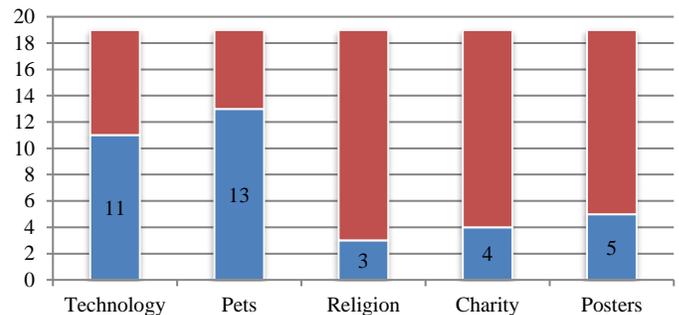


Figure 2: Representation of Participants across the Sub-Categories of Object/Activity Reliance

“Because that game character isn’t part of me, and I can be that guy and not have any care in the world.” Technology references include video games, computer games, cell phones, iPads, television shows, movies, digital arts/graphic design, photo editing, and online schooling. Technology use was most often videoed during treatments. One participant mentions that with CF, he “*get[s] to watch more TV*” than others. Some teens expressed excitement about their devices, such as when Alexis states: “*I love playing on this thing when I’m doing my TOBI and PT and all that*”. Others use technology as an escape: “*Its like I could get on there and be someone else for temporary time*” and emphasize its value by saying “*gaming is a lot to me in life.*”

“She lays on my chest when I have trouble.” Referencing a pet appeared at least once in 59% of participant’s tapes. Observations of significant amounts of time playing with, talking about, and taking care of pets were coded as *Object/activity* reliance. In some cases, direct references were made about the ways in which their pets aided with CF, and we also coded cases of repeated inclusion of the pet in the tapes.

“I wanted to go skydiving someday so this kind of spoke to me.” Posters on the walls of a participant’s room is a subcategory for *Object/activity* reliance due to its surprising frequency and because of the idea that posters may be used as tools which provide comfort, inspiration, and divert attention. In one tape Christopher that his room is *“where I spend a lot of time when I’m at home.”* A different participant with more severe disease spends a large portion of his tapes discussing the organization of this room, including the meaning of each poster that he has on his wall.

“The Bible is just a great thing to carry up through your life.” Religion as a coping tool was observed surprisingly infrequently in our sample. We found that only three participants who openly discuss their religious beliefs related them to life with CF. Those that do discuss religion seem to use it for the purpose of making sense of CF or helping them accept it in their lives. In this study participants are either religious and use it to see the light in their disease, or they are not and they have a different explanation for why they have CF.

“Every year her and her husband take what money they get and will buy stuff for Shands as gifts for the children’s unit. And you know, I thought that was awesome.” Charity participation is included as a subcategory for occasions where charity events in the past or future are discussed, or where references are made about experiencing benefits from charities. Participants reference CF walks, Make a Wish Foundation, sorority fundraisers, and events put on by their families. One participant describes the laptop that he uses everyday, which was donated to him by a charity while another speaks about going to Hawaii on a trip funded by Make A Wish.

Attitudes

Coders identified patterns of coping attitudes, which include displays of optimism, being realistic, feeling alone with CF, and feeling self-doubt. A teacher states about one participant’s CF: *“you see it as a blessing sometimes and at other times you see it as something you want to move past and be like everybody else [...] I feel it’s made you stronger.”* The development of attitudes and perspectives towards CF is viewed as a coping mechanism that sheds light on how they feel about their situations and could help explain actions surrounding their choices to commit to the maintenance of their health, or not.

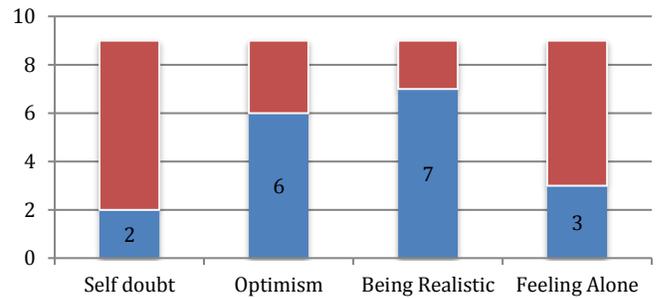


Figure 4: Representation of Participants across the Sub-Categories of Coping Attitudes

“I wouldn’t mind if there wasn’t [a cure] because this routine I have to go through every day helps me get into motion with things and helps me out with life.” Being optimistic in spite of their illness was a common attitude throughout the participants. Optimism was coded in situations where a participant reflects on the positives that have come with having CF or times when they *“just hope for the best.”*

“How do you stay healthy? Awwhh that’s a joke.” Self-doubt in relation to having CF was coded least frequently. Most notably, participants who expressed self-doubt mentioned that society placed limitations on them when hearing their diagnosis. One participant reflects that her dream to continue her family’s military legacy is destroyed due to CF and she doubts that she could even pursue her back-up career as a police officer

“In the end I know I have a very restricted amount of health I can control.” Demonstrating a realistic outlook on their situation was coded for occasions where they were accepting of their situations, or they acknowledged CF could limit them in some way in the future. Being realistic serves to gain acceptance, as opposed to being in denial, and better prepares a person with a chronic illness for the long journey ahead.

“I’ve only seen a few kids with CF.” Feeling alone with cystic was not demonstrated as frequently as predicted. This attitude was coded in cases where a participant notes that they do not know others with CF, or when they express sentiment that no one understands.

DISCUSSION

The purpose of this project is to develop a better understanding of what it takes to live with CF in order to improve communication and relationships between the physician and the patient. The coping mechanisms we identified bring about questions that probe further inquisition about how we can use this information towards reaching our goal.

Maturity. We speculate that the increased development of interests and appreciation for art, nature, and academia are consequences of living with a chronic disease. We question whether or not participants have developed these deeper interests due to increased self-reflection, which

results from being faced with the constant hardships of CF. Does having a life-threatening chronic disease alter the way an individual views life? Does the threat of their disease allow for more self-reflection and a greater appreciation for things that other, equally aged people might take for granted? How could understanding these ideas make a physician more relatable to someone who is living with CF?

When it comes to using humor despite feeling ill or while acknowledging a serious topic about their health, we question whether this is a positive or negative coping method. In cases of older participants with CF, we speculate that humor is used as a tool to lighten the mood and it may reveal that the individual can look past their situation, however temporarily, and accept CF as part of their lives. In cases of younger participants using humor, it is possible that they have not yet internalized CF and that they do not take their treatments seriously, which is dangerous for their health in the long term.

Object/Activity Reliance. Reliance on activities and exploring interests is a form of healthy coping such that it allows the individual to enjoy life as a typical teen. We question, however, if these activities can become detrimental to effective coping. One participant spends countless hours in his tapes playing videogames. In clinic another participant, who is immersed in a handheld device, fails to acknowledge healthcare staff entering the room. Can the “escape” that technology provides be detrimental to effective coping and acceptance of CF? How might a physician use this reliance on technology to aid a person with CF in coming to terms with the disease?

For an individual who has little control over his or her health, charity events are opportunities to actively make a difference or improve outcomes in another way. For example, by participating in walks and other events, participants can raise awareness and money for research. Charity references appeared to focus on the communal support by being around others who have the disease and feeling that they are not fighting CF alone.

Attitude development. Forming attitudes towards life with CF conveys the idea that patients view their situations through particular lenses, which ultimately affects the actions they will take in their lives -- importantly those that help in maintaining their health. Past studies suggest that optimism may be associated with better quality of life and less distress among patients with CF.⁸ Can doctors make a difference in adherence, and thus health outcomes, simply by promoting positivity?

Self-doubt and lack of confidence towards their own abilities may be a commonality to all adolescents. However, through our tapes we recognize there is a stigma created by society when someone hears that the individual has CF. Participants mention that they do not want others to know about their CF because they will be thought less of

or be seen as less capable than they are, and will possibly be denied a position in society.

Feeling alone, along with participation in charity events, presents a major implication with CF. The pathology of the disease itself limits the safe contact that individuals with CF can have with one another due to the high risk of opportunistic infection. Doctors should emphasize a balance between taking the proper precautions with contact while finding the support they need from others with CF. Feeling alone was coded in only 3 participants, which may be attributed to the fact that technology facilitates communication without face-to-face contact.

CONCLUSIONS

This study identified three overarching themes of coping in adolescents with cystic fibrosis including displays of heightened maturity, reliance on an object or activity, and the development of particular attitudes. Knowledge of these coping mechanisms work to better our understanding of what life with a chronic illness entails. This information can help physicians better understand and work with patients, with the goal of improved patient-provider relationships and more positive patient outcomes.

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