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Does a Voice Disorder Exist in Individuals with Cystic Fibrosis?

Jacquelyn Gadsby

Submitted in Partial Completion of the
Requirements for Commonwealth Honors in Communication Sciences and Disorders

Bridgewater State University
May 9, 2017

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Title: Does a Voice Disorder Exist in Individuals with Cystic Fibrosis?

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Does a Voice Disorder Exist in Individuals with Cystic Fibrosis?

Abstract:

Cystic Fibrosis (CF) is a genetic disease of the exocrine gland (Gardner, 2007). The disease is characterized by thick secretion in organs (Lorenco, Costa and da Silva Filho, 2014). Chronic coughing can also be seen due to the thick secretions accumulating (Gardner, 2007). The transmembrane regulator gene is responsible for encoding an epithelial chloride channel (Lorenco, Costa and da Silva Filho, 2014). Thick viscous secretions through the respiratory tract and other organs, occur because the channel does not properly transport chloride and sodium to the epithelial membranes (Lorenco, Costa and da Silva Filho, 2014). The secretion in the respiratory system leads to decrease lung function (Lorenco, Costa and da Silva Filho, 2014). Many of the characteristics that are seen in CF are factors that affect voice, for example optimal respiration is required as a power source for phonation. Vocal fold thickness and the excessive mucus that covers them as a result of the disease are known to change vibratory patterns and voice abnormalities. Chronic coughing can also contribute to voice disorders (Gibson and Vertigan, 2009). This study utilizes the Voice-Handicap Index and the Voice-Related Quality of Life, as well as Qualtrics Survey Software to understand the perception of one's voice in those living with Cystic fibrosis.

Research Questions:

1. What are the attitudes of individuals living with Cystic Fibrosis toward their vocal quality of life?
2. What are the attitudes of individuals with Cystic fibrosis related to voice as a handicapping condition?

Does a Voice Disorder Exist in Individuals with Cystic Fibrosis?

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Background:

Cystic Fibrosis (CF) is a genetic disease of the exocrine gland (Gardner, 2007). The transmembrane regulator gene is responsible for encoding an epithelial chloride channel. Thick viscous secretions through multiple body organs occur because the channel does not properly transport chloride and sodium to the epithelial membranes (Lorenco, Costa and da Silva Filho, 2014). Primarily, these secretions are seen in the respiratory, gastrointestinal and reproductive systems (Gardner, 2007) however, they can also occur in the vocal folds (Lorenco, Costa and da Silva Filho, 2014). The secretion in the respiratory system leads to decreased lung function (Lorenco, Costa and da Silva Filho, 2014). Chronic coughing can also occur due to the thick secretions accumulating (Gardner, 2007).

Many of the characteristics that are seen in CF are factors that affect voice, for example optimal respiration is required as a power source for phonation. Vocal fold thickness and the excessive mucus that covers them as a result of the disease are known to change vibratory patterns and voice abnormalities. Chronic coughing can also contribute to voice disorders (Gibson and Vertigan, 2009). Despite these facts about CF, only a few studies exist that focus on the effect of the disease on vocal fold function and voice production. Lorenco, Costa and da Silva Filho (2014) found that that intensity could be affected due to decreased lung function limiting sub glottal air pressure. Lorenco and authors define jitter as the index of fundamental frequency variability and shimmer as the index of intensity variability. It was also shown that thick mucus on the vocal folds can result in abnormal jitter and shimmer, which are related to

vocal harshness. An additional finding was low that harmonics to noise ratio (HNR) which can be perceived as hoarseness (Lorenco, Costa and da Silva Filho, 2014).

A previous study conducted by the author of this paper focused on a 20 year old participant living with cystic fibrosis. Analysis of the participant's Rainbow Passage voice recording showed appropriate pitch and loudness with slight breathiness and hoarseness.

People living with CF have previously participated in surveys for research. Surveys related to mental health, (Abbott, J et al., 2015) satisfaction with care received at facilities (Byrne and Hardy, 2005). There is limited research available regarding the voice of those living with cystic fibrosis. Voice has a significant impact on a person's quality of life. More research is needed to understand the effects the cystic fibrosis has on the vocal tract and overall quality of voice. This study is being conducted in an effort to reduce the gap in research for this area.

Research Design

Voice-Handicap Index (VHI)

The Voice Handicap Index (VHI) includes subscales in the survey. The subscales categorize the questions in relation to function, emotion, or physical characteristics of voice. Results are reported according to the corresponding subscales.

Functional Subscale Results

The statements from the functional subscale are stimuli to measure how voice affects everyday life. (Jacobson, et al.,1997). These statements relate to the respondents ability to hold a job, communicate efficiently with others, and maintain a positive social life. The following are sample statements from the responses of participants to this subscale:

“My voice makes it difficult for people to hear me.”

“People have a difficult time understanding me in a noisy room.”

“My family has difficulty hearing me when I call them throughout the house.”

“I use the phone less often than I would like.”

“I tend to a voice groups of people because of my voice.”

“I speak with friends, neighbors, or relatives less often because of my voice.”

“People ask me to repeat myself when speaking face-to-face.”

“My voice difficulties restrict my personal and social life.”

“I feel left out of conversation because of my voice.”

“My voice causes me to lose income.”

Emotional Subscale Responses

Stimuli from the Emotional Subscale elicit “a persons’ affective response to a voice disorder” persons’ and their attitudes when interacting with others. (Jacobson, et al.,1997). The following are sample statements from the responses of participants to this subscale:

“I’m tense when talking with others because of my voice.”

“People seem irritated with me because of my voice.”

“I find other people don’t understand my voice problem.”

“My voice problem upsets me.”

“I am less out going because of my voice.”

“My voice makes me feel handicapped.”

“I feel embarrassed when people ask me to repeat.”

“My voice makes me feel incompetent.”

“I’m ashamed of my voice.”

Physical Subscale

Items in this scale focus on “self-perception of laryngeal discomfort and voice output characteristics” (Jacobson, et al.,1997). A person may agree with these statements if they feel their voice is too high pitched, is not consistent throughout the day, or require a great deal of effort, or pain. The following statements are examples from this scale.

“I run out of air when I talk.”

“The sound of my voice varies throughout the day.”

“People ask, “What’s wrong with your voice?””

“My voice sounds creaky or dry.”

“I feel as though I have to strain to produce voice.”

“The clarity of my voice is unpredictable.”

“I try to change my voice to sound different.”

“I use a great deal of effort to speak.”

“My voice is worse in the evening.”

“My voice “gives out” on me in the middle of speaking.”

Voice-Related Quality of Life (V-RQOL)

Stimuli from the V-RQOL address a combination of the three domains: functional, emotional, and physical (Hogikan, and Sethuraman, 1999). The following are sample statements from the subset:

“I have trouble speaking loudly or being heard in noisy situations.”

“I run out of air and need to take frequent breaks when breathing.”

“I sometimes do not know what will come out when I begin speaking.”

I am sometimes anxious or frustrated (because of my voice).

I sometimes get depressed (because of my voice).

I have trouble using the telephone (because of my voice).

I have trouble doing my job or practicing my professions (because of my voice).

I avoid going out socially (because of my voice).

I have to repeat myself to be understood.

I have become less outgoing (because of my voice).

Procedures:

The study involved an online survey of participants living with CF. The survey, which was conducted using the Qualtrics Survey Platform (2007) utilized items from The Voice Handicap Index (Jacobson, et al 1997) and Voice Related Quality of Life (Hogikan, and Sethuraman, 1999). Data were collected and analyzed using Qualtrics Survey Software (2007).

Participants accessed the survey on closed Facebook Groups. Permission from the page administrator was received before posting. The following closed Facebook groups participated in posting the survey: Cystic Fibrosis, Cystic Fibrosis II, and Cystic Fibrosis of South Hampton. A total of 21 participants began the survey and 14 fully completed it. Participants ranged from 18-42+. Participants also answered a question regarding the speaking needs in their place of work.

Regarding age, the following ranges were used:

- 18-25
- 26-33
- 34-41
- 42+

Regarding speaking intensity of work environments, the following categories were used:

- Highly Speaking Intensive
- Slightly Speaking Intensive
- Neutrally Speaking Intensive
- Little Speaking Required
- No Speaking Required
- I am currently not working

Results:

The survey had a total of 21 responses from November 9, 2016 to November 20, 2016. Of the 21 responses, only 14 completed the entire survey. The survey included all 21 responses in the data analyzing because it was believed, although incomplete, the responses provided important information. The survey contained items from both the Voice-Related Quality of Life (V-RQOL) and the Voice Handicap Index (VHI). Demographic information such as age and speaking intensity of jobs was collected.

The Voice Handicap Index (VHI)

Functional Subscale Results

When participants responded to this subset of stimuli there was not a wide variability in responses. In 100% of the statements, disagreement was greater than agreement. In 40% of the statements, neutrality was greater than agreement as well. This demonstrates that most of the respondents to this survey do not feel that their voice impacts their everyday life. Table 1.1 includes responses to this section as they correspond to age and Table 1.2 corresponds to job speaking intensity levels.

Table 1.1 Functional Subscale of the Voice Handicap Index

Table 1.1 Voice Handicap Index (VHI) Functional Scale Compared by Age					
Statement	18-25	26-33	34-41	42+	Total
My voice makes it difficult for people to hear me					19
Strongly Agree		1			1
Somewhat Agree	6	1			7
Neither Agree nor disagree			1	1	2
Somewhat Disagree	1			1	2
Strongly Disagree	2	2	2	1	7
People have a difficult time understanding me in a noisy room.					19
Strongly Agree		1			1
Somewhat Agree	1				1
Neither Agree nor disagree	5	1	1	1	8
Somewhat Disagree	1	1	1	1	4
Strongly Disagree					5
My family has difficulty hearing me when I call them throughout the house.					19
Strongly Agree	2				2
Somewhat Agree	1				1
Neither Agree nor disagree	2	2			4
Somewhat Disagree				2	2
Strongly Disagree	4	2	3	1	10
I use the phone less often than I would like.					19
Strongly Agree		1			1
Somewhat Agree	2				2
Neither Agree nor disagree	1			1	2
Somewhat Disagree	2	1		2	5
Strongly Disagree	4	2	3		9

I tend to avoid groups of people because of my voice.					19
Strongly Agree					
Somewhat Agree	1				1
Neither Agree nor disagree	3				3
Somewhat Disagree		1			1
Strongly Disagree	5	3	3	3	14
I speak with friends, neighbors, or relatives less often because of my voice.					19
Strongly Agree					
Somewhat Agree					
Neither Agree nor disagree	3				3
Somewhat Disagree		1			1
Strongly Disagree	6	3	3	3	15
People ask me to repeat myself when speaking face-to-face					19
Strongly Agree	1				1
Somewhat Agree	3	1			4
Neither Agree nor disagree	2				2
Somewhat Disagree	1	1		1	3
Strongly Disagree	2	2	3	2	9
My voice difficulties restrict my personal and social life.					17
Strongly Agree					
Somewhat Agree					
Neither Agree nor disagree	2				2
Somewhat Disagree	1				1
Strongly Disagree	4	4	3	3	14
I feel left out of conversation because of my voice.					17
Strongly Agree	1				1
Somewhat Agree					
Neither Agree nor disagree					
Somewhat Disagree		1			1
Strongly Disagree	6	3	3	3	15
My voice causes me to lose income.					17
Strongly Agree					
Somewhat Agree					
Neither Agree nor disagree					
Somewhat Disagree					

Strongly Disagree	7	4	3	3	17
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Table 1.2 Functional Subscale of the Voice Handicap Index

Table 1.2 Voice Handicap Index (VHI) Functional Scale Compared by Age				
Statement	Slightly Speaking Intensive	Neutrally Speaking Intensive	Highly Speaking Intensive	Not working (at time of survey)
My voice makes it difficult for people to hear me				
Strongly Agree			1	
Somewhat Agree	1		2	4
Neither Agree nor disagree				2
Somewhat Disagree				2
Strongly Disagree	2	2	2	1
People have a difficult time understanding me in a noisy room.				
Strongly Agree				1
Somewhat Agree				1
Neither Agree nor disagree	2		3	3
Somewhat Disagree	1	1		2
Strongly Disagree	2	1	2	
My family has difficulty hearing me when I call them throughout the house.				
Strongly Agree				2
Somewhat Agree				1
Neither Agree nor disagree	1		2	1
Somewhat Disagree	1			1
Strongly Disagree	3	2	3	2
I use the phone less often than I would like.				
Strongly Agree				1
Somewhat Agree	2			
Neither Agree nor disagree				2
Somewhat Disagree	1	1	3	

Strongly Disagree	2	1	2	1
I tend to avoid groups of people because of my voice.				
Strongly Agree				
Somewhat Agree			1	
Neither Agree nor disagree	1		1	1
Somewhat Disagree				1
Strongly Disagree	4	2	3	5
I speak with friends, neighbors, or relatives less often because of my voice.				
Strongly Agree				
Somewhat Agree				
Neither Agree nor disagree			1	2
Somewhat Disagree				1
Strongly Disagree	4	2	5	4
People ask me to repeat myself when speaking face-to-face				
Strongly Agree				1
Somewhat Agree	1		3	
Neither Agree nor disagree	1		1	
Somewhat Disagree	1		2	
Strongly Disagree	2	2	2	3
My voice difficulties restrict my personal and social life.				
Strongly Agree				
Somewhat Agree				
Neither Agree nor disagree	1		1	
Somewhat Disagree			1	
Strongly Disagree	4	2	3	5
I feel left out of conversation because of my voice.				
Strongly Agree			1	
Somewhat Agree				
Neither Agree nor disagree				
Somewhat Disagree				1
Strongly Disagree	4	2	4	5
My voice causes me to lose income.				
Strongly Agree				
Somewhat Agree				

Neither Agree nor disagree				
Somewhat Disagree				
Strongly Disagree	5	2	4	6

Emotional Subscale Responses

When participants responded to this subset of stimuli there was, again, not a wide variability in responses. In 100% of the statements, disagreement was greater than agreement. In 67% of responses neutrality was equal to or greater than agreement. This demonstrates that most of the respondents to this survey do not feel that their voice has an emotional impact on their life. It is important to note that many also felt neutral to these statements. Table 2.1 includes responses to this section as they correspond to age and Table 2.2 corresponds to job speaking intensity levels.

Table 2.1 Emotional Subscale of the Voice Handicap Index

Table 2.1 VHI- Emotional Subscale Compared by Age	18-25	26-33	33-41	42+	Total
I'm tense when talking with others because of my voice.					19
Strongly Agree					
Somewhat Agree	2				2
Neither Agree nor disagree	2				2
Somewhat Disagree	1	1		2	4
Strongly Disagree	4	3	3	1	11
People seem irritated with my voice.					19
Strongly Agree					
Somewhat Agree	2				2
Neither Agree nor disagree				1	1
Somewhat Disagree	3	1			4
Strongly Disagree	4	3	3	2	12

I find other people don't understand my voice problem.					17					
Strongly Agree										
Somewhat Agree						2				
Neither Agree nor disagree						2	1	1	4	
Somewhat Disagree						1			1	
Strongly Disagree						2	3		2	10
My voice problem upsets me.					15					
Strongly Agree										
Somewhat Agree						2	1			3
Neither Agree nor disagree									1	1
Somewhat Disagree						1			1	2
Strongly Disagree						3	2	3	1	9
I am less outgoing because of my voice.					15					
Strongly Agree										
Somewhat Agree										
Neither Agree nor disagree						1	1			2
Somewhat Disagree						1				1
Strongly Disagree						4	2	3	3	12
My voice makes me feel handicapped.					15					
Strongly Agree										
Somewhat Agree										
Neither Agree nor disagree						1				1
Somewhat Disagree						2				2
Strongly Disagree						3	3	3	3	12
I feel embarrassed when people ask me to repeat					15					
Strongly Agree										
Somewhat Agree						1				1
Neither Agree nor disagree						1	2		1	4
Somewhat Disagree						3			1	4
Strongly Disagree						1	1	3	1	6
My voice makes me feel incompetent.					14					
Strongly Agree										
Somewhat Agree										

Neither Agree nor disagree					
Somewhat Disagree	2				2
Strongly Disagree	4	3	3	2	12
I'm ashamed of my voice.					14
Strongly Agree					
Somewhat Agree		1			1
Neither Agree nor disagree	1				1
Somewhat Disagree	1				1
Strongly Disagree	4	2	3	2	11

Table 2.2 Emotional Subscale of the Voice Handicap Index

Table 2.2 VHI- Emotional Subscale Compared by Career Speaking Intensity				
Statement	Slightly Speaking Intensive	Neutrally Speaking Intensive	Highly Speaking Intensive	Not working (at time of survey)
I'm tense when talking with others because of my voice.				
Strongly Agree				
Somewhat Agree	1			1
Neither Agree nor disagree			1	1
Somewhat Disagree	2			2
Strongly Disagree	2	2	4	3
People seem irritated with my voice.				
Strongly Agree				
Somewhat Agree	1		1	
Neither Agree nor disagree				
Somewhat Disagree			1	3
Strongly Disagree	4	1	3	4
I find other people don't understand my voice problem.				
Strongly Agree				
Somewhat Agree	1		1	
Neither Agree nor disagree	1			3

Somewhat Disagree	1			
Strongly Disagree	3	1	3	3
My voice problem upsets me.				
Strongly Agree				
Somewhat Agree	1			2
Neither Agree nor disagree				
		1		
Somewhat Disagree	1		1	
Strongly Disagree				
	2	1	3	3
I am less outgoing because of my voice.				
Strongly Agree				
Somewhat Agree				
Neither Agree nor disagree				
	1			1
Somewhat Disagree	1			1
Strongly Disagree	3	2	4	3
My voice makes me feel handicapped.				
Strongly Agree				
Somewhat Agree				
Neither Agree nor disagree				
	1			
Somewhat Disagree	1		1	
Strongly Disagree				
	2	2	3	5
I feel embarrassed when people ask me to repeat				
Strongly Agree				
Somewhat Agree				
				1
Neither Agree nor disagree	1	1	1	1
Somewhat Disagree	3		1	
Strongly Disagree		1	2	3
My voice makes me feel incompetent.				
Strongly Agree				
Somewhat Agree				
Neither Agree nor disagree				
Somewhat Disagree	2			
Strongly Disagree	2	2	4	4
I'm ashamed of my voice.				
Strongly Agree				
Somewhat Agree				
				1
Neither Agree nor disagree				
			1	

Somewhat Disagree	1			
Strongly Disagree	2	2	4	3

Physical Subscale Responses

When participants responded to this subset of stimuli, results were more varied than any other subset. In 10% of statements, agreement was greater than disagreement. In another 10% of statements, agreement and disagreement were equal. This gives a total of 20% of opportunities when agreement was greater than or equal to disagreement. Still, in 80% of responses disagreement was greater than agreement. This demonstrates that most of the respondents to this survey do not feel physical constraints in their voice. However, it is important to note that 53% of participants agreed that they ran out of air when they talked. A total of 63% either agreed or felt neutral towards this statement. Without looking at neutrality, 59 % agreed over disagreement. When it came to voice being consistent throughout the day, without factoring in neutrality, agreement and disagreement was an equal 50%. These are both two very important factors of voice and vocal health. Table 3.1 includes responses to this section as they correspond to age and Table 3.2 corresponds to job speaking intensity levels.

Table 3.1 Physical Subscale of the Voice Handicap Index

Table 3.1 VHI- Physical Subscale Compared by Age	18-25	26-33	33-41	42+	Total
I run out of air when I talk.					19
Strongly Agree	2	1			3
Somewhat Agree	3	2	1	1	7
Neither Agree nor disagree	2				2
Somewhat Disagree		1		1	2
Strongly Disagree	2	2		1	5
The sound of my voice varies throughout the day.					19

Strongly Agree	2				2
Somewhat Agree	4			1	5
Neither Agree nor disagree	1	2	1	1	5
Somewhat Disagree	1	1	1		3
Strongly Disagree	1	1	1	1	4
People ask, "What's wrong with your voice?"					19
Strongly Agree	1				1
Somewhat Agree	3				3
Neither Agree nor disagree					
Somewhat Disagree		1			1
Strongly Disagree	5	3	3	3	14
My voice sounds creaky and dry.					17
Strongly Agree	2				2
Somewhat Agree	1	2			3
Neither Agree nor disagree	1			1	2
Somewhat Disagree	2	1			3
Strongly Disagree	1	1	3	2	7
I feel as though I have to strain to produce voice.					16
Strongly Agree					
Somewhat Agree	2	1			3
Neither Agree nor disagree	1				1
Somewhat Disagree	2	1		1	4
Strongly Disagree	1	2	3	2	8
The clarity of my voice is unpredictable.					17
Strongly Agree	3				3
Somewhat Agree	2	1			3
Neither Agree nor disagree				1	1
Somewhat Disagree					
Strongly Disagree	2	3	3	2	10
I try to change my voice to sound different.					17
Strongly Agree					
Somewhat Agree	1				1
Neither Agree nor disagree					

Somewhat Disagree	2				2
Strongly Disagree	4	4	3	3	14
I use a great deal of effort to speak					17
Strongly Agree	1				1
Somewhat Agree	1	2	1		4
Neither Agree nor disagree	2				2
Somewhat Disagree	1	1		1	3
Strongly Disagree	2	1	2	2	7
My voice is worse in the evening					17
Strongly Agree	1				1
Somewhat Agree	2			1	3
Neither Agree nor disagree	1	1			2
Somewhat Disagree	1	2			3
Strongly Disagree	2	1	3	2	8
My voice "gives out" on me in the middle of speaking					15
Strongly Agree					
Somewhat Agree	5				5
Neither Agree nor disagree					
Somewhat Disagree		1			1
Strongly Disagree	1	2	3	3	9

Table 3.2 Physical Subscale of the Voice Handicap Index

Table 3.2 VHI- Physical Subscale Compared by Career Speaking Intensity	Slightly Speaking Intensive	Neutrally Speaking Intensive	Highly Speaking Intensive	Not working (at time of survey)
Statement				
I run out of air when I talk.				
Strongly Agree	1		1	1
Somewhat Agree			2	5
Neither Agree nor disagree	1			1
Somewhat Disagree	1			
Strongly Disagree	1	2	2	
The sound of my voice varies throughout the day.				

Strongly Agree	1			1
Somewhat Agree	2		2	1
Neither Agree nor disagree	1		1	3
Somewhat Disagree		1		2
Strongly Disagree	1	1	2	
People ask, "What's wrong with your voice?"				
Strongly Agree			1	
Somewhat Agree			1	2
Neither Agree nor disagree				
Somewhat Disagree	1			
Strongly Disagree	2	2	4	6
My voice sounds creaky and dry.				
Strongly Agree	1			1
Somewhat Agree			1	2
Neither Agree nor disagree	2			
Somewhat Disagree	1		1	1
Strongly Disagree	1	2	2	2
I feel as though I have to strain to produce voice.				
Strongly Agree				
Somewhat Agree			1	2
Neither Agree nor disagree			1	
Somewhat Disagree	1		3	
Strongly Disagree	2	2	1	3
The clarity of my voice is unpredictable.				
Strongly Agree	1		1	1
Somewhat Agree	1			2
Neither Agree nor disagree	1			
Somewhat Disagree				
Strongly Disagree	2	2	3	3
I try to change my voice to sound different.				
Strongly Agree				
Somewhat Agree	1			
Neither Agree nor disagree				
Somewhat Disagree			1	1

Strongly Disagree	4	2	3	5
I use a great deal of effort to speak				
Strongly Agree				1
Somewhat Agree				4
Neither Agree nor disagree	2			
Somewhat Disagree	1		2	
Strongly Disagree	2	2	2	1
My voice is worse in the evening				
Strongly Agree				1
Somewhat Agree	2		1	
Neither Agree nor disagree	1			1
Somewhat Disagree	1		2	
Strongly Disagree	1	2	1	4
My voice "gives out" on me in the middle of speaking				
Strongly Agree				
Somewhat Agree	2		2	1
Neither Agree nor disagree				
Somewhat Disagree			1	
Strongly Disagree	2	2	1	4

Voice-Related Quality of Life (V-RQOL) Responses

Responses to this subset of stimuli were slightly varied. In 10% of responses to these subset statements, agreement and disagreement were split at 50%. This was for the statement “I run out of air and need to take frequent breaths when talking”. Still, in 90% of statements, disagreement was stronger than agreement. In 40% of statements, neutrality was greater than or equal to agreement. This demonstrates that most of the respondents to this survey did not feel their voice affected their overall quality of life. However, it is again important to note the 50% of agreement and disagreement regarding air capacity during speaking. This may highlight the possibility of a voice disorder and suggest that voice assessments may be a beneficial addition to

healthcare services that CF patients receive. Table 4.1 includes responses to this section as they correspond to age and Table 4.2 corresponds to job speaking intensity levels.

Table 4.1 Voice-Related Quality of Life

Table 4.1					
Voice Related Quality of Life (V-RQOL)					
Compared by Age	18-25	26-33	33-41	42+	Total
Statement					
I have trouble speaking loudly or being heard in noisy situations.					14
Strongly Agree		1			1
Somewhat Agree	2				2
Neither Agree nor disagree	1	1			2
Somewhat Disagree	2			1	3
Strongly Disagree	1	1	3	1	6
I run out of air and need to take frequent breaths when talking					14
Strongly Agree	1	1			2
Somewhat Agree	2	2	1		5
Neither Agree nor disagree					
Somewhat Disagree	2			1	3
Strongly Disagree	1	2		1	4
I sometimes do not know what will come out when I begin speaking.					14
Strongly Agree					
Somewhat Agree	2	2		1	5
Neither Agree nor disagree					
Somewhat Disagree				1	1
Strongly Disagree	2	2	3	1	8
I am sometimes anxious or frustrated (because of my voice).					14

Strongly Agree					
Somewhat Agree	1				1
Neither Agree nor disagree				1	1
Somewhat Disagree	2				2
Strongly Disagree	3	3	3	1	10
I sometimes get depressed (because of my voice).					14
Strongly Agree					
Somewhat Agree	1				1
Neither Agree nor disagree					
Somewhat Disagree					
Strongly Disagree	5	3	3	2	13
I have trouble using the telephone (because of my voice).					14
Strongly Agree					
Somewhat Agree	2				2
Neither Agree nor disagree		1			1
Somewhat Disagree	1	1			2
Strongly Disagree	3	1	3	2	9
I have trouble doing my job or practicing my profession (because of my voice).					14
Strongly Agree					
Somewhat Agree					
Neither Agree nor disagree	1	2			3
Somewhat Disagree					
Strongly Disagree	5	1	3	2	11
I avoid going out socially (because of my voice).					14
Strongly Agree					
Somewhat Agree					
Neither Agree nor disagree					
Somewhat Disagree	1				1
Strongly Disagree	5	3	3	2	13

I have to repeat myself to be understood.					14
Strongly Agree					
Somewhat Agree	1	2			3
Neither Agree nor disagree	1				1
Somewhat Disagree	1			1	2
Strongly Disagree	3	1	3	1	8
I have become less outgoing (because of my voice).					14
Strongly Agree					
Somewhat Agree					
Neither Agree nor disagree	1				1
Somewhat Disagree	1				1
Strongly Disagree	4	3	3	2	12

Table 4.2 Voice-Related Quality of Life

Table 4.2 Voice Related Quality of Life (V-RQOL)	Slightly Speaking Intensive	Neutrally Speaking Intensive	Highly Speaking Intensive	Not working (at time of survey)
I have trouble speaking loudly or being heard in noisy situations.				
Strongly Agree				1
Somewhat Agree	1			1
Neither Agree nor disagree			2	
Somewhat Disagree	2			
Strongly Disagree	1	2	1	2
I run out of air and need to take frequent breaths when talking				
Strongly Agree	1			
Somewhat Agree			1	4
Neither Agree nor disagree				

Somewhat Disagree	2		1	
Strongly Disagree	1	2	1	
I sometimes do not know what will come out when I begin speaking.				
Strongly Agree				
Somewhat Agree	2		2	1
Neither Agree nor disagree				
Somewhat Disagree	1			
Strongly Disagree	2	1	2	3
I am sometimes anxious or frustrated (because of my voice).				
Strongly Agree				
Somewhat Agree	1			
Neither Agree nor disagree	1			
Somewhat Disagree	1		1	
Strongly Disagree	2	1	3	4
I sometimes get depressed (because of my voice).				
Strongly Agree				
Somewhat Agree	1			
Neither Agree nor disagree				
Somewhat Disagree				
Strongly Disagree	3	2	5	4
I have trouble using the telephone (because of my voice).				
Strongly Agree				
Somewhat Agree	1		1	
Neither Agree nor disagree	1			
Somewhat Disagree	1			1
Strongly Disagree	2	2	2	3
I have trouble doing my job or practicing my profession (because of my voice).				
Strongly Agree				

Somewhat Agree				
Neither Agree nor disagree	1		1	1
Somewhat Disagree				
Strongly Disagree				
Strongly Disagree	3	2	3	3
I avoid going out socially (because of my voice).				
Strongly Agree				
Somewhat Agree				
Neither Agree nor disagree				
Somewhat Disagree	1			
Strongly Disagree				
Strongly Disagree	3	2	4	4
I have to repeat myself to be understood.				
Strongly Agree				
Somewhat Agree				
Neither Agree nor disagree	1			
Somewhat Disagree	1		1	
Strongly Disagree				
Strongly Disagree	2	1	3	2
I have become less outgoing (because of my voice).				
Strongly Agree				
Somewhat Agree				
Neither Agree nor disagree	1			
Somewhat Disagree				
Strongly Disagree	3	2	3	4

Discussion:

The purpose of this study was to understand if those living with CF perceived any aspects of their voice to be limiting their quality of life, as well as to investigate the possibility of a voice disorder. The following research questions were used to guide the direction of the study: What are the attitudes of individuals living with Cystic Fibrosis toward their vocal quality of life? What are the attitudes of individuals with Cystic fibrosis related to voice as a

handicapping condition? The study utilized the VHI and V-RQOL. Results were reported by different subscales: VHI: Functional Subscale, VHI: Emotional Subscale, VHI: Physical Subscale and V-RQOL. Under the VHI: Functional Subscale, in 100% of the statements, disagreement was greater than agreement. Under the VHI: Emotional Subscale, in 100% of the statements, disagreement was greater than agreement. Under the VHI: Physical Subscale, in 10% of statements, agreement was greater than disagreement. In another 10% of statements, agreement and disagreement were equal. In 80% of responses disagreement was greater than agreement. Under the V-RQOL subscale, in 10% of responses to these subset statements, agreement and disagreement were split at 50%. In 90% of statements, disagreement was stronger than agreement.

In most questions, more participants disagreed to some degree than those that agreed to some degree. All subscales included, in 92% of statements, agreement was greater than disagreement. Overall, this data shows that patients living with CF do not perceive their disease to have an effect on their voice that impacts their overall quality of life. The overall response ratio for the entire survey is 1:37:2 (ratio= greater agreement: greater disagreement: equal responses)

Assessing one's own voice is a complicated task. Ferrand (2012) explains that "normal voice is also very much a function of the listener's perception". Specifically it is addressed that "A trained voice therapist might consider a young woman's voice that is slightly low-pitched and husky to be deviant and in need of remediation, whereas the same voice might be considered attractive by the individual herself and by her friends and family" (Ferrand, 2012). The greater disagreement that resulted from the survey shows that those living with CF, for the most part, do not feel handicapped from their voice or do not feel that it affects their overall quality of life.

This does not exactly rule out the possibility of a voice disorder in the CF community. This is even more true when it is considered that perception of voice is not the only factor of a disorder, physical components are important to address as well because “even if the voice sounds clear and pleasant to listeners, if the speaker feels strained or discomfort or fatigued in the production of the voice, it cannot be considered normal” (Karnell et al., 2007).

Limitations

This study has a few limitations due to experience of the researcher. Limitations of this study should be considered in future studies. Surveys should not be lengthy, and should not give the option for participants to remain neutral. There should also be demographic questions relating to overall health of the participant, including lung function. Survey software that does not include participants that do not complete the entire survey should strongly be considered due to the effects of incomplete participation on survey answers.

The overall length of the survey resulted in many participants exiting without completing all questions. Only 14 participants completed the survey, compared to the 21 that began (only 67%). The survey combination of the entire VHI and V-RQOL resulted in 40 stimuli. Instead, it may have been more appropriate to include the most important from each, and limit the survey to 15-20 questions.

Neutral answers may have also affected a surveys answer as well. 20% of the responses to items included “neither agree nor disagree”. Participants should have been presented questions in which they had to choose; do they agree or not, and to what degree. It would have been more appropriate to limit the stimuli selection to “strongly agree”, “slightly agree”, “slightly disagree” and “strongly disagree”.

Future Implications

Results of this study show the possibility that there are voice abnormalities in the CF community, especially in terms of loudness. This should be further explored. Participants responses do shed light on important factors (such as physical components of a disorder including regularity throughout the day and air capacity). A voice disorder cannot be diagnosed from interpretation of these result, they can simply provide information about the status of participant's voice. An evaluation would need to be completed by a certified speech-language pathologist to diagnose a voice disorder. Future studies should address the physical components of voice disorders in those living with cystic fibrosis.

Cystic Fibrosis can range from very decreased lung function, to less severe depending on a variety of factors. If the survey had included a question about the severity of the disease, it would have been possible to determine whether there was a correlation between the rates of agreement/disagreement and the severity levels. In the future, a demographic question on overall health of the participant should be included. Voice is an important component regarding quality of life. Voice of those living with Cystic fibrosis should continue to be researched to improve quality of life in the community.

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