Patient Perspectives on a Tailored Self-Management Education and Support Intervention for Low-Income Seniors with Chronic Health Conditions.

Running Title: Patient Perspectives on a Health Education Program

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Current word Count: 5997
ABSTRACT:

Background:
The Assessing outcomes of enhanced Chronic disease Care through patient Education and a value-based formulary Study (ACCESS) was a 2x2 factorial randomized trial that tested the impact of a tailored self-management education support (SMES) program, which demonstrated a 22% reduction in adverse clinical events. We sought to qualitatively explore participants’ perspectives on the SMES intervention, and the ways in which it may have improved self-management skills.

Methods:
We used a qualitative descriptive approach and conducted individual semi-structured interviews. We conducted inductive and deductive thematic analysis using NVivo 12.

Results:
We interviewed twenty participants who had recently completed the three-year SMES intervention. Three main themes emerged from the data: 1) empowerment, 2) intervention acceptability, and 3) suggestions for improvement. Under empowerment, we identified subthemes of health literacy, self-efficacy, self-management, and active role in health. Several participants reported that it promoted health behavior change or improved confidence in self-management. Under acceptability, we identified subthemes of ease of use and presentation style. Most participants expressed positive feelings towards the intervention and felt that it was easy to understand. Finally, we identified subthemes of learning style, content, and engagement strategies under suggestions for improvement. Some participants said that the messages were too general and did not address the complex health concerns they had.

Conclusion:
Our results highlighted key strategies to promote patient engagement and self-management behaviors and demonstrated how they may have been used to improve clinical endpoints. Additionally, we demonstrated the novel use of marketing principles in SMES interventions.

Abstract Word Count: 247
1: Introduction

Chronic medical conditions are highly prevalent, increasing overtime and increasing disproportionately among older adults, particularly those with lower socioeconomic status\(^1,2\). These conditions can have significant effects on quality of life, and drastically increase the risk of cardiovascular disease-related morbidity and mortality\(^3,4,5\). Despite the availability of effective treatments and self-management practices, not all patients are able to adhere to these\(^6\), with only 38-60% successfully undertaking physician recommended behaviors\(^7\). Developing effective solutions for the management of chronic conditions has become increasingly important\(^8\).

Self-management education and support (SMES) interventions have been successful in helping patients make and maintain healthy changes\(^9,10\). These interventions work by providing support, with the aim of improving health literacy and self-management\(^11,12\). Prior literature has demonstrated that SMES interventions can result in sustained health behavior change\(^10,16\), potentially leading to lower rates of hospitalization and adverse outcomes among those with chronic conditions\(^14,17\). Most recently, the Assessing outcomes of enhanced Chronic disease Care through patient Education and a value-based formulary study (ACCESS) tested the impact of a novel SMES program that incorporated principles of commercial advertising. We demonstrated a 22% reduction in the primary composite endpoint, driven by a 34% reduction in avoidable hospitalizations\(^18\). However, SMES programs can also be ineffective. This is often due to being inadequately tailored to the target population\(^19,20\). It is unclear what specific aspects of SMES interventions make them successful. Understanding how the features of these programs are perceived by patients can assist in the development of future interventions.

In this study, we interviewed participants of ACCESS, to explore perspectives of a tailored SMES program. This study expands on the previously reported study findings, with the aim better elucidating what did and did not work for participants during this RCT\(^18\). With this improved understanding, it is our hope that the development and implementation of future SMES programs can be better tailored to the needs of patients to assist in cardiovascular prevention efforts.

2: Methods

2.1 Study Context

The study was based in Alberta, Canada. Alberta has 4.5 million residents, and all residents have universal public health insurance that fully covers hospital and physician services. Most have a primary care physician, and some patients have access to dieticians, physiotherapists, and disease educators through their primary care networks\(^21\). All residents can be referred to specialists through their primary care physician. SMES programs are accessed at the patient’s discretion.
2.2 ACCESS Trial

The present study was nested within ACCESS (Clinical Trials.gov #: NCT02579655), a 2x2 factorial randomized controlled trial conducted to test the impact of two interventions in 4761 low-income seniors with cardiovascular (CV)-related chronic conditions\textsuperscript{22}. The first of these interventions was a tailored SMES program and the second was the elimination of patient co-payments for cardioprotective medications. Both interventions were provided for a duration of 36 months.

Participants eligible for the trial were adults ≥65 years with an annual household income of <$50,000 CAD who were diagnosed with any one or combination of: chronic kidney disease, coronary artery disease, heart failure, or stroke; or at least two of: diabetes, high cholesterol, hypertension, or smoking. Patients with self-reported cognitive impairment were excluded. Enrollment primarily occurred through community pharmacists and physicians, with participants’ diagnosed chronic conditions being self-reported at time of registration\textsuperscript{23,24}. Participants were randomly assigned 1:1:1:1 to each intervention, both, or neither, and followed for three years for the study’s outcomes, including both patient-reported measures and clinical outcomes.

The SMES program consisted of weekly tri-fold postcards for three years, as well as health support tools. The program and messages were co-developed by a marketing firm (EMERGENCE Creative; New York, NY) and several Calgary-based clinicians with expertise in managing patients with chronic health conditions. Messages were designed to reflect a post-card from a fictional ‘peer’ (named MOXIE). Each week, the messages opened with a story pertaining to the information that was presented. Messages targeted several aspects of CV health promotion, such as diet, physical activity, and medication adherence. Using individual participant characteristics (ie. presence of diabetes, CV risk factors, smoking status, and current medication use), participants were assigned to one of 50 pre-determined tracks which dictated the specific information they would receive. Participants were provided with additional health tools such as reusable grocery bags (3 months), health tracking books (6 months) and pedometers (12 months), with the goal of encouraging engagement. The intervention also included a facilitated relay component wherein participants were sent letters regarding medications specific to their baseline health data. Participants were instructed to take these letters to their pharmacist and physician to facilitate discussions about preventative medications (specifically statins and ACE inhibitors/angiotensin receptor blockers (ARBs)).

In addition to the postcards, participants had the option of enrolling in the electronic version of the intervention which provided them with three weekly tailored emails and access to a secure personalized website built in collaboration with an IT-consultant.
(Locus Health, Charlottesville, VA). Participants in the electronic stream were frequently reminded via email to check their tailored portal where they received additional personalized health tips.

As aforementioned, the trial found that the SMES program was associated with a statistically significant 22% reduction in the composite primary endpoint, and a 34% reduction in avoidable hospitalizations. There were no differences observed in mortality, major adverse cardiovascular events, medication adherence, quality of life, or healthcare costs (18).

2.3 Conceptual Frameworks and Study Design

The study design and execution were largely influenced by two conceptual frameworks. First, we utilized the framework proposed by Bravo et al., regarding the indicators of patient empowerment. This framework was used to inform the development of the interview guide, with questions to assess aspects of participant empowerment through behaviors and capacities. The second framework, developed by Bzowicky et al., was used to evaluate the educational intervention. This framework was used to guide the analysis and data synthesis.

A qualitative descriptive approach was used to allow for the analysis and results to best retain the original language of the participants. Ethics approval was obtained from the University of Calgary Conjoint Health Research Ethics Board (REB13-1241). Informed consent was obtained from all participants. Rigor was maintained throughout the study process by use of a well-maintained codebook, a project journal detailing meeting records, a field journal to document all participant interactions, and the use of independent data coders with a third member brought in to assist with discrepancies.

2.4 Sampling

The sampling frame for this study was ACCESS participants who exclusively received the tailored SMES intervention and completed an end of study follow up survey. Interviews were conducted within six months after individuals completed their time in ACCESS. This timeframe was chosen as the participants had a staggered ending of the SMES intervention and we chose to only sample from the most recently completed group to mitigate differences in recall. We anticipated needing to interview a minimum of 15 individuals, with the intention of continuing sampling until thematic saturation was achieved. Several characteristics were identified as potential factors affecting participant perspectives and purposive sampling was done with consideration for each of:

- Gender (men/women - self reported).
- Intervention type (paper-based only/paper plus electronic).
• Whether a participant was taking medications (i.e. ACE Inhibitors/ARBs or statins) that were being targeted to increase use, both at baseline and mid-point check-ins.
• Level of medication adherence at baseline and changes in medication adherence.

2.5 Data Collection

Individual semi-structured interviews\textsuperscript{31} were conducted over the telephone. Interviews ranged between 30-60 minutes. The interviewer was made aware of some prior responses from the participant surveys collected throughout the ACCESS study, which were used to tailor the questions. This includes the details of the sampling criteria, as well as the specific chronic health conditions of interest that the interviewee had. Interviews were conducted by KP (female, research assistant) who was trained in qualitative interviewing and had no prior relationship with participants. Participants were informed of the purpose of the interviews. The main topics covered in the interview were: (A) participants’ opinions of the intervention (B) changes that the intervention had on self-management, and (C) suggestions for future interventions. Field notes were taken during all interviews, proceedings were digitally recorded and transcribed by a professional transcriptionist.

2.6 Data Analysis

Interview transcripts were imported into NVivo 12 Software to assist in the organization of data. Analysis was completed by two independent reviewers (KP and SS). Thematic analysis techniques were used to code the transcripts\textsuperscript{32}. A preliminary coding template was developed from the interview guide, and codes were added through inductive open coding. The coders met with a third team member (TSS) to resolve discrepancies. Focused coding was done by KP to synthesize the data and identify broader themes, with regular check-ins conducted with KD and DJTC.

3: Results

We contacted 31 individuals out of a potential 79 individuals who would have been eligible for participation; 11 people declined to participate or were unreachable, and we conducted individual interviews with 20 individuals. There was an even split between self-reported gender, and a near-even split between electronic versus non-electronic (Table 1). There was representation of varying adherence patterns and change in medications during the program. We categorized the feedback received into three overarching themes: Empowerment; Intervention Acceptability; and Suggestions for Improvement. Further data can be found in supplementary table S1.
Table 1: Participants Classification

<table>
<thead>
<tr>
<th></th>
<th>Interviews (n)</th>
<th>Proportion</th>
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<tbody>
<tr>
<td><strong>Intervention Delivery</strong></td>
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<tr>
<td>Postcards and Electronic</td>
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<tr>
<td>Postcards</td>
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</tr>
<tr>
<td>Man</td>
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<tr>
<td><strong>Change In Type of Medication Used</strong></td>
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<td></td>
</tr>
<tr>
<td>Started one or more target medication * during trial</td>
<td>14</td>
<td>0.7</td>
</tr>
<tr>
<td>Discontinued one or more target medication* during trial</td>
<td>6</td>
<td>0.3</td>
</tr>
<tr>
<td><strong>Change in Adherence to Medications</strong></td>
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<td></td>
</tr>
<tr>
<td>No Change- Adherent</td>
<td>5</td>
<td>0.25</td>
</tr>
<tr>
<td>No Change- Non-Adherent</td>
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<tr>
<td>Change- More Adherent</td>
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<tr>
<td>Change – Less Adherent</td>
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<td></td>
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<tr>
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<tr>
<td>Heart Failure</td>
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<tr>
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<tr>
<td>Hypertension</td>
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**Smoking Status**

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</tr>
<tr>
<td>Former Smoker</td>
<td>10</td>
<td>0.5</td>
</tr>
</tbody>
</table>

* Target medication= statins and ACE inhibitor/ARBs ; ACE - Angiotensin-Converting-Enzyme ; ARB – Angiotensin Receptor Blocker

### 3.1A: Empowerment

Empowerment was comprised of four subcategories: (1) health literacy and (2) self-efficacy, which are considered ‘empowered capacities’; and (3) self-management and (4) active participation, which are illustrative of ‘empowered behaviors’. Participants expressed a positive influence in all four domains and felt confident that the changes would be sustained after the intervention.

With regards to health literacy, participants expressed that the intervention improved their knowledge about their conditions, which helped them make educated decisions: “I found [the messages] were getting me back on track...understanding why I should be taking the medication and keep on taking it” [P14-Diabetes].

Several participants expressed that the intervention helped improve self-efficacy, making them more confident in managing their condition: “[MOXIE] helped me feel more confident....” [P11-Hypertension and Heart Disease]

Under self-management, participants shared that they were more consistent in their health-related behaviors or had introduced improved behaviors because of the SMES intervention. This included improved dietary patterns, physical activity, more regular self-monitoring, and improved organizational systems to aid with medication adherence. One participant expressed that the messages helped motivate him to choose healthier meals: “The food guide I get through MOXIE helps me make choices at mealtime. We can take the better one or the worse one according to MOXIE, and the vegetables that are the best to take as well. So, it helps me with the diet.” [P13-Hypertension and Heart Disease]

Finally, under the theme of active participation in health, several participants expressed that the intervention encouraged them to ask more questions regarding their health needs and pursue information from additional sources: “I would have to look things up and then sometimes check with the doctor to just make sure, the dietitian as well.” [P6-Hypertension and Stroke]
3.1B: Intervention Acceptability
There were two predominant subthemes in acceptability: Ease of use and presentation style.

Under ‘ease of use’, participants expressed that the messages were simple to read and understand: “[The messages] were easy to read and the… it got so you were getting a message from a friend. You know, you looked forward to them” [P1-Heart Disease].

Many participants reported the style of presenting information through stories to be engaging and an enjoyable way to learn: “I read it and then there’s these little stories behind it. They were interesting and yeah, it’s very informative. I have nothing but praise for it.” [P11-Hypertension and Heart Disease].

Finally, under style, several participants expressed a desire for both mail and electronic options. Some participants expressed merit in both delivery options and liked having the choice: “Electronically nowadays is probably more effective, although paper mailers are harder to ignore than an email which I get way too many every day.” [P20-Heart Disease].

Overall, most participants expressed positive feelings towards the intervention. Several reported that the messages had a positive effect on their mood, particularly during isolation due to the COVID-19 pandemic: “I enjoy it, it’s educational and you know, when you live by yourself, especially with this COVID you know, you are hunkered down in dodge and I don’t see anyone, only my son. You get these little cards, and they are a pick me up.” [P1-Heart Disease]

It was observed during our focused coding that individuals who enjoyed the delivery style of the messages were more likely to express positive changes in their self-management skills or a greater sense of empowerment compared to those who did not relate well to the MOXIE character.

3.1C: Suggestions for Improvement
While most feedback was positive, there were some suggestions for improvement, which were divided into three sub-themes: learning style, content, and engagement strategies.

Regarding learning style, we received feedback from some participants who felt that the stories in the mailers distracted from the information and that a more direct approach about the consequences of conditions would have been more impactful. As expressed by one participant: “Well instead of stories that have no relevancy, it might have been better, if I understood more about the results of diabetes unchecked. Diabetes is
unchecked; here is what is going to happen to you: X, Y, Z. The MOXIE stuff was kind of hearts and flowers and goodie stuff, but then diabetes is a nasty disease. [P12-Hypertension, Heart Disease, and Diabetes]

The most frequent complaint under the theme of content was that the messages were too generic or common sense. One participant said: “There are some things that are plain ordinary common sense.” [P4-Hypertension, Heart Disease, and Diabetes].

Additionally, participants expressed a desire for more personalized content that considered their health complexity, specifically, how to manage multiple co-morbidities. For instance: “You know, if you are a diabetic and have a heart condition, and a gastric condition, what is the difference from being just one...you can’t lump, say diabetes is this when you have the other conditions that affect diabetes too. One affects the other and you can’t get a straight answer for anything.” [P21-Hypertension, Heart Disease, Diabetes, and Stroke]

Finally, under the subtheme of engagement strategies, most participants expressed that they would like to have more personal contact or social interaction in future interventions. Suggestions included the development of a website with a Q&A feature, a non-emergency helpline, or a social support group that connects individuals enrolled in the intervention.

4: Discussion

This study explored the participants’ perspectives on the successful ACCESS SMES intervention. Although previous literature has demonstrated the benefits of SMES11,13,33,34, there has been little research done on the perspectives of participants of these interventions. Overall, the SMES intervention was received positively. Participants felt that the messages provided them with accessible and trustworthy information and assisted them in positive health behavior changes.

One possible factor influencing the patient perceived acceptability of this intervention, was its source being from an academic institution, rather than a website that they had sought out. This concept of trust in professional authority is reflected in the literature, with patients expressing a greater trust in the information provided by a professional35. Having a trusted institutional body deliver the SMES intervention could play a role in its ultimate success.

The SMES intervention had a positive effect on many aspects of health behavior, including improved health literacy, changes in self-management behavior, and greater engagement with their healthcare team. Comparable results have been observed in a prior qualitative study of this SMES intervention, which assessed participant perspectives in the initial months of the intervention, as well as in the quantitative
studies\textsuperscript{36}. However, in this study we were able to better assess the durability of these changes over three years, and the participants' confidence that they could maintain these changes several months after the program concluded. This is valuable because the overall aim of SMES programs is to create sustainable change, which can go beyond the duration of the intervention. Previous studies on chronic health conditions have found that the development of behavioral habits and organizational systems are essential for long-term health self-management\textsuperscript{37,38}. The tactics employed in this intervention were seen to have a positive effect on habit building and may be effective in promoting sustained behavior change. This includes the repetition of reminders, and the inclusion of habit-focused advice such as how to organize a medication schedule or develop physical activity routines.

The SMES intervention was intended to feel like receiving a ‘message from a friend,’ with the inclusion of stories and informal language that aimed to support the participants in improving their self-management skills in an accessible way. This is a commonly used marketing technique, often employed to engender audience engagement and information retention. Prior literature supports that the use of an authentic voice or narrative messaging can be beneficial in health education, with participants being more likely to identify the aim of the information\textsuperscript{39,40}. In this study, participants receiving the tailored self-management intervention appeared to be more receptive to the messages because of the delivery and structuring of the MOXIE character, with many citing this as a major factor in their enjoyment. The observed link between participant enjoyment and health behavior change suggests that SMES interventions are most successful when using strategies to engage participants, like how marketing tactics are intended to engage the audience. Future SMES interventions may be able to capitalize on this finding by utilizing a character voice in their messaging, as well as other possible marketing techniques.

An unanticipated result from this study was the revelation that many older adults in Alberta feel socially isolated. At the start of the ACCESS trial, we could not have predicted the COVID-19 pandemic or how this would impact mental well-being. It became clear that many felt isolated in the past few years both socially and from their health care team. Each participant of this sub-study received the SMES intervention for at least one year in pandemic conditions. A common theme was that the messages offered a sense of support and reminded them that they were not alone. The messages acted as encouragement of the health behaviors and a connection during isolation. This result is a valuable reminder of the negative effects of isolation and stressed the importance of social support among this demographic. Following COVID-19, isolation among seniors remains high, with as many as 30% of Canadian seniors being at risk for social isolation, and a greater risk being seen among those with chronic health conditions and low socio-economic status\textsuperscript{41}. Social isolation is a known barrier to health and addressing this should be considered as a valuable component of any treatment plan\textsuperscript{42-44}. 
Tailoring is a significant challenge in the development of SMES interventions, due to the wide variance in life and health conditions among participants. Prior literature supports the notion that tailoring interventions to the participants base level capacities, such as health-literacy, can improve the effectiveness of the intervention\(^4\). As indicated by our results, a similar consideration should be given to physical and health behavior capacities when tailoring interventions – including the living conditions of participants, the resources available to them, and their underlying health status. Additionally, the issue of co-morbidities was frequently mentioned among participants, and our results suggest that the interactions between co-morbidities is a significant knowledge gap among seniors. Future SMES programs should be developed to address the interactions between co-morbidities and the management of multiple chronic health conditions. Furthermore, improved tailoring may assist in providing participants with less generic information, which was identified as a suggestion for improvement. Our study did not tailor messages by the length of time that participants have managed their condition, their external access to health information, or their baseline health literacy levels. It is possible that for some participants, the information was not new as they had prior experience managing chronic health conditions.

There are several limitations in this study. First, the results only represent the subjective experiences of those participants interviewed. Not all participants will share the opinions represented in this study. While we did manage to collect an even split of participants across our sampling criteria and achieved saturation wherein no new information was being added to the data during our final interviews\(^{29}\), we cannot be sure that the data reflected in this study is indicative of all perspectives. However, we believe that we captured an accurate representation of the perspectives of those who received this intervention. Secondly, as this study was conducted at the end of a three-year long trial, there may be challenges in recalling certain experiences throughout the intervention. To mitigate this limitation, we structured the interview questions to have significant repetition and gave ample time for participants to answer all questions. Participants with self-reported cognitive impairment were not included in the ACCESS study, however memory challenges were expressed by some during the interview when it came to specific messages. As we focused on the general feelings of participants on the SMES program, and not on specific messages, we believe that it is reasonable for participants to have retained these impressions and that this is not a threat to the study validity. Finally, we are aware that the predominantly positive feedback may have been influenced by the power imbalance between the interviewer, a representative of the University, and the interviewee, a low-income senior. Precautions were taken in the study design to minimize this, such as having the interviews conducted by an external team member who had no prior connection to the participants. Due to the COVID-19 pandemic and its associated restrictions that were in force at the time, it was not possible to have group interviews or focus groups. However, individual participants were allowed to have a family member or partner join them for the interview if it was
their preference to do so.

A strength of this study is that we explored the long-term sustainability of the self-management effects of the SMES intervention by exploring participant perspectives at the end of the three-year trial and by beginning interviews two months after the conclusion of the intervention. This expands on our earlier analysis which assessed the acceptability of the intervention in the beginning phase\textsuperscript{36} and establishes the potential effects of the intervention on the maintenance of behavior change. Furthermore, it better elucidates the perspectives of participants of the SMES program, building off the previously completed quantitative outcomes study\textsuperscript{20}. Additionally, this study offers a novel participant perspective of the successful use of advertising principles within SMES messaging, which expands on prior literature of health education techniques.

5: Conclusion

This study provides a better understanding of how the SMES intervention was perceived by participants and gives insights on how SMES interventions could be tailored and implemented to best meet the needs of seniors with chronic health conditions. The findings from this study suggest that SMES interventions such as this can be valuable tools for creating sustained behavioral change and self-management skills. Understanding the way that participants receive an SMES intervention is valuable in guiding the development of future educational programs. Efforts in SMES design and implementation should explore new ways of tailoring messages to better suit the personal needs of each patient.
Sources of Funding:

This study was funded by a Canadian Institutes of Health Research Foundation Grant (Number 201509-FDN-353640) (BJM), and a Major Research Grant from the Clinical Research Fund from the Cumming School of Medicine. The Interdisciplinary Chronic Disease Collaboration (ICDC) is funded through an Alberta Innovates Collaborative Research & Innovation Opportunity Team Grant.
Disclosures:

RP is CEO of Emergence Creative, the social impact creative design firm that created the SMES intervention.
Patient Consent Statement:

The authors confirm that patient consent forms have been obtained for this article.
References:


20. Tran SHN, Weaver RG, Manns BJ, Saunders-Smith T, Campbell T, Ivers N, Hemmelgarn BR, Tonelli M, Pannu R, Campbell DJT. Factors Affecting the


Tailored Education Program to Improve Chronic Health

**CHRONIC DISEASE**

- Increases CV Risk

**EDUCATION PROGRAMS**

- Improves Self-Management
- Decreases CV Risk

**Phon e Interview 20 Participants** + **Thematic Qualitative Methods**

- Empowerment
  - Active Role in Health
  - Self-Management

- Capacities
  - Health Literacy
  - Self-Efficacy

- Intervention Acceptability
  - Ease of Use
  - Presentation Style

- Suggestions for Improvement
  - Learning Style
  - Content
  - Engagement Strategies

Demonstrates effective strategies in education programming leading to positive reception of the program and improved self-management of chronic health conditions.