Symptom Assessment and Monitoring/Management

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Introduction

SAAM stands for Symptom Assessment and Monitoring/Management for cancer patients receiving chemotherapy. The goal of our application is to provide this patient population with timely side-effects self-management strategies and recommendations. The self-management strategies focus on practical tips that patients can do to manage their symptoms from the side-effects of chemotherapy, where the recommendations focus on when to seek medical help.

What

Chemotherapy, one of the treatments for cancer, is often associated with numerous predictable and preventable side effects (Henry et al., 2008; Reilly et al., 2013). Without timely management of these side-effects, patients often go to the emergency department (ED) for symptom relief, which is not appropriate for this purpose (Yao, Green, and Krzyzanowska, 2018). Cancer patients undergoing chemotherapy are at risk of exposing themselves to numerous infections within the ED, due to their weakened immune system from chemotherapy (Quach et al., 2012).

Surprisingly, 43,593 out of 64,407 ED visits in Ontario are related to those who recently received chemotherapy from April 2014 to March 2015 (Yao et al., 2018). From those visits, more than half of them were deemed as potentially preventable and can be managed outside of the emergency setting (Yao et al., 2018). This data is consistent with previously published data from 1980 to 2011 (Vandyk et al., 2012).

Why

One of the potential solutions to the problem mentioned is to provide patients and families with tailored information and support regarding side effects managements via electronic monitoring tools (Basch et al., 2016; Berry et al., 2014). Studies have shown that patients with side effects managements support via electronic validated tools reduced symptoms severity, improved patient's quality of life, prolonged patient survival, reduced ED usage and hospitalization (Basch et al., 2016; Berry et al., 2014). These benefits are due to the early responsiveness to patient symptoms preventing adverse downstream consequences. To date, Ontario has implemented a web-based symptom assessment tool for patients and health care providers to use (Cancer Care Ontario, 2014). Our team wishes to take this concept further by providing self-management strategies and recommendations based on the symptom assessed.

How

Our application, SAAM, uses an existing algorithm from the Canadian Oncology Symptom Triage and Remote Support (COSTaRS) to provide patients with automated messaging feedback related to recommendations as to when to seek medical care and self-management strategies for the common symptoms related to chemotherapy. COSTaRS is initially developed as a tool to manage cancer-related symptoms via standardized and quality telephone support. COSTaRS assesses for seventeen of the most common symptoms related to cancer patients.

For each of these symptoms, recommendations relate to when to seek medical care will be based on symptom severity. For example, when assessing for pain, COSTaRS will ask for patient-reported severity on a scale of 0 (none) to 10 (worst). COSTaRS will then request additional information about the symptom to assess severity. See below for questions related to pain.

Ask patient to indicate which of the following are present or absent

Patient rating of current pain (see above)	0 – 3	☐	4 – 6	☐	7 - 10	☐
Patient rating of worst pain (see above)	0 - 3	☐	4 – 6	☐	7 - 10	☐
Patient rating of pain at best	0 - 3	☐	4 – 6	☐	7 - 10	☐
Patient rating of worry about pain (see above)	0 - 5	☐	6 – 10	☐		☐
Was the pain onset sudden?	No	☐	Yes	☐	Yes	☐
Is the pain from a new location?	No	☐	Yes	☐	Yes	☐
How much does pain restrict your daily activities (walking, eating, bathing, sleep)?	None	☐	some	☐	Severe limitations	☐
Does the pain interfere with your mood?	No	☐	Yes	☐		☐
Are you able to get relief of pain from your medications?	Yes, relief	☐	Yes, some	☐	No	☐
How much does the pain medicines restrict your daily activities?	None	☐	some	☐	Severe limitations	☐
Are you feeling other symptoms: constipation, nausea/vomiting, fatigue, itchiness, confusion, new weakness in legs or arms? If yes, see other symptom practice guide(s).	None	☐	Some	☐	Several, with ≥1 symptoms assessed as severe	☐
	🟢 1 **Mild** (Green)		🟡 2 **Moderate** (Yellow)		🔴 3 **Severe** (Red)	
2. Triage patient for symptom management based on highest severity (Supporting evidence: 5 guidelines)[2,3,4,6,8]	☐ Review self-care. ☐ Verify medication use, if appropriate.		☐ Review self-care. ☐ Verify medication use, if appropriate. ☐ Advise to call back if symptom worsens, new symptoms occur, or no improvement in 1-2 days.		☐ Refer for medical attention immediately.	

Figure 1. Pain related question form

The final recommendation, which is color coded by green, yellow, and red, is based on the highest level of severity indicated (left column = less severe, right column = most severe). Even if there is one answer on the highest severity column (right column), the patient will be recommended to seek medical attention immediately.

Regarding self-management strategies, the information will be provided based on yes or no questions. For example, one of the self-management questions for pain is asking if patients are doing light exercise. If the answer is no, the tool will suggest specific light exercises for patients along with the rationale.

Statement of Functionality

The following describes the functionalities of SAAM and shows the corresponding screenshots.

Sign in and Sign up

When a user opens the app, the user can either register a new account or log in with credentials.
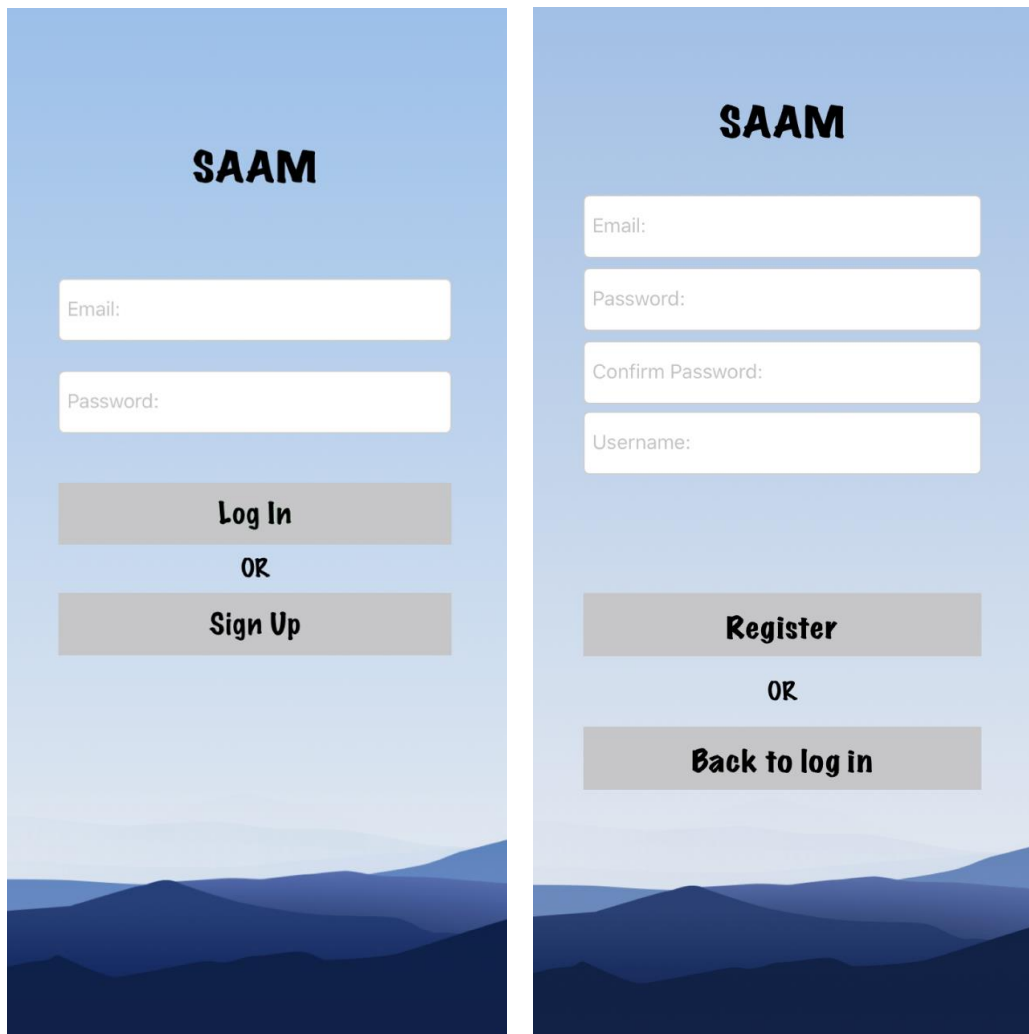

Figure 2. Sign in and sign up page

Profile/Home Screen

After a user logs in or signs up, the user will be redirected to the profile page. The profile page integrates most important functions like "New Assessment", "Report" and "Skip Setup".

Figure 3. Profile page

New Assessment

Choosing "Start" on the profile page will start a new assessment. There are seven main questions like pain, nausea, and anxiety. For every main question, the answer is set to 11 levels from 0 to 10, where 0 means no symptom and 10 means the worst possible symptom subjectively. Under the number bar, there is a text box showing the objective meaning of a specific number.

After the patient submits the answer, the application will provide a box asking, "Can we ask you additional questions related to this symptom". If the patient chooses "Accept", he or she will be asked follow-up questions for this main symptom. He or she will be asked about details related to this symptom, like the frequency of the symptom, medications used, and self-care strategies tried.
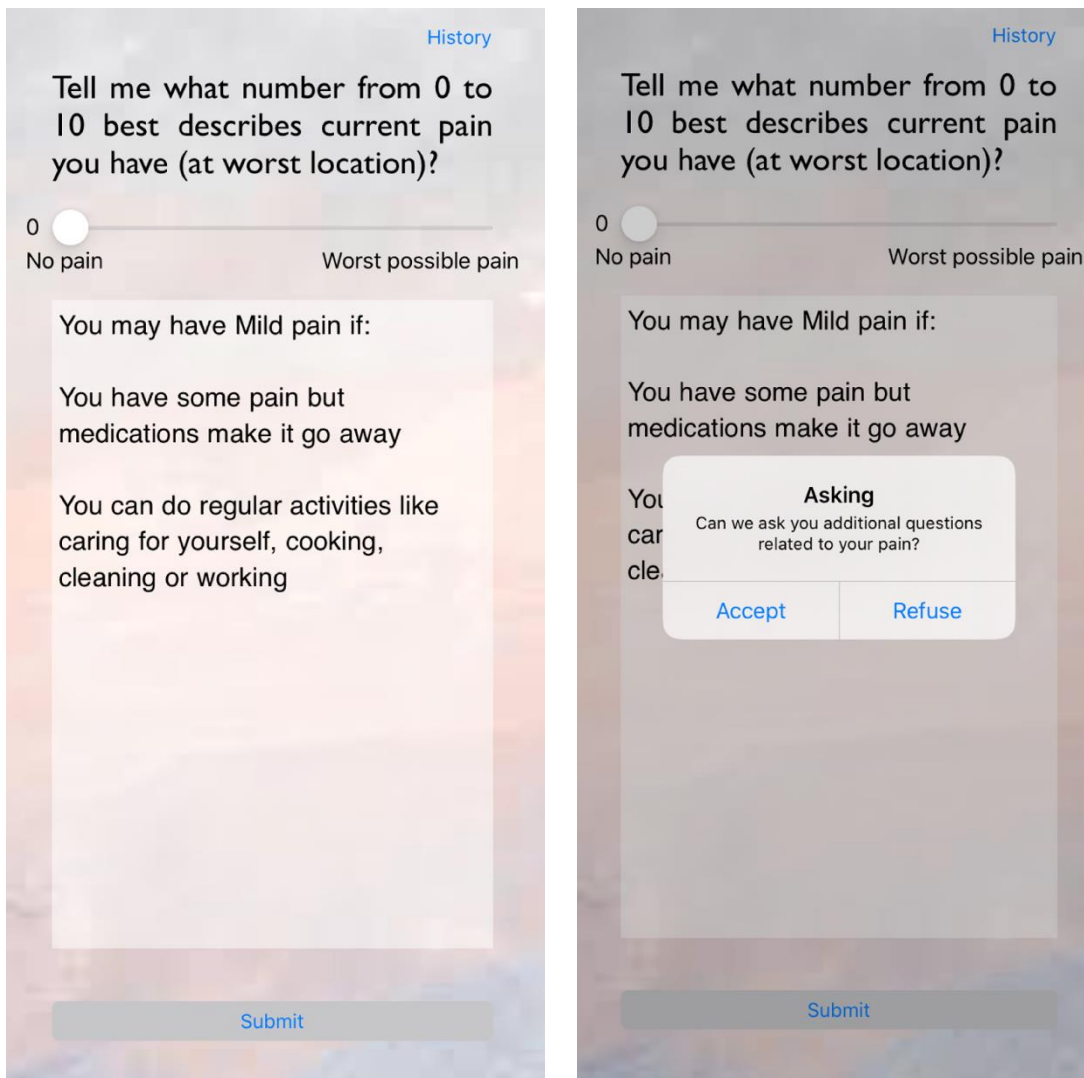
Figure 4. Main question page

What do you currently use for pain including prescribed, over the counter, and or herbal supplements? (choose all that applies)

Acetaminophen

Asking

May we ask you about a few questions related to self care strategies?

Accept   Refuse

sennosides

bisocodyl

lactulose

Polyethylene Glycol

Submit

Do you understand the plan for taking routine and breakthrough medicines for pain?

No

Yes

Figure 5. Sub question page

In the top right corner of the screens above, there is a "History" button. The patient can view the answered questions and click that question if they want to change the answer.

Figure 6. History function page

If the patient cannot finish the assessment and quit the application, he or she will be able to continue with the unfinished assessment. The previously answered parts will be stored in the database.

Figure 7. Function to continue with an unfinished assessment

After the patient finishes all the questions, he or she will be given feedback according to the answers. The recommendation is on th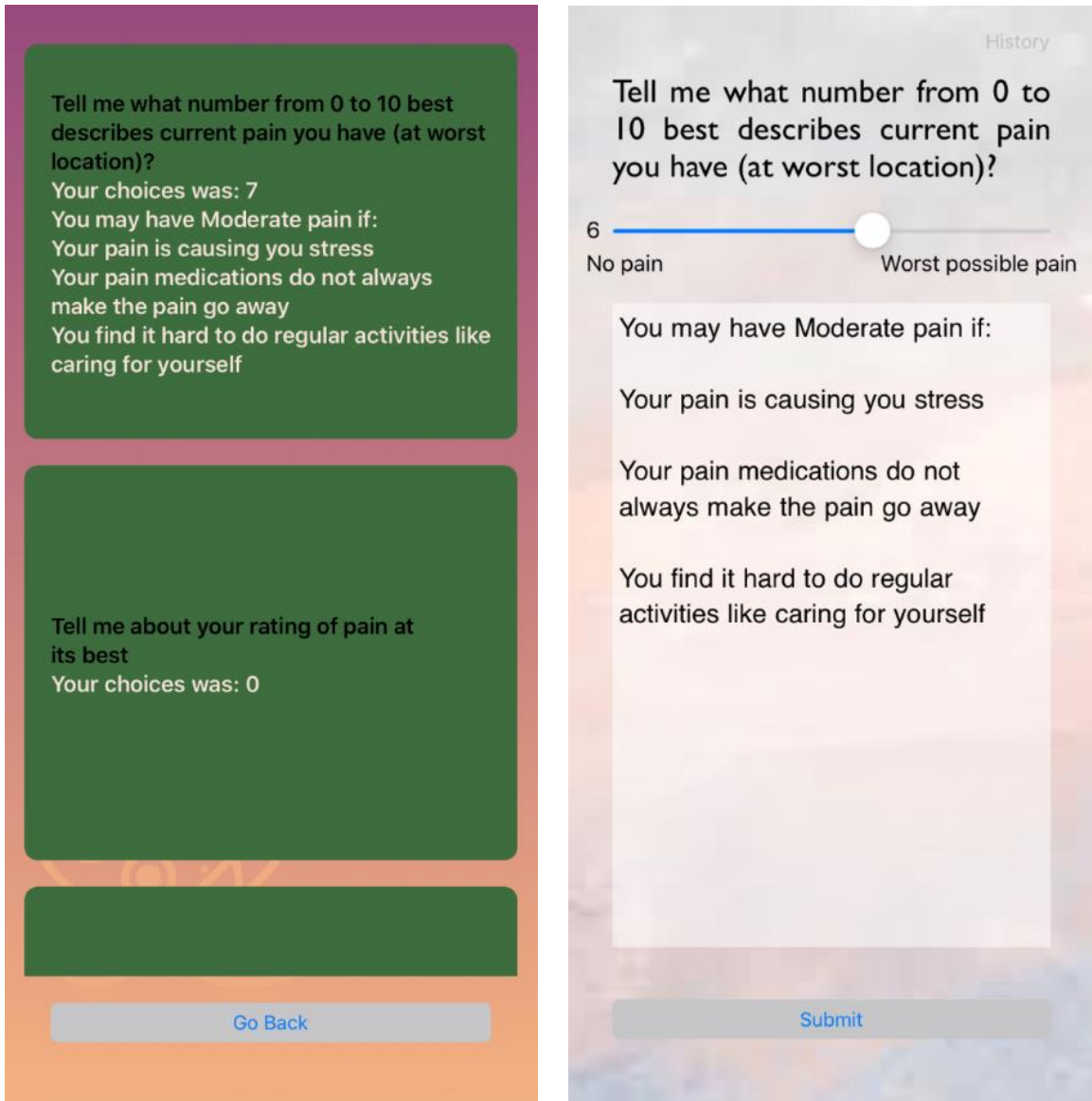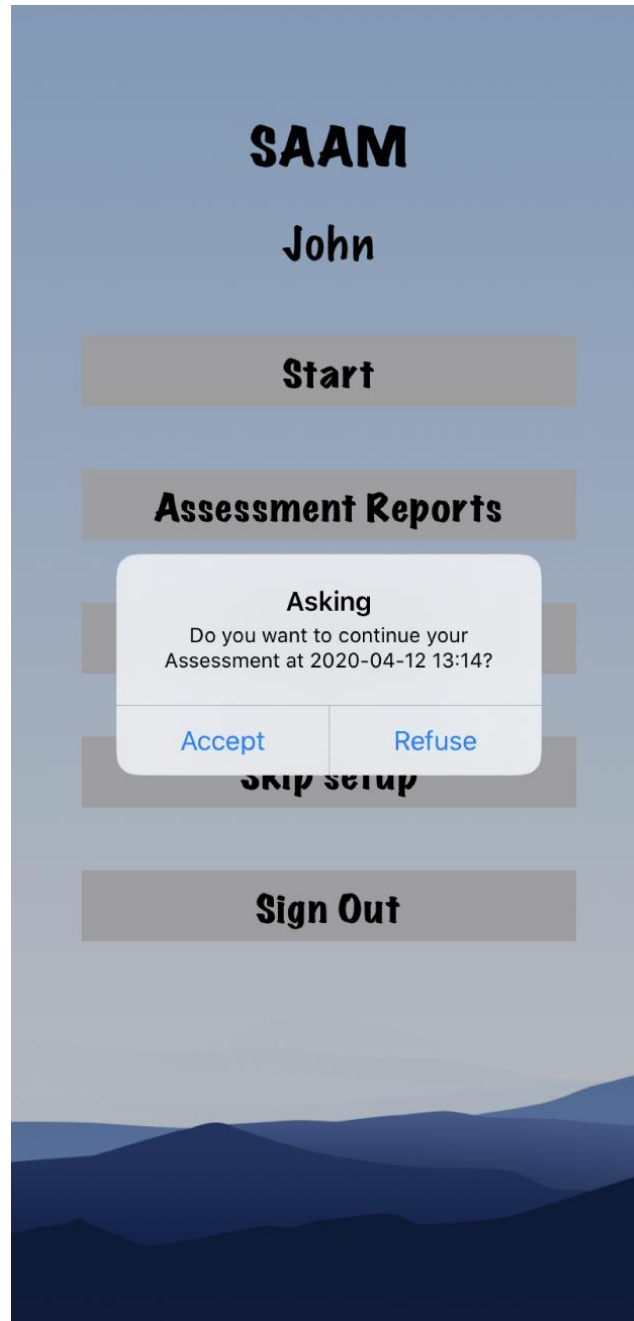e top of the "Assessment Result" page, and self-management tips are in the text box below. The recommendation is the general suggestion like whether to go to the hospital or continue with the current medical plan, which is given based on the highest score the patient has input. When the situation is not as severe, the recommendation is in a green font. If the situation is severe, the font will be red, which is based on the COSTaRS algorithm mentioned in the introduction section. Self-management tips teach the patient how to treat the symptom and take care of himself or herself.

Assessment Result

Please call your medical team in 1-2 days if any symptoms worsen, new symptoms occur, or no improvements on any symptoms

Self-management tips:

1. It is normal to feel nervous about taking pain medication. Some people do not take pain medications because they worry about addiction. Your family may also worry about addiction and might not want you to take your pills. If you take your medication as your doctor prescribed, you should not worry. Addiction happens when a person takes medications for reasons other than pain. Some people think they should save their pain medication in

Back To The Profile

Assessment Result

Please seek medical attention immediately

Self-management tips:

1. It is normal to feel upset and frustrated when you are in pain. You can find support in your community and through your health care team. If you feel depressed or anxious, ask to speak to a social worker, psychologist, psychiatrist or someone who is an expert in helping people with cancer. To learn more about online support groups check out the Canadian Cancer Society's Peer Support Service and talk to someone who has been there. For more information go to: www.cancer.ca/support
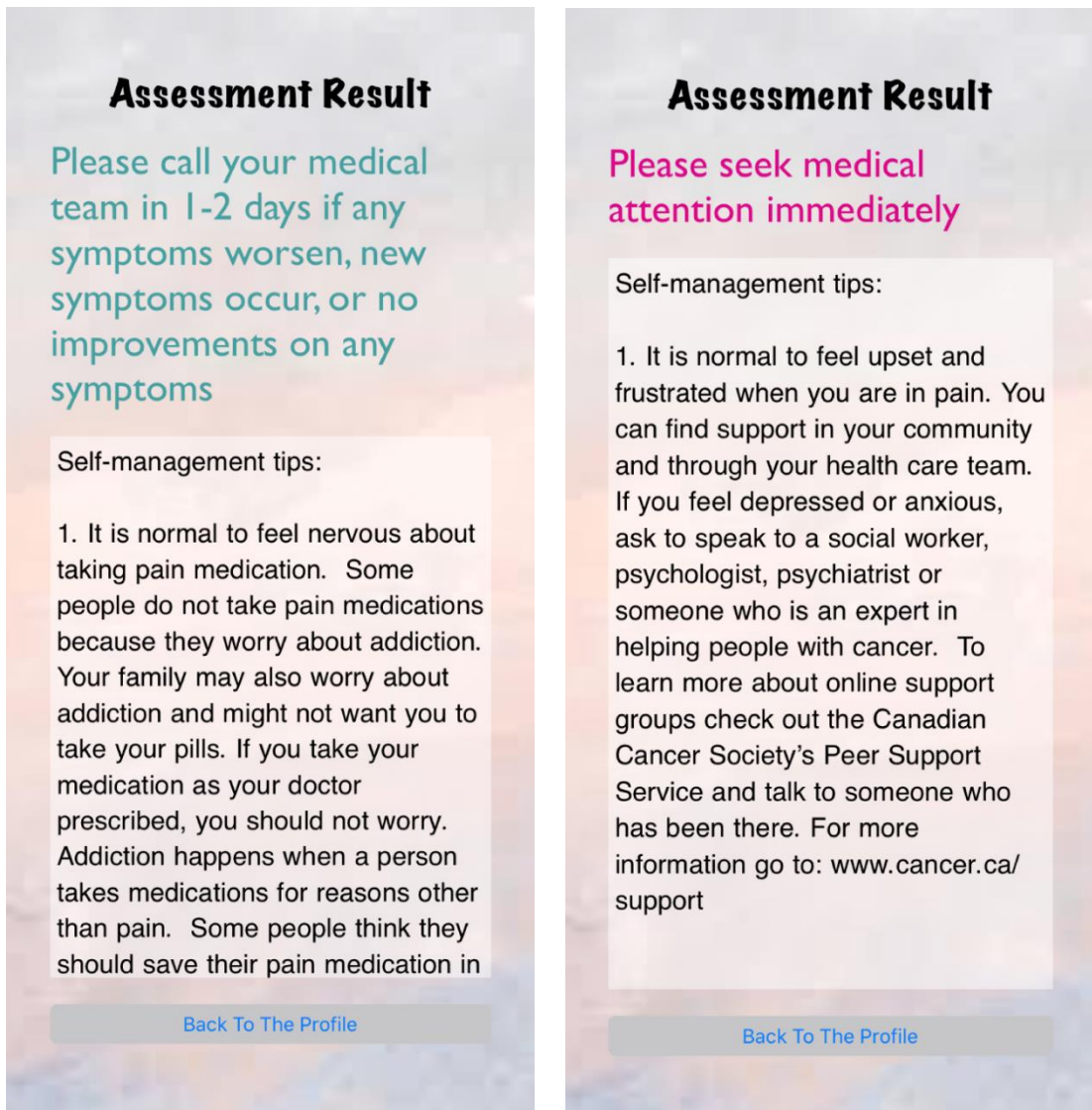
Back To The Profile

Figure 8. Feedback page

Assessment Reports

        After selecting "Assessment Reports", the patient will be able to view a list of the answered assessment in chronological order with the latest assessment at the top. The report contains all the questions and answers to the assessment, recommendation, and self-care strategies. After clicking the "PDF" button on the top right, the patient can see a PDF form of the report. If the patient wants to bring this to his or her health care provider, he or she can print it or save it to the phone, as shown below.
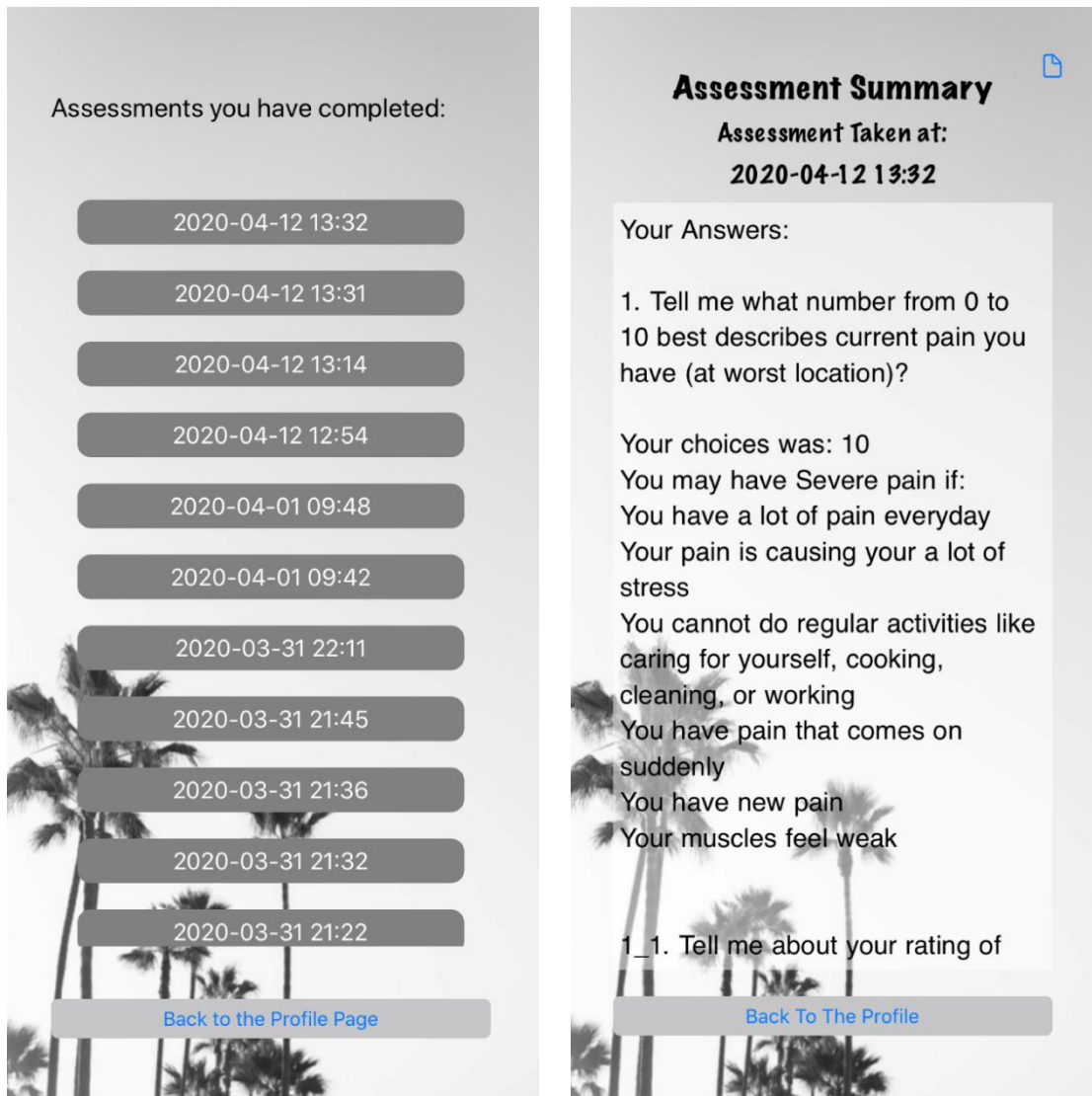

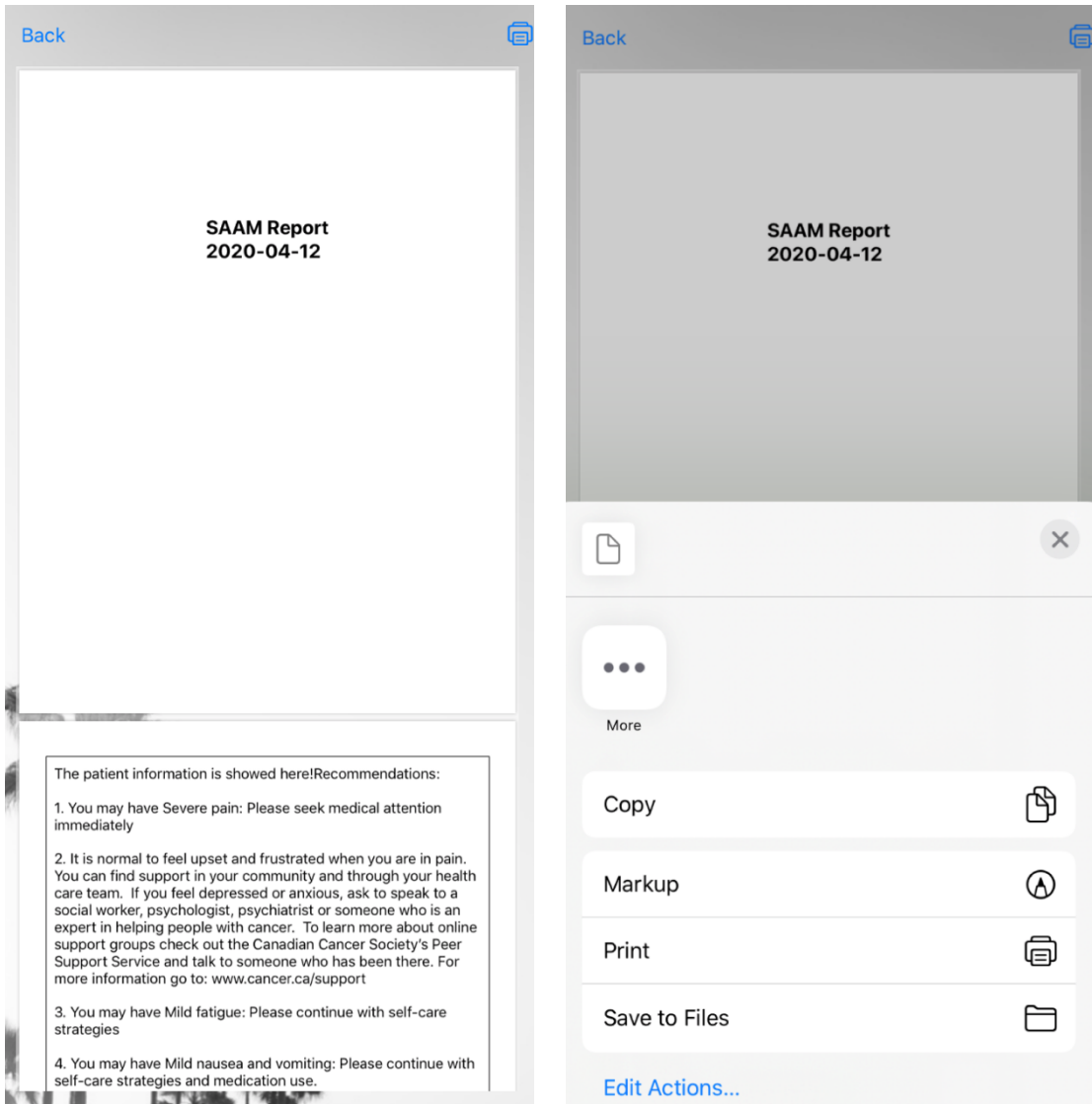**Figure 9.** Assessment summary page

SAAM Report
2020-04-12

The patient information is showed here!Recommendations:

1. You may have Severe pain: Please seek medical attention immediately

2. It is normal to feel upset and frustrated when you are in pain. You can find support in your community and through your health care team. If you feel depressed or anxious, ask to speak to a social worker, psychologist, psychiatrist or someone who is an expert in helping people with cancer. To learn more about online support groups check out the Canadian Cancer Society's Peer Support Service and talk to someone who has been there. For more information go to: www.cancer.ca/support

3. You may have Mild fatigue: Please continue with self-care strategies

4. You may have Mild nausea and vomiting: Please continue with self-care strategies and medication use.

SAAM Report
2020-04-12

More

Copy

Markup

Print

Save to Files

Edit Actions...

Figure 10. PDF report

Trend Report

      The patient will be able to see a graphical representation of every symptom according to multiple assessments, which shows the user whether the symptom gets better or worse; and provide patients and their health care providers with evidence as to what treatments are working or not.

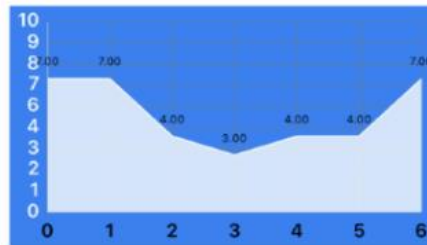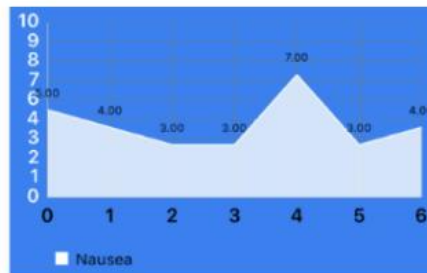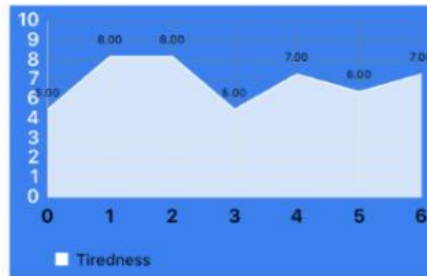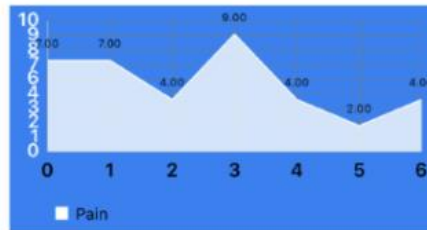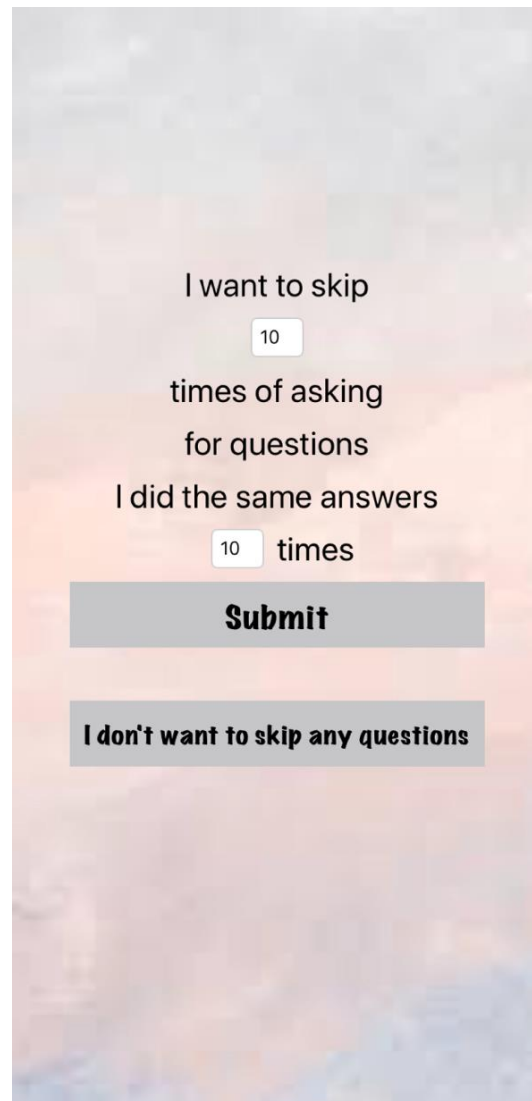**Figure 11.** Trend chart page

Skip Setup

Clicking "Skip setup", the user will be able to change the frequency of questions in the assessment. For example, he or she can set that one question will be skipped for ten times if the answer is unchanged for ten previous assessments. This feature will help the patient to save time and focus on other essential questions.

Figure 12. Skip setup page

Overall Design

   The system structure can be divided into three parts. Local Front-end part is for user's views or user's screens. It consists of a UI system to interact with the user. The local back-end part is the back-end part of the system running on users' cellphones. It is the back-end of the application. It is mainly for data computation and processing. The remote service that we are using is the Firebase system provided by Google. It is primarily for user authentication and fire storage.
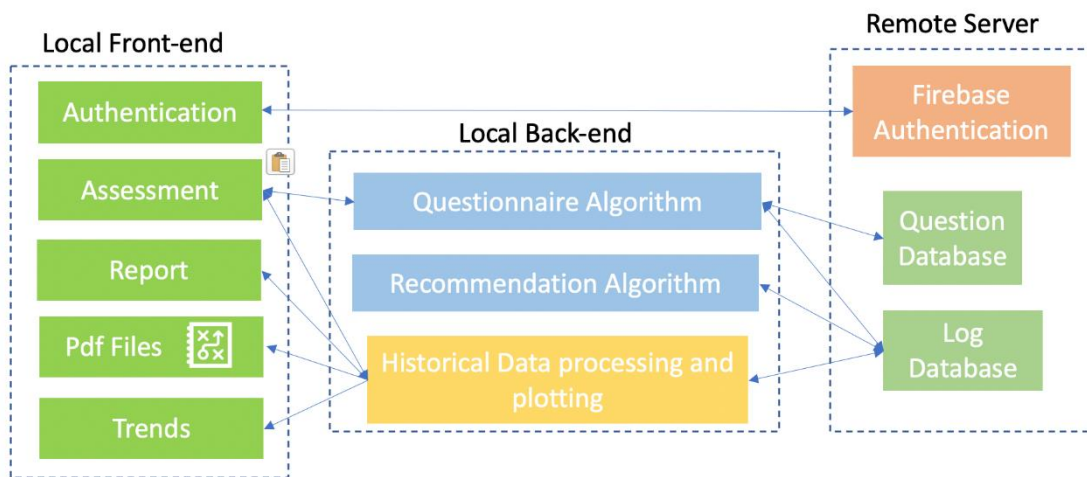

Figure 13. Structure of the SAAM system

   Local Front-end is the UI system of the application. Users can use the authentication page to log into the app. The authentication module in the local Front-end part is directly communicating with the Firebase authentication module, which is a part of the remote service. There are different screens for different question types for the assignments, such as the screen for multiple-choice questions. The report module is to display the reports for assessments with the corresponding pdf files. The Trends module can get the data from the local back-end and present it to the user in a graphical format.

   The application back-end, or the local back-end, is mainly for data processing. The Questionnaire Algorithm can use the raw data for questionnaires saved in the remote database to arrange different assessments for different users. Based on the user's answers, the Recommendation Algorithm can generate various recommendations to users. Historical Data Processing and Plotting module can get the response of the user's past assessments and create a graphical representation of the different symptoms that the user may be suffering.

   For the remote service, we use the firebase authentication system for the user's registration and login operations. We also use the firebase data storage service to save the questionnaire and the user's data.

Reflection

We learned many things from this project. The first thing was that we should have asked our potential users for suggestions before adding features. Some of the features were hard to implement but not necessary for users. We spent more than a week working on the question skipper function. Due to the nature of the COSTaRS algorithm, translating the algorithm to our application and adding the question skipping mechanism was difficult and time-consuming. After getting feedback from various co-workers and fellow students, we found that this skipping mechanism is not useful and confusing to use.

Also, we need to focus on critical features instead of all the features when we were presenting our application. Due to the amount of time spent on the feature mentioned, we were hoping to show all those features to the audiences. As a result, we sped up our demonstration and tried to explain everything within two minutes.

Furthermore, we should be more careful when we are using source control tools since we almost destroyed our program one time within GitHub.

Fortunately, we were able to speak to one of the COSTaRS' committee members and gave us insight as to how COSTaRS will be implemented in a digital setting and its latest research studies.

Group Member Contributions

- Logo design (Felix)
- Feature design (Felix)
- Providing expertise within the medical field (Felix)
- Meeting with COSTaRs Committee member (Felix)
- Login and profile page (Jianfeng)
- Optimize user Interaction (UI) (Xiaoyi, Jianfeng)
- Dynamic questionnaire Algorithm (Xiaoyi, Jianfeng, Felix)
- Converting recommendations and self-care strategies from COSTaRS (Felix)
- Data processing for recommendations and self-care strategies (Xiaoyi, Jianfeng)
- Database design (Xiaoyi, Jianfeng, Felix)
- Data summary function (Jianfeng)
- PDF generator for assessment result printing (Jianfeng)
- Trend plots module for symptoms (Jianfeng)
- Ability to change the answer of the assessment (Xiaoyi)
- Ability to continue with unfinished assessments (Xiaoyi)
- Reducing the frequency of questioning stable symptoms (Xiaoyi)
- Application Test (Xiaoyi, Jianfeng, Felix)

Specialist Context

I am a full-time master's student in the Nurse Practitioner program with a collaborative specialization in Palliative and Support care. I am also a nurse working in the emergency department since 2012.

Palliative and supportive care is an approach to care in which it focused on improving the quality of life for patients and their families with serious illness by addressing physical, psychosocial, and spiritual pain and other problems. In practice, there is a common misconception that palliative care is only related to caring for the end of life. Palliative care can be given at all stages of a chronic illness. It can be delivered at any age and along with any other active medical treatments.

With SAAM, our team was able to combine my clinical expertise and academic knowledge from my collaborative specialization in palliative and support care. At the patient level, SAAM applies the principles of palliative care by improving the quality of life for patients and families via continuous symptom monitoring and management, which may ultimately reduce emergency room visits as a downstream consequence.

At the research level, there is currently a lack of a framework for understanding how to design and deliver healthcare digitally (Mettler & Eurich, 2012). SAAM, while it does not provide any solution to digital healthcare delivery, sheds some insight into the existing difficulty of creating such a framework. For example, the issue with the privacy of digital healthcare information and the legality of health-related recommendations provided (Kuziemsky et al., 2019).

At the population level, SAAM provides an alternative model for symptom management within the cancer population. With Canada's aging population, the number of new cancer cases is projected to be 79% higher in 2028 to 2032 than from 2003 to 2007 (Government of Canada, 2019). Given the current usage of ED from this patient population, the ED system will not be able to sustain the predicted growing number of cases within Canada, if the lack of an alternative model of management persists.

Future Work

If we have more time, we will complete the entire dataset of the COSTaRS algorithm. The amount of questions within the COSTaRS algorithm is enormous and contains more than a hundred different items. We did build a system structure for the assessment and monitoring, but we did not input all the questions because data inputting is not the key objective of this project. If we have more time, we will finish the questionnaire data inputting so that the SAAM system can be useful in a clinical setting.

A client application for health care providers can be built so that health care providers, such as doctors, can help manage patients' symptoms as administrators. It can also let doctors to set different assessment configurations for their patients, monitor symptom severity as needed, and receive an alert if the patient needs to seek urgent medical attention.

Currently, the questionnaire is directly built and input on Firebase database client as raw data. A user-friendly client, such as a web application, can be made for content developers to develop and modify the questionnaire efficiently.

Finally, the privacy of the patient is vital because this is a medical application. We may use some data encryption methods like AES methods to protect patient privacy better.

Group Consent

Video	YES
Report	YES
Source Code	YES

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