


Opening the digital front door for individuals using long-term in-home ventilation (LIVE) during a pandemic- implementation, feasibility and acceptability

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Abstract

Background: The COVID-19 pandemic led to an unprecedented need for virtual healthcare that was safe, acceptable and feasible to deliver. In May 2020, we launched the Long-term In-Home Ventilator Engagement (LIVE) program for ventilator assisted individuals using ventilators hosted on an e-platform in Ontario, Canada.

Objectives: To assess the acceptability, appropriateness, feasibility and usability of the LIVE program reported by patients, family caregivers, and healthcare providers (HCP).

Design and Methods: We conducted a cross-sectional study. We provided HCPs participating in the LIVE program anonymized questionnaires (Acceptability of Intervention Measure (AIM), Intervention Appropriateness Measure (IAM), Feasibility of Intervention Measure (FIM), and mHealth App Usability (MAUQ). Patients and family caregivers completed the AIM and MAUQ. Questionnaires were administered via an e-platform.

Results: We recruited 105/251 (42%) patients and family caregivers and 42/48 (87.5%) HCPs. Patients and caregivers rated a mean (SD) overall AIM score of 4.3 (0.7) (maximum score 5; higher scores indicate greater acceptability) and a mean (SD) overall MAUQ score of 5.8 (1.5) (maximum score 7; higher scores indicate greater useability). HCPs rated a mean (SD) overall AIM score of 4.3 (0.7), IAM score of 4.3 (0.8), FIM score of 4.2 (0.7) and overall MAUQ score of 5.6 ± 1.5 . There were no differences in AIM ((4.3 (0.7) vs 4.3 (0.8), $p = 1$) or MAUQ (5.8 (1.5) vs 5.6 (1.5), $p = 0.5$) scores between patients/ family caregivers and HCPs.

Interpretation: This study suggests that the LIVE program was acceptable, appropriate, feasible, and usable from the perspective of patients, family caregivers and HCPs.

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Introduction

The COVID-19 pandemic disrupted life for many, especially those with chronic medical conditions. Ventilator assisted individuals (VAI) were at risk for a complicated course from COVID-19 given their reliance on technology due to ongoing chronic respiratory failure. Given the risk of contracting COVID-19, but also the need for increased healthcare support for symptom management and early intervention, VAIs were an ideal population for virtual care who would benefit from bringing ventilator experts ‘virtually’ into their homes. As such, we developed and implemented The Long-term In Home Ventilator Engagement (LIVE) virtual intervention during the pandemic.¹

The LIVE program was led by the Ontario Ventilator Equipment Pool (VEP), operated and managed by the Kingston Health Sciences Centre which is funded by the provincial Ministry of Health and provides a ventilator loan program to all VAIs in the province. We customized a virtual care app for VAIs with the input of clinicians, VAIs, families, and researchers, that would allow VAI to receive healthcare support without having to travel to a clinic. LIVE included (1) virtual home clinic visits and ad hoc consultations; (2) patient and family facing virtual care plan; (3) weekly and monthly questionnaires that review clinical symptoms and ventilator issues; (4) remote bluetooth downloading of ventilators instead of in-person downloads, and (5) secure communication via messaging, audio, and video calls (see Figure 1). Further details of the program are described elsewhere.¹ The LIVE program launched in May 2020.

Our aim was to explore the acceptability, appropriateness, feasibility and usability of the LIVE program from the perspective of key stakeholders including pediatric and adult VAIs, family caregivers (FC) and healthcare providers (HCP).

Methods

We conducted a cross-sectional evaluation of the LIVE program from April 2021 to June 2021, between 4–11 months after the program began for all participants. This study was approved by the Research Ethics Board at the Hospital for Sick Children (REB #1000073189).

Inclusion criteria for LIVE were: (1) identified by the local home mechanical ventilation (HMV) team as high priority because of medical fragility; (2) living at least 1 h drive from the HMV center. VAIs and FCs were consented by the VEP; patient information was subsequently

forwarded to the central onboarding team. The onboarding team created an app account and reviewed its features and functionality with the VAI and FC. A subscriber identity module (SIM) enabled tablet was loaned if a device compatible or internet access was not available.

Eligible participants for the current study from the LIVE participants comprised all pediatric or adult VAIs or primary FCs and HCPs enrolled in, or delivering, the LIVE program. The HCPs included physicians, nurse practitioners, and respiratory therapists. There were no exclusion criteria. Eligible individuals were invited via a recruitment message, sent via the app. Those interested in participating clicked on the link to the participant information sheet, consent form, and then the questionnaires. Therefore, the consent form was completed prior to participants completing the questionnaires.

We administered the following validated questionnaires: Acceptability of Intervention Measure (AIM), Intervention

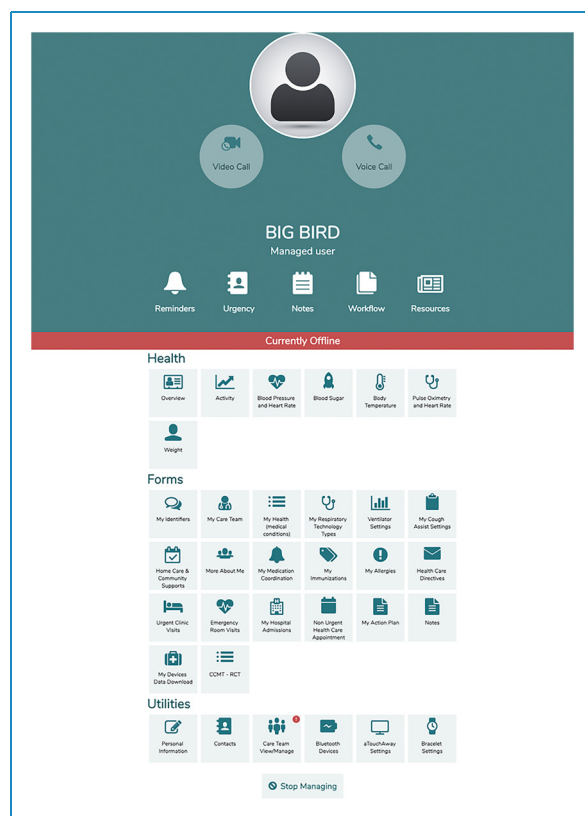


Figure 1. The eHealth program’s healthcare provider’s view of the app interface for a patient.

Appropriateness Measure (IAM) and Feasibility of Intervention Measure (FIM)² and mHealth App Usability (MAUQ³). The AIM (4 questions), IAM (4 questions) and FIM (4 questions)² use 5-point Likert scales, with a maximum score for each questionnaire of 20 and higher scores indicating greater acceptability, appropriateness, and feasibility. We did not administer the IAM and FIM to VAIs as the questions were deemed not relevant. The MAUQ³ (21 questions) uses a 7-point Likert scale. A score of more than 4 indicates usability.⁴ We also asked two open-ended questions: (1) What did you like best about the LIVE program; and (2) What would you like to change about the program? Participants entered their responses to the questionnaires directly into the app. We collected demographic and clinical information for the LIVE cohort from data entered on the aTouchAway app and directly exported into Microsoft Excel (Microsoft, USA).

Questionnaires were sent to LIVE participants between April to June 2021. Potential participants were sent a completion reminder at 72 h and at 1 week. Questionnaire data were exported on study completion to Microsoft Excel as anonymized data.

Statistical analysis

Questionnaire scores and demographic characteristics were summarized using descriptive statistics using Graph Pad Prism (San Diego, California, USA). Overall questionnaire

and domain scores were compared between VAI/FCs and HCPs using t-tests for normally distributed data and Kruskal-Wallis test for non-normative data.

Results

A total of 251 VAIs were enrolled in the LIVE program (see Table 1). Of those enrolled, 105 (40%) completed questionnaires; 42/48 (87.5%) were received from HCPs.

AIM, IAM and FIM

For the AIM, overall mean (SD) scores of 4.3 (0.7) and 4.3 (0.8) were reported for VAIs/FCs and HCPs, respectively. There was no difference in overall AIM score ($p = 1.0$) or AIM statement scores between the two groups. The IAM overall mean (SD) score was 4.3 (0.8) and FIM was 4.2 (0.7) reported by HCP. See Table 2 for additional details on the AIM, FIM and IAM scores.

MAUQ

There was no difference in the overall mean (SD) MAUQ scores of VAIs/FCs and HCPs (5.8 (1.5) vs 5.6 (1.5), $p = 0.5$). For both VAIs/FCs and HCPs the highest scoring domain for the MAUQ was 'Usefulness'. See Table 3 for a summary of the total MAUQ scores by domain and for each statement.

Table 1. Demographics of the LIVE cohort.

Demographics	N = 251
Mean Age (years), mean (SD), range	26.1 (24.0); range 1–79.8
Female Gender (n (%))	90 (36%)
Pediatric (n (%))	153 (61%)
Duration receiving ventilation (years), mean (SD), range	5.7 ; range 0–25.9
Noninvasive Ventilation (n (%))	201 (80%)
Caregiver (n (%))	214 (85.2%)
Distance Traveled to HMV Center 1 way	N = 251
Mean Distance Per Patient, mean (SD), range (km)	105.6 (SD) (range 1–1554 km)
Connectivity	
Downloaded and used the app on a personal device, n (%)	240 (96%)
Onboarding time in minutes, mean (SD)	31.1 (13.1)
Clinical Check-in time in minutes, mean (SD)	35.8 (15.7)

Note: these demographics represent the LIVE cohort in its entirety and not just the survey respondents.

Table 2. Acceptability of intervention measure (AIM), intervention appropriateness measure(IAM) and feasibility of intervention measure (FIM) mean(SD) scores for VAIs, FCs and HCPs of the LIVE program.

	VAI/ FC (n = 105)	HCP (n = 42)	P value
Overall Score	4.3 (0.7)	4.3 (0.8)	1.0
<i>AIM</i>	4.3 (0.7)	4.3 (0.8)	1.0
1	The LIVE Program meets my approval.	4.3 (0.7)	
2	The LIVE Program is appealing to me.	4.3 (0.7)	
3	I like the LIVE Program.	4.2 (0.8)	
4	I welcome the LIVE Program.	4.3 (0.8)	
5	I would recommend the LIVE Program to others.	4.3 (0.7)	
<i>IAM</i>		4.3 (0.8)	
6	The LIVE Program seems fitting.	4.4 (0.7)	
7	The LIVE Program seems suitable.	4.2 (0.8)	
8	The LIVE Program seems applicable.	4.4 (0.8)	
9	The LIVE Program seems like a good match.	4.3 (0.8)	
<i>FIM</i>		4.2 (0.7)	
10	The LIVE Program seems implementable.	4.2 (0.8)	
11	The LIVE Program seems possible.	4.4 (0.7)	
12	The LIVE Program seems doable.	4.3 (0.8)	
13	The LIVE Program seems easy to use.	4.0 (0.8)	
14	I am comfortable using apps and technology in general.	4.3 (0.7)	

Narrative comments

Narrative comments by VAIs/FCs and HCPs indicated appreciation of the ease of communication and the patient-centered nature of care enabled by the LIVE program (see Tables 4 and 5). VAIs/ FCs liked the security of knowing that their healthcare team was easily accessible. VAI/FC participants also reported that the app was easy to use and navigate. HCPs appreciated the ease of communication with patients and families, the ability to address medical issues in real-time, and to obtain and access remote ventilator data downloads, as well as the ability of the app to improve patient access to care and communication.

VAIs/FCs and HCPs highlighted several aspects of the LIVE program they would recommend changing (see Tables 4 and 5). VAIs/FCs expressed a desire for all their care providers not just the HMT team to be available on

the app. Suggestions for optimizing app usability included (1) improved interface for those with limited hand dexterity; (2) ability to track other health conditions such as seizures; (3) ability to provide sleep study equipment at home; and (4) having access to ventilator data in real time. HCP suggestions for LIVE program improvement included (1) app integration with the electronic medical record; (2) ability to send a mass text message; and (3) more intuitive navigation.

Discussion

Overall, we demonstrated that the LIVE program for pediatric and adult VAIs implemented during the pandemic was perceived as acceptable, appropriate, feasible and usable by VAIs, FCs and their HCPs. This demonstrates that the

Table 3. MAUQ mean (SD) scores for patients and family caregivers of the LIVE program.

	VAIs + FCs (n = 105)	HCPs (n = 42)	P value
Overall	5.8 (1.5)	5.6 (1.5)	0.5
<i>Domain 1: Ease of use and satisfaction</i>	5.9 (1.3)	5.6 (1.4)	0.2
1 This app was easy to use.	6.0 (1.1)	5.9 (1.0)	
2 It was easy for me to learn to use this app	6.1 (1.0)	6.1 (1.0)	
3 I like the interface of this app.	5.7 (1.3)	5.8 (1.1)	
4 The information in this app was well organized, so I could easily find the information I needed.	5.9 (1.2)	5.7 (1.1)	
5 I feel comfortable using this app in social settings.	5.5 (2.0)	4.6 (2.2)	
6 The amount of time involved in using this app has been fitting for me.	5.9 (1.4)	5.2 (1.5)	
7 I would use this app again.	6.2 (1.0)	5.9 (1.1)	
8 Overall, I am satisfied with this app.	6.1 (1.1)	5.9 (1.1)	
<i>Domain 2: Interface and satisfaction</i>	5.4 (1.9)	5.4 (1.6)	1.0
9 Whenever I made a mistake using this app, I could recover easily and quickly.	4.4 (2.4)	4.6 (1.8)	
10 This app provides an acceptable way to deliver healthcare services.	6.0 (1.2)	5.8 (1.2)	
11 This app adequately acknowledged and provided information to let me know the progress of my action.	5.0 (2.2)	5.2 (1.8)	
12 The navigation was consistent when moving between screens.	5.7 (1.8)	5.8 (1.1)	
13 The interface of this app allowed me to use all the functions (such as entering information, responding to reminders, viewing information) offered by this app.	5.7 (1.6)	5.5 (1.6)	
14 This app has all the functions and capabilities I expected it to have.	5.5 (1.5)	5.3 (1.5)	
<i>Domain 3: Usefulness</i>	6.0 (1.4)	5.7 (1.5)	0.3
15 This app would be useful for my/family member's health and well-being.	6.1 (1.2)	5.9 (1.3)	
16 This app improved my/family member's access to healthcare services.	5.9 (1.3)	5.6 (1.6)	
17 This app helped me manage my/family member's health effectively.	5.8 (1.4)	5.6 (1.5)	
18 This app made it convenient for me to communicate with my/family member's healthcare provider.	6.1 (1.5)	5.8 (1.5)	
19 Using this app, I had many more opportunities to interact with my/family member's healthcare provider.	5.9 (1.6)	5.5 (1.5)	
20 I felt confident that any information I sent to my/family member's provider using this app would be received.	6.1 (1.4)	5.5 (1.4)	
21 I felt comfortable communicating with my/family member's healthcare provider using this app.	6.2 (1.2)	5.9 (1.4)	

Table 4. Narrative survey responses from VAIs and family caregivers.

Respondent	Question
	What did you like best about LIVE?
VAIs and Family Caregivers	<p><i>Connections with the Healthcare Team</i></p> <ul style="list-style-type: none"> • Healthcare providers can communicate with me without having to schedule clinic appointments • The security of knowing your team is just a touch away • Patient centered and provides patients' needs first <p><i>App Functionality</i></p> <ul style="list-style-type: none"> • Easy to navigate and allows easy access to my health information • Texting and group texting functionality • Virtual ventilator downloads being available
	What would you like to change about LIVE?
VAIs and Family Caregivers	<p><i>Improving Patient Centered-Care</i></p> <ul style="list-style-type: none"> • Have all the team assigned to the patient using it not just the ventilator team. • To know how the information collected helped the providers make decisions re: care to be provided. There was no feedback as to how the patient was doing. <p><i>Optimizing App Usability</i></p> <ul style="list-style-type: none"> • Allow me to use the cursor keys to scroll up and down to help with my limited hand movement • Would be nice to have tracking features for seizures and other health conditions • The ability to add text to options that don't always apply • No option to delete messages if sent by mistake • The done button -want to push it to navigate instead of the arrow • I've noticed if the person is offline you can't access the messages unless you go through the history, so maybe to be able to read messages between healthcare providers even when they aren't online. • A way to only have to go into the app if there were any changes to my child's health. But if he's stable and has no issues, I don't want to have to go into the app to answer questions if there hasn't been any changes. • Make the messaging tools easier to use. • To add voice commands. <p><i>Ideal Aspects of a Future Program</i></p> <ul style="list-style-type: none"> • I would like to be able to access the data from my daughter's bipap unit directly, ideally in real time. • Access to sleep study equipment at home for monitoring.

LIVE program met its intended purpose of connecting patients with their HCPs during the pandemic to enable ongoing outpatient clinical care and troubleshooting in an effective and meaningful way. Notably, the most valuable aspects of the LIVE program were: (1) the timely access to care; (2) ease of communication with the healthcare team; (3) having the medical health and ventilator settings in one easily accessible location that could be viewed and updated by multiple users including the VAI or FC; (4) travel distance saved. Other studies have demonstrated similar findings with most VAIs and FCs being in favor of telehealth⁵ and telemonitoring.^{6,7}

Opportunities for improvement include optimization of the app's usability and extending the program to the entire healthcare team, beyond HMV clinicians. Integration with the electronic medical record would also be advantageous.

Despite high acceptability and usability ratings VAIs, FCs and HCPs suggested ways to optimize the app's functionality including group messaging and an easier to

navigate face screen. HCPs did highlight however the increased burden of care using the LIVE program due to double documentation as data from the app was not integrated with the electronic medical record. Unfortunately, due to the necessity to pivot to virtual care during the pandemic and the desire to implement the project in a timely manner, development of an app integrated with the medical record was not possible.

The pandemic resulted in a massive digital transformation in healthcare. Following the pandemic, standardization, compatibility, and interfacing of apps to electronic medical record platforms is a virtual care priority. Our participants expressed a desire for access to the LIVE program to be extended to other healthcare teams which aligns with the need for virtual care standardization across medical specialties and healthcare sectors.

In the LIVE program, digital access was addressed by providing a tablet with a SIM card for all patients and families that did not have a personal device compatible with the app or stable internet connection. Surprisingly, only 4% of

Table 5. Narrative survey responses from healthcare providers.

Respondent	Question
	What did you like best about LIVE?
Healthcare Providers	<p><i>Ease of Communication with patients</i></p> <ul style="list-style-type: none"> • The ability to send a quick text to patients through the app – I found they were read/acknowledged faster and more often than email or phone calls to patients • Patient access to expert care during the pandemic. • It is patient centered and provides patients needs first • Leveraging technology to improve patient access and communication <p><i>App Functionality</i></p> <ul style="list-style-type: none"> • Direct messaging with the patient and the team • Access to remote download data and patient demographics on hand • Having our patient’s respiratory information all in one place • Giving patients and care givers more resources to have access to their medical care team • Able to access downloads from their NIV in collaboration with VEP. Improved clinic flow. • I like being able to see all of the documentation for the home technology in one place and to see the correspondence with other team members as well. • Ease/stability of video-conferencing.
	What would you like to change about LIVE?
Healthcare Providers	<p><i>Improving the Usability of the App</i></p> <ul style="list-style-type: none"> • Integration with the EMR • Would be nice to have a notification if there has been a change in ventilator settings • More intuitive navigation through all the headings • Need an easy way to send out common information to families.

LIVE participants required this. Virtual care therefore has the potential to increase inequities in access to care.

Ai-Chi Loh and colleagues proposed a framework for interpreting the digital divide in health care which includes: (1) digital access; (2) digital literacy and (3) digital assimilation.^{8,9} Digital assimilation is the degree to which digital technologies are incorporated and used in everyday life. Our participants reported very high usability scores despite enrollment of VAIs/FCs including those over 65 years of age. This highlights acceptability across the life-span of VAIs and high digital literacy was achieved. During the pandemic, for this cohort of patients, the LIVE program became the primary mode of interfacing with the HMV care team. However, understanding the role of the LIVE program’s digital assimilation now that the pandemic has receded needs further study.

There are some notable limitations to our study. Firstly, the questionnaires were anonymously completed by participants. Therefore, we are not able to comment on the patient/caregiver or healthcare provider demographics as a result. Secondly, our participation rate for patients and families was 40% and 87.5% for healthcare participants. We are presenting the results based on the questionnaires answered appreciating that our results may potentially have been different if all participants had completed the study questionnaires.

In summary, the LIVE program was perceived as acceptable, feasible and highly usable by VAIs, FCs and HCPs. Next steps include understanding the need for virtual interventions post-pandemic as well as rigorous evaluation of virtual care and telemonitoring in this patient population to establish efficacy and cost-effectiveness.

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Contributorship: RA, and LR researched literature and conceived the study. All authors were involved in protocol development and data analysis. RA and MA were involved in gaining ethical approval. AQ and MQ were involved in patient recruitment. RA, MA and AQ wrote the first draft of the manuscript. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

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