

Understanding the Lives of Youth with Cystic Fibrosis Using Video  
Intervention/Prevention Assessment

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BMS 4905

April 29, 2017

### Introduction:

I had the opportunity of conducting research in the Pediatric Pulmonary Unit in Shands with children whom are diagnosed with Cystic Fibrosis in my undergraduate career. The title of our project is “Understanding the Lives of Youth with Cystic Fibrosis Using Video Intervention/Prevention Assessment.” I have been a part of this research team since my sophomore year and have truly learned a lot from this opportunity. As a healthy teen, I was able to take a look at the videos of children with Cystic Fibrosis with an open-ended mind. They filmed their everyday lives and were able to talk about anything that they wanted to. The purpose of these videos was to truly get to know them and how they deal with their illness everyday. The main purpose of my research was to discover any themes that I could see between children that have Cystic Fibrosis from the different tapes. In this research we use qualitative research where one lets the theory emerge from the data. Rather than testing the hypothesis, qualitative research is used to generate a hypothesis however we do approach qualitative research with a set of open-ended questions.

### Background:

The disease we are focusing on is called Cystic Fibrosis. Cystic Fibrosis is an inherited disease that causes the mucous found within the individual's body to become a thick and sticky consistency, which then causes blockage in the airways and makes it much easier for bacteria to harbor and to grow. In the lungs, the mucous can clog the airways and trap the bacteria, thus leading to infections, lung damage, and respiratory failure. In the pancreas, the mucous can inhibit the release of digestive enzymes that allow the body to process food and absorb nutrients. To inherit Cystic Fibrosis, a child must inherit two copies of the defective Cystic Fibrosis gene, one from each parent. Approximately 30,000 individuals in the United States are diagnosed with this disease. Many individuals that carry only one copy in them of the defective CF gene are known as carriers, but they do not experience the disease. There are an additional 10 million people who are carriers of the Cystic Fibrosis gene, but do not experience the disease. When two CF carriers give birth to offspring these are the chances of having or being a carrier of CF: 1 in 4 will have CF, 1 in 2 will be a carrier of CF, and 1 in 4 will not be a carrier nor have CF. The CF gene has an abnormality, which is called a mutation. Thus, there are above 1,700 mutations that are known for this disease. There are more than 30,000 individuals whom are living with cystic fibrosis, about 70,000 around the entire world.

### Hypothesis Tested:

This research consisted of qualitative research, rather than quantitative research. A useful concept in qualitative research is “grounded theory”, which means that rather than having a preformed theory that one has to test; one lets the theory emerge from the data. We do not have a pre-formed hypothesis, thus we are not testing it as you would in quantitative research. Instead we take a look at the data in an open-ended way to see what we can learn from them. Quantitative research is sometimes said to generate hypothesis that can later be tested quantitatively. Qualitative researchers do ask general questions of the data. In this case we asked, “What are the themes that come up when healthy young adults view tapes of children with chronic illnesses?”

### Methods:

This study was part of a larger research project exploring various dimensions of the lives of adolescent CF patients (Horky, 2014). 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.

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. Participants’ narratives and loggers’ comments were coded.

The purpose of our particular study was to comprehend how healthy teens view teens that are surviving and coping with Cystic Fibrosis. We have three sources of information about how healthy young adults respond and react to videotapes made by teens that are diagnosed with CF. The three sources that we have of how healthy young adults respond and react to videotapes made by teens that have CF are: the follow up surveys we conducted with former research assistants, asking what impacted them most about working on the project, research assistants who transcribed the videotapes inserted their own comments into the transcription, and I have viewed the videos and have a log of my reactions, feelings, themes and things I noticed. After reviewing all of the sources listed above, I have come up with 6 common themes that I took note of.

### Accomplishments, Results, Conclusions:

After reviewing the three sources that I had of children with CF, I was able to come up with 6 common themes overall (Horky 2014 Horky submitted for publication 2017). The first theme that I found was research assistants’ comments on the participants’ interests in music, video games, art, animals, and nature. The second theme I found was the research assistants’ comments on the participants’ outlook on death in general. The third theme that I found was research assistants’ comments on the participants’ religious views. The fourth theme that I found was research assistants’ comments on the participants’ school relations. The fifth theme that I found was research assistants’ comments on the participants’ impact of and coping with illness of the patient and family. The sixth theme I found was the research assistants’ comments on the participants’ attitude and feelings. I found that many of the themes that I discovered overlapped with the themes that were discovered by healthcare providers. Also, many of the research assistants’ comments overlapped with these themes too, which means that many people found these themes in the scripts and videos.

For the first theme, participants’ interest in music, video games, art, animals, and nature, I found many participants who spent a majority of their time with these hobbies. Some of these kids had no other siblings, and so they had dogs, rabbits, and cats to keep them company as companions. I noticed that they really cared about their pets and took

well care of them on camera. They allotted a lot of their time to taking care of these animals and treating them with care, which I thought, was very nice.

For the second theme of the participants' outlook on death I found that many of the children with CF were comfortable with talking about death. Especially the older ones who have been dealing with it for a while, it is saddening to see that they have come to terms with death and don't seem frightened when talking about it. They have probably become desensitized from hearing the doctors, family, or people around talk about CF and the complications.

For the third theme I found the research assistants' comments on the participants' religious views. Many of the participants believed in some sort of religion and spoke about it on camera. Some had many religious items around their room and talked about how it was a major part of their lives.

For the fourth theme, I found that research assistants' comments on the participants' school relations quite often. Many of these kids miss so many classes due to treatments and hospitalizations; it amazes me that most of them have very good grades and don't fall behind! They are very focused on school and strive to do well in their classes; many have them have A's. Most of the participants said that their teachers were very accommodating and nice to help them when they are absent from school so often. There was one participant whom said their teacher gave them trouble and wouldn't let them make up an assignment, which hindered their grade a lot and caused them to do bad in a class. I believe this is unethical and that the parent should go in and speak with principal because this is out of the student's control.

For the fifth theme, what I found was research assistants' comments on the participants' impact of and coping with illness of the patient and family. I noticed that many of the parents in these videos speak for their children and don't allow the kids to really say what they feel. I noticed that in a couple of videos, many of the parents know everything and help the children with their procedures. Most of the parents were very attentive and caring for their kids, you could just tell by how they would talk about the disease and treatment.

For the sixth theme, I found based on the research assistants' comments on the participants' attitude and feelings. This was the broadest category because there was such a difference in attitudes and feelings since everyone is very different. Most were enthusiastic and confident with themselves. Most participants seemed happy and occupied with their time because they had love and affection. Some of the participants were a little drier in their responses and seemed to not be happy with their situation. They could just be more reserved individuals and not talk as much as the others.

#### Comments:

I really enjoyed performing this research in my undergraduate career. I learned so much from this experience and really feel as if this helped me in understanding children with chronic illnesses a little bit more. Performing it for credit has allowed me to have my own project and really set and learn how to organize a project, along with writing a final paper.

References cited:

Citation: Horky S, Sherman LA, Polvinen J, Rich M. Hearing the patient voice: Using video intervention/prevention assessment to understand teens with cystic fibrosis. Patient Experience Journal 1(2) January 2014.

Citation: Horky S, Sherman LA, Polvinen J, Saxena M, Rich M. I'm Going To Tell You A Little About Myself: Illness Centrality, Self-Image and Identity in Cystic Fibrosis. Submitted for Publication, January 2017.

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 #T72MC00002/ University of Florida Pediatric Pulmonary Center/PI: 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