Cystic Fibrosis Symptom Tracker

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ABSTRACT

Existing questionnaires used in monitoring symptoms for Cystic Fibrosis (CF) are not specific to the disease, and are used for multiple different diseases. Available digital applications focus on one area of symptoms, such as respiratory or digestive issues, without incorporating a broader range of symptoms. We have created a Cystic Fibrosis tracking system utilizing Matlab functions and GUI applications as well as SQLite databases that cover both digestive and respiratory symptoms caused by Cystic Fibrosis. This tracking system is user specific to ensure privacy and retains all symptom inputs which enables users to view previous symptoms for later comparison.

1. INTRODUCTION

Cystic fibrosis (CF) is a debilitating disease that affects the lungs, pancreas, and other organs. In a person without cystic fibrosis, mucus acts like a lubricant to keep tissues like the lungs, stomach, and intestines from drying out [1]. It also can catch dust and germs in the respiratory tract, helping to prevent infection. However, in those with CF, defective genes cause mucus to become sticky and thick, which clogs tubes and ducts in organs in the body [2]. This primarily affects the lungs and pancreas, although other organs are affected too. Over the past decades, the longevity and quality of life of those with cystic fibrosis has been improving, but in 2019, CF patient's median age of death was 48.4 years [3]. There are approximately 40,000 people in the United States with CF, and approximately 105,000 people worldwide with CF that spans 94 countries [2].

It is important to continue to research cystic fibrosis to further improve CF patients' life expectancy. Having data to understand the disease progression over time is useful as a backbone for future studies conducted. There is a need to get more data on long-term symptom progression. Additionally, there is a need for an easy way for patients to communicate their symptoms with their doctors and if they are getting better or worse.

Cystic fibrosis is a genetic based disorder that causes the buildup of mucus in the lungs and pancreas due to a mutation in the CFTR gene. This results in the lack of CFTR protein, which is a protein responsible for regulating mucus buildup. An individual must inherit two mutated CFTR genes, one from each parent, in order to get cystic fibrosis [4]. It has negative effects on mainly breathing and digestion. Symptoms may include stunted growth, nausea, coughing, fatigue, loss of appetite, and more [5]. If left untreated, cystic fibrosis can lead to death. However, there are treatments for it that increase the life expectancy, which involve medicines, therapy, or lung transplants. Cystic fibrosis may also lead to other diseases such as diabetes, cirrhosis, and osteoporosis.

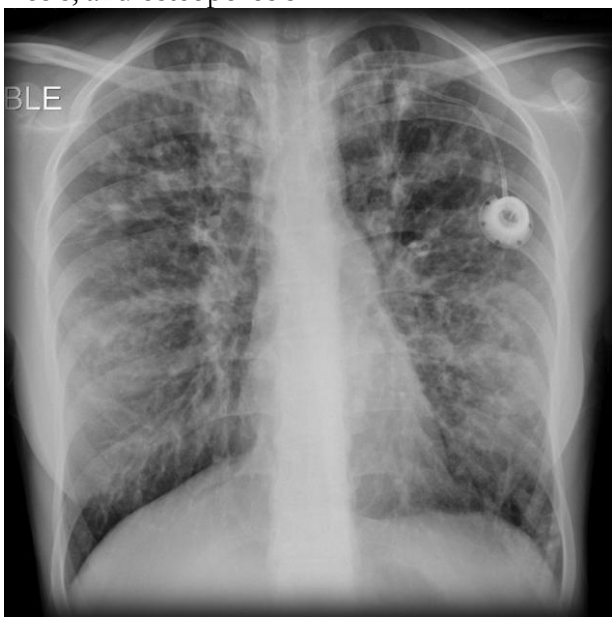

Figure 1. Frontal chest radiograph depicting CF pathology by showing bronchiectasis, increased interstitial markings, and bronchial wall thickening. [6]

This application is being developed to aid patients with Cystic Fibrosis in tracking their symptoms. The end users would be the patients themselves, their caregivers, and their doctors who would be able to help monitor these symptoms and any changes that may be

presented. Most of the questionnaires that are regularly used to track Cystic Fibrosis are not specific to this particular disease [7]. Furthermore, there aren't any available existing symptom trackers that encapsulate a wide range of the symptoms that a patient may experience from respiratory to digestive. Therefore, this will greatly impact how this disease is managed and provide the correct information towards an accurate treatment. Additionally, the application of this symptom tracker may aid in research and studies to compare symptoms between users by accessing the reported symptom information stored in their database.

Some existing solutions include previously mentioned medical questionnaires and a few that are being developed to focus more acutely on Cystic Fibrosis. Norrish et al. developed a study to create a more specific questionnaire, the Cystic Fibrosis Symptom Progression Survey (CF-SPS), in monitoring patient symptoms as well as having relevance in a clinical setting [8]. Another existing application is a 'CF Tummy Tracker' which focuses on monitoring stomach symptoms through a smartphone app, though it does not account for symptoms in other areas such as the lungs [7]. Similarly, another existing solution is the Cystic Fibrosis Respiratory Symptom Diary (CFRSD) and Chronic Respiratory Infection Symptom Score (CRISS©) which only focuses on respiratory issues within Cystic Fibrosis [9]. Our symptom tracker will use survey questions from the Norrish et al. study in a digital application setting like the CF Tummy Tracker and CFRSD or CRISS© format to create a more convenient way to record their symptom data in a broader sense.

2. METHODS AND IMPLEMENTATION

We utilized Matlab .m and .mlapp files as well as databases created through SQLite to create the symptom survey. In Matlab, the database toolbox was used. Additionally, we implemented an 'md5.m' code from a third party that was used to encrypt the password the user creates to ensure privacy is maintained for the user [10]. This file was not modified from its original source code when utilized in our application. We used .mlapp files to create the GUIs for the login screen, user registration, symptom survey, and symptom tracker. In order to have the different GUIs interact with each other, multiple .m files were created that allowed us to dictate what would happen when the user interacted with the GUIs. The .m files were also responsible for creating the databases we stored user information and symptoms inside and extracting the information for tasks such as showing the symptoms log and logging in. A User Database table in SQLite was created to store user registration information, which was linked to the Symptoms database which stored the appropriate symptom data for each user on a specific date.

The user will start off with the login screen, in which they will be met with two options. Either enter their username and password to access their account or push the "New User" tab to create their account. When hitting "New User", they will be met with a new GUI that asks for information about the user and prompts the user to create a username and password. The user will be met with errors if the username they selected already exists, the password and confirm password entries do not match, a date of birth in the future is selected, or any of the entries are not filled out.

Once this information is submitted, the user will be brought back to the login screen, where they will be able to input their username and password to access their account. The user will be met with errors if the username and/or password they entered is incorrect or if one of the entries is not filled out. After logging in, the user is met with a symptom survey, where they will be able to fill out what their symptoms are related to cystic fibrosis. The user will be met with errors if they do not fill in all entries, enter a number outside of the allowed range, or enter a date in the future. Alternatively, they can choose the "See Previous Symptoms" to look at symptoms they have previously entered. Upon selecting this option, they will be shown a table of all previous entries they have submitted in chronological order.

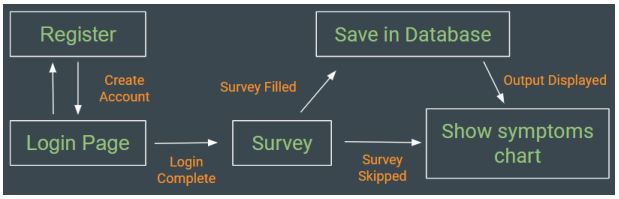

Figure 2. GUI applications method flowchart.

3. EXPERIMENTS AND RESULTS

The cystic fibrosis symptoms survey will be utilized the same for anyone with cystic fibrosis, with only a slight difference if they are a new or returning user. When a user opens up the application, they will log in if

they are a returning user and will register if they are a new user. After completing registration, they will log in to access the symptoms survey. The symptoms survey will be filled out for the date they want to report, and they will fill out each category with valid values shown in **Figure 3**. After submitting, they will see a table with each of the reported values on every date they have submitted. If they do not wish to submit the survey and want to just see the results, they will hit the see previous symptoms button to see all previous submission results.

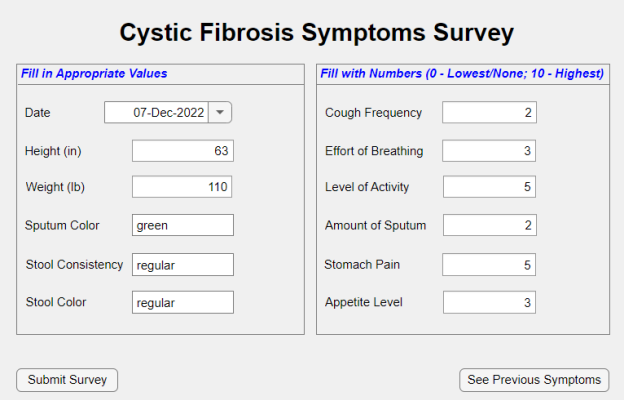

Figure 3. This application has twelve fields to fill out to keep track of the height, weight, and cystic fibrosis symptoms.

In the symptoms survey **Figure 3**, the left panel includes a date picker, two numeric entries for height and weight, and three text entries for qualitative assessment of symptoms. The survey then utilizes on the right panel a qualitative scale from 0-10 to describe how low or high the symptoms are on a particular day, with 0 being the lowest or none and 10 the highest.

Cystic Fibrosis Symptoms Over Time

Date	Height	Weight	Sputum Color	Stool Consist	Stool Color	Cough Frequency
07-Dec-2022	63	110	green	regular	regular	2
06-Dec-2022	63	110	yellow	regular	regular	3
05-Dec-2022	63	111	clear	regular	regular	5

Cystic Fibrosis Symptoms Over Time

Cough Frequency	Effort Breathing	Level of Activity	Amount of Sputum	Stomach Pain	Appetite Level
2	3	5	2	5	3
3	1	4	2	7	6
5	2	3	6	4	7

Table 1. This database table presents the twelve inputs from the symptom survey GUI in Figure 3 over numerous days.

The results in **Table 1** are comparable to results produced by the CF-SPS Questionnaire since many of the survey questions were implemented from this survey. The output of the databases was similar to the CF Tummy Tracker, CFRSD, and CRISS© since these are in a digital setting that could monitor the progression of the symptoms. However, our application differs by combining the questions to accept a broader range of symptoms in the digital setting.

4. DISCUSSION

We have created a GUI that is able to access a specific user's account so they can input symptoms and look at any previous submissions they made as well. This is helpful in seeing the symptom progression of not only the disease but for experimental treatments or therapies to combat the symptoms of this disease as well. This survey is an easy way to see if disease symptoms are getting better, worse, or staying the same. The survey is valid because the symptom questions presented in the survey were relevant to Cystic Fibrosis, as they were referenced from previous studies and questionnaires [7][8][9].

All of the symptom data collected related to cystic fibrosis is qualitative, which is subjective in nature. For instance, even if two users have the same amount of sputum, they may input different numbers for them on the scale. This also makes statistical testing much more difficult and less effective if someone were to attempt to use this in a study due to its non-parametric nature.

An experimental study that focuses on retrieving quantitative results for symptoms such as the amount of sputum would help to reduce the impact of the limitations this survey suffers from. Quantitative results are more effective for experimental studies and would be more useful to keep track of due to its high accuracy and non-subjective nature. Additionally, a focus group should be created to ensure all inputs are understandable to the users. This GUI was not tested with users with Cystic Fibrosis over an extended period of time, so further user testing and verification of this survey should be implemented.

The first step in improving our application would be to add graphs for all numeric data inputs. Having graphs will allow users and their doctors to see their symptom progression more easily over a period of time. In addition, the categories and their corresponding inputs can be improved once quantitative results can be defined to replace the ordinal data scale of 0-10. The application can also be improved through having a "forgot my username or password" option. If a user forgets

their login info, they will no longer have access to their survey with the current GUI system.

Our symptom tracker can be used in many different research studies in the future. If a new treatment comes out, this could be used to see if it improves symptoms and which ones throughout a period of time. Additionally, it could be used to see which symptoms are most prevalent in the cystic fibrosis population. The symptom tracker has many versatile applications that will hopefully benefit those with cystic fibrosis in the future.

5. REFERENCES

[1] Wein, H. (2020, September 1). Marvels of mucus and phlegm. National Institutes of Health. Retrieved December 7, 2022, from https://newsinhealth.nih.gov/2020/08/marvels-mucus-phlegm#:~:text=It%20serves%20as%20a%20lubricant,expert%20at%20Johns%20Hopkins%20University

[2] About cystic fibrosis. Cystic Fibrosis Foundation. (n.d.). Retrieved December 7, 2022, from https://www.cff.org/intro-cf/about-cystic-fibrosis

[3] McBennett, K. A., Davis, P. B., & Konstan, M. W. (2022, February). Increasing life expectancy in cystic fibrosis: Advances and challenges. Pediatric pulmonology. Retrieved December 7, 2022, from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9004282/

[4] Centers for Disease Control and Prevention. (2022, May 9). Cystic fibrosis. Centers for Disease Control and Prevention. Retrieved December 7, 2022, from https://www.cdc.gov/genomics/disease/cystic_fibrosis.htm#:~:text=Cystic%20fibrosis%20(CF)%20is%20a,makes%20infections%20more%20likely%3B%20and

[5] Pennmedicine.org. (n.d.). Retrieved December 7, 2022, from https://www.pennmedicine.org/for-patients-and-visitors/patient-information/conditions-treated-a-to-z/cystic-fibrosis#:~:text=Definition,is%20a%20life%2Dthreatening%20disorder.

[6] El-Feky, M. (2021, October 16). Cystic fibrosis (pulmonary manifestations): Radiology reference article. Radiopaedia Blog RSS. Retrieved December 7, 2022, from https://radiopaedia.org/articles/cystic-fibrosis-pulmonary-manifestations-1

[7] Smyth, A. (n.d.). CF Tummy Tracker. Retrieved December 7, 2022, from https://cftummytracker.org/

[8] Norrish, C., Norrish, M., Fass, U., Al-Salmani, M., Lingam, G. S., Clark, F., & Kallesh, H. (2015). The Cystic Fibrosis Symptom Progression Survey (CF-SPS) in Arabic: A Tool for Monitoring Patient's Symptoms. Oman medical journal, 30(1), 17–25. https://doi.org/10.5001/omj.2015.04

[9] C, G., DL, P., & B, M. (n.d.). Cystic fibrosis respiratory symptom diary (CFRSD) and chronic respiratory infection symptom score (Criss©). Cystic Fibrosis Respiratory Symptom Diary (CFRSD) and Chronic Respiratory Infection Symptom Score (CRISS©) - Seattle Quality of Life Group - Measure and Improve Health Disparities in Children, Adolescents, Adults from Stigmatized Populations. Retrieved December 7, 2022, from https://depts.washington.edu/seaqol/CFRSD-CRISS

[10] Stefan Stoll (2022). MD5 signature of a file (https://www.mathworks.com/matlabcentral/fileexchange/5498-md5-signature-of-a-file), MATLAB Central File Exchange. Retrieved December 1, 2022.