

END USER ENGAGEMENT IN DEVELOPING A SELF-CARE ONLINE APP

PATIENT AND INFORMAL CAREGIVER ENGAGEMENT IN DESIGNING A
HEART FAILURE ONLINE APPLICATION (HFAPP) TO PROMOTE SELF-
CARE IN THE HOME SETTING FOR OLDER ADULTS

By STEPHANIE CHIU, B.SC.

A thesis submitted in partial fulfilment of the requirements for the degree of
Master of Science in eHealth

McMaster University © Copyright by Stephanie Chiu, November 2015

McMaster University MASTER OF SCIENCE (2015) Hamilton, Ontario

TITLE: Patient and informal caregiver engagement in designing a heart failure online application (HFApp) to promote self-care in the home setting for older adults

AUTHOR: Stephanie Chiu, B.Sc.

SUPERVISORS: Dr. Catherine Demers, Dr. Norm Archer, Dr. Ruta Valaitis

NUMBER OF PAGES: 98

Lay Abstract

Approximately half a million Canadians suffer from heart failure (HF), a leading cause of hospitalization. This study focuses on the involvement of potential users in the design of HFApp, an online HF self-care application (“app”). These users include older patients with HF and their family and close friends. One of HFApp’s objectives is to potentially decrease hospital visits for older patients with HF. A design based on patient preferences called persona-scenarios was used to conduct this study. Participants were asked to create pretend individuals that were similar to themselves and describe scenarios in which these individuals would interact with HFApp. These could include: (1) how they learn about HFApp, (2) how they might access HFApp, (3) where they are when using HFApp, (4) who might help them with HFApp, and (5) how often they use HFApp. These interactions will be used to identify user requirements and preferences for HFApp’s design.

Abstract

Approximately half a million people in Canada suffer from heart failure (HF), a leading cause of hospital admission. HF outcomes can be improved by self-care behaviors, to which patients often show low adherence. This study focuses on the co-design of an online self-care application and community intervention, called HFApp, which patients with HF and their informal caregivers could use to potentially improve HF outcomes.

The intended users for HFApp are older adults with HF and their informal caregivers. The primary objective of this study is to identify themes for the development of HFApp. The secondary objective is to apply these findings to identify user needs and preferences for HFApp.

Persona-scenario discussion sessions were conducted with 4 older patients with HF (≥ 60 years) and 4 informal caregivers from the Hamilton Health Sciences Heart Function Clinic. One persona-scenario discussion session was held for each participant type (i.e. patients with HF or informal caregivers). Participants were divided into pairs and participant pairs created personas and scenarios together. Scenarios included: (1) how they learn about HFApp, (2) how they might access HFApp, (3) where they are when they use HFApp, (4) who might help them with HFApp, and (5) how often they use HFApp. All discussions were audio recorded.

Data analysis, using NVivo 10^{*}, provided six categories of design themes which were used to develop a list of user requirements for HFApp. Some of these requirements help users perceive HFApp to be more useful and give a sense of self-care confidence. However, some requirements may be excluded due to low feasibility. It is recommended that a larger persona-scenario group

* NVivo 10: a software used to organize and analyze qualitative research data.

session be conducted in the future to support the requirements gathered in this study as well as identify any new requirements.

Keywords: eHealth, Heart Failure, Self-care

Acknowledgements

First and foremost, I would like to express my deepest gratitude to my supervisor, Dr. Catherine Demers, for her unending guidance and support. Thank you for sharing your knowledge and experience with me, for being patient with me during my entire thesis process, and for being such a great mentor.

I would also like to thank my thesis committee: Dr. Norm Archer for sharing his expertise, providing encouragement, as well as being a source of inspiration during the eHealth program; Dr. Ruta Valaitis for providing support and insightful advice on the research topic; and Dr. Karim Keshavjee for generously reviewing and providing helpful comments for my thesis.

A special thanks to Linda Nguyen for her assistance in the research process. Thank you for your many hours of hard work. You are such a wonderful person to work with.

I would also like to extend my thanks to Iris Kehler for being so positive and supportive during my studies.

Finally, I would like to extend a big thanks to my family and friends for their ongoing support during my entire eHealth journey.

Table of Contents

Introduction and Background	1
Epidemiology of Heart Failure (HF).....	1
The Importance of Self-Care in HF.....	1
Barriers to Self-Care.....	3
Role of the Informal Caregiver in Promoting Self-Care.....	4
Use of Loop Diuretics to Treat Patients with HF.....	5
Review of Existing HF Technological Interventions.....	6
Older Adults and Use of Technology to Support Self-Care.....	8
HFApp – An Online Self-Care App and Community Intervention.....	9
Persona-Scenarios.....	10
Aim and Objective.....	11
Methods	13
Personas-Scenarios.....	13
Population Selection.....	13
Persona-Scenarios Discussion Sessions.....	14
Analysis.....	15
Ethical Issues.....	15

Results	17
Baseline Demographics.....	17
Design Themes.....	18
Category 1: Comfort in Using Technological Devices (i.e. Computers or Tablets) by Patients or Informal Caregivers.....	21
Category 2: Willingness or Interest in HF Self-Care.....	22
Category 3: Provision of Knowledge.....	24
Category 4: Support and Security.....	27
Category 5: Connection to a Secondary Person to assist in HF Self-Care.....	31
Category 6: Tailoring the Self-Care Intervention based on the Needs of Patients, Caregivers	32
Actions and Items.....	33
Specifications for the Design of HFApp	42
Discussion	46
Challenges.....	52
Study Limitations.....	54
Additional Work.....	56
Conclusion	60
References	61

Appendix A: Participant Recruitment Telephone Script	84
Appendix B: Persona-Scenario Discussion Guide	86
Appendix C: Informal Feedback Discussion – Questions Asked	89
Appendix D: Research Ethics Board Approval Form	90
Appendix E: Persona-Scenario Session Consent Form	92
Appendix F: Personas and Scenarios Created by Patient Participants with HF and their Informal Caregivers	95

List of Figures

Figure 1: The Process of HF Self-Care.....	2
Figure 2: Required Actions in HF App.....	43

List of Tables

Table 1: Characteristics of Study Participants Overall (n=8)	18
Table 2: Breakdown of Themes in 6 Categories based on Patient and Informal Caregiver Results.....	19
Table 3: Design Categories, Nodes, Actions and Items.....	35
Table 4: Tips and Suggestions for using the Persona-Scenario Technique.....	58

List of Acronyms and Abbreviations

App – An abbreviation for “Application”. It is usually a software program that runs on an electronic device to perform specific functions for the user. †

HF – Heart Failure

HFApp – Name of the proposed online self-care intervention and community intervention

MCI – Mild Cognitive Impairment

SDDST – Standard Diuretic Decision Support Tool

UCD – User-Centered Design

† Margaret Rouse. App Definition. Tech Target. <http://searchmobilecomputing.techtarget.com/definition/app>. Published November 2011. Accessed November 1, 2015.

Declaration of Academic Achievement

The following is a declaration that the work presented in this thesis was completed by Stephanie Chiu. Guidance at all stages of the research (study design, data collection, data analysis) conducted for this thesis was provided by Dr. Catherine Demers, Dr. Norm Archer, Dr. Ruta Valaitis, and Linda Nguyen. Stephanie Chiu was responsible for writing this manuscript. Dr. Catherine Demers, Dr. Norm Archer, Dr. Ruta Valaitis, and Dr. Karim Keshavjee contributed to manuscript review and revisions.

Introduction and Background

Epidemiology of Heart Failure (HF)

Heart failure (HF) is a complex health condition that affects patients worldwide with a significant burden on the health care system. In Canada, approximately half a million people live with HF (1.5% prevalence) and every year, 50,000 new patients are diagnosed¹. Although the treatment and survival rate of patients presenting with acute coronary syndromes has improved over time, HF has become the final common pathway for many patients with increasing prevalence^{2,3}. This increase in HF prevalence is especially significant in individuals older than 65 years of age^{4,5}.

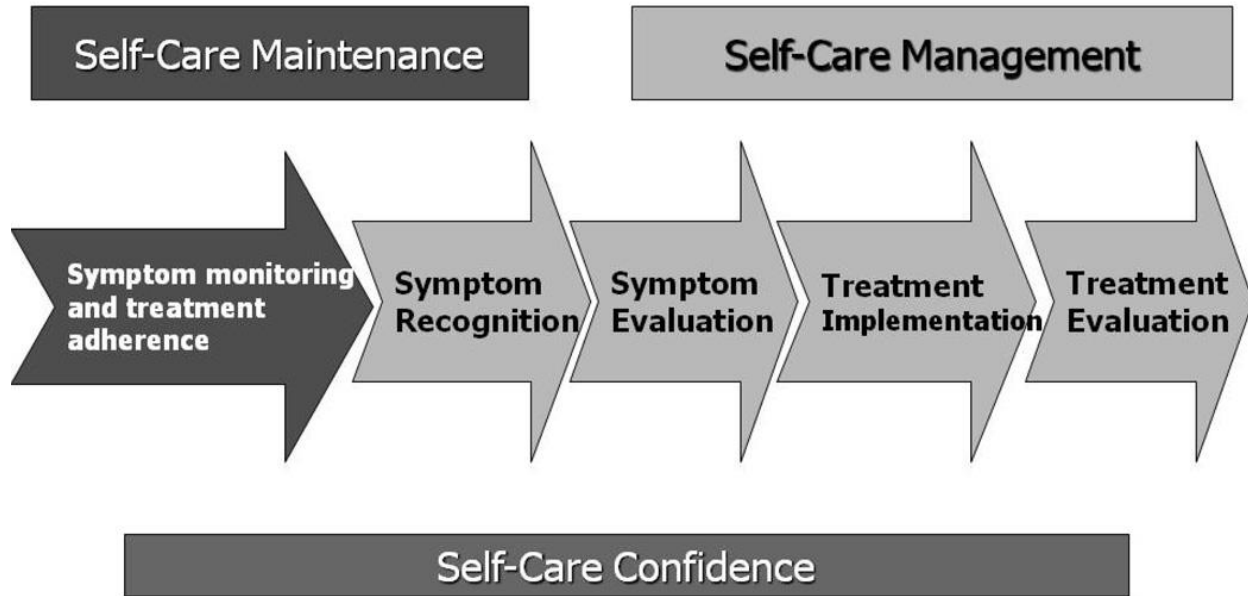
HF is a leading cause of hospital readmissions and particularly affects older individuals^{6,7}. HF-related hospital readmissions make up for a large portion of health care system spending^{8–11} and up to 70% of costs related to HF management¹². HF is the cause of up to 1.9% of hospital readmissions in Canada and is the most common cause of readmission in individuals over 65 years of age¹³. Up to 50% of patients discharged from hospital with a diagnosis of HF are readmitted to hospital within 6 months to one year after discharge^{5,14–16}. Of these readmissions, up to half are preventable¹⁷ and are in part the result of noncompliance with medical treatment, limited knowledge about HF signs and symptoms, and lack of physician follow-up^{18–21}.

The Importance of Self-care in HF

Self-care in HF is a decision making process that combines “self-care maintenance (the choice of behaviors to maintain physiologic stability such as following medication advice from healthcare providers, eating a low sodium diet, exercising, practicing preventative behaviors and

monitoring for any HF signs and symptoms), self-care management (response to signs and symptoms when they occur), and self-care confidence”^{22,23}. Figure 1 below shows this process of HF self-care²⁴.

*Figure 1: The Process of Heart Failure Self-Care*²⁴



There is some evidence supporting the role of HF self-care in preventing hospitalizations or readmissions to hospital^{25,26}, having a positive impact on quality of life among patients with HF^{4,27-29}. Self-care behaviors reported by patients with HF include monitoring daily weights, following exercise recommendations, eating a low sodium diet, and using medications as prescribed³⁰.

The Barriers to Self-Care

Although self-care is considered one of the key behaviors in preventing HF readmissions, many patients show low adherence to self-care behaviors worldwide, and this must be improved if readmission rates are to be reduced³¹. Potential barriers associated with poor self-care behaviors include: low confidence when performing self-care^{32,33}, lack of self-care education, financial constraints (e.g., loss of insurance or benefits, unable to afford medication)³⁴, lack of perceived benefit from self-monitoring, and low self-efficacy²⁷.

Older patients with HF can experience mild cognitive impairment (MCI) that is associated with poorer HF outcomes³⁵. MCI results from structural changes in the brain that can result in functional deteriorations leading to alterations in attention, memory, concentration, and learning³⁶. In one study that assessed whether or not MCI could be a predictor of self-care in patients with HF, results showed that patients with HF and MCI tended to have poorer self-care management and lower self-care confidence³⁷. This supports the idea that MCI in patients with HF can negatively affect their ability to make decisions about their own care, such as knowing how to react to certain HF signs and symptoms³⁶.

Level of HF experience has also been shown to have an impact on HF self-care³⁸. Patients who are more experienced living with HF have higher self-care abilities^{39,40} and are more likely to monitor HF symptoms, adhere to self-care maintenance behaviors, and make decisions when HF symptoms change²² compared to novice patients who are newly diagnosed with HF.

Role of the Informal Caregiver in Promoting Self-Care

Older patients with HF require complex care due to cognitive decline, co-morbidities and multiple medication regimens⁴¹. This care is most often provided by the patient with the aid of an informal caregiver, who is defined as a family member, friend or neighbor who provides unpaid long-term care to patients with chronic illnesses or disabilities on an ongoing basis⁴². Informal caregivers do not include individuals who provide voluntary care through an organization⁴³. They play a key role in “sharing the care” with the patient by focusing on symptom assessment and management, medication consumption, emotional support, and regular daily household tasks^{44–48} and this support is recognized in international guidelines⁴⁷. There is evidence showing that informal caregivers have an impact on better self-care^{47,49,50}, lower hospital readmission rates and higher medication adherence⁵¹. In contrast, patients with HF who live alone are at higher risk of social isolation and are more vulnerable to poor self-care, higher mortality and morbidity, and psychosocial distress⁴⁹.

Although informal caregivers are an important source of support for patients with HF, studies show that they often lack the information and knowledge on how to manage HF^{44,52,53}. To fulfill their roles as informal caregivers, they need to be well informed. However, studies show that informal caregivers are not usually present or involved when patients receive information following hospital discharge^{54,55}. Moreover, the health condition of patients with HF can prevent the patient from understanding or managing information that they receive from their health care provider⁵⁶. Technology-based caregiver interventions have been shown to enhance knowledge and understanding of chronic diseases for the informal caregivers, resulting in decreased caregiving burden⁵⁷.

Use of Loop Diuretics to Treat Patients with HF

Loop diuretic therapy is central in treating the symptoms of shortness of breath and leg swelling that occurs in patients with HF by impacting their overall fluid status⁵⁸⁻⁶¹. Loop diuretics have also been linked to potentially serious side effects such as worsening renal function, electrolyte abnormalities (e.g. hypokalemia), and rarely mortality based on the dose taken⁶²⁻⁶⁵. Traditionally, the dosage of diuretics is carefully adjusted by the patient's health care providers (e.g. doctor, nurse). However, research suggests that patients could more efficiently manage their HF by self-adjusting their diuretic dosage according to any daily weight change⁴⁰ they might experience. HF patient adherence to diuretic self-adjustment has been shown to be associated with fewer HF-related hospitalizations and decreased HF-related morbidity⁶⁶.

Recognizing significant weight change as a sign of fluid overload and making the decision to take an extra dose of a diuretic is part of HF self-care management. This practice would require patient training at the time of discharge from the hospital. However, research shows that current self-care education provided to the patient is not sufficient to reduce readmission rates⁶⁷. The optimal strategy in promoting this self-adjusted diuretic self-care management practice in patients with HF is the “teach-to-goal” educational methods that provides continuous informational support over one month compared to a brief one hour education intervention⁶⁸. The continuous self-care educational program is associated with greater general HF knowledge, better achievement of self-care goals, and improvement of HF symptoms⁶⁸. Social support, which includes informational support (e.g., advice or suggestions), is shown to have a positive indirect effect on diuretic self-care management through its influence on self-care confidence⁶⁹.

Review of Existing HF Technological Interventions

Several reviews have highlighted the existing interventions that target patients with HF to promote self-care^{4,70-78}. The majority of these interventions focus on educating patients about HF, guidelines for taking medications, symptom management, restricting and monitoring diet, or providing instructions on when to contact their nurse or physician^{4,70}. The delivery methods used in these HF interventions commonly include one-on-one or group counselling, education sessions, multimedia (e.g., video or CD-ROM education), Telehealth modalities (e.g., web-based monitoring systems or clinical information systems that transfer data over telephone lines), or telephone contact with a nurse⁷⁹.

Among the existing interventions that target HF self-care, some were technological interventions (delivered on computer, telephone, mobile phone, or mobile tablet). Most of these use telemonitoring or Telehealth techniques to deliver counselling and/or education sessions to patients⁷⁹. Computer-based interventions that have been studied include a web-based telehealth monitor with medication dispenser that generated daily reminders and questions related to self-care⁷², and an interactive CD-ROM with education modules and self-assessment⁷³. Telephone-based interventions include American Heart Association HF self-care guidelines delivered through telephone by nurse⁷⁴, telehealth monitoring coupled with home visits or video education⁸⁰, and multiple follow-up phone calls after hospital discharge⁷⁶. These interventions have helped improve self-care behavior⁷⁴ and develop self-care skills⁷⁷ such as daily weighing, medication management, exercise adherence⁷⁸ and some have led to lower hospital readmission⁷⁵. However, computer and telephone-based interventions have a few limitations. Patients reported that the lack of portability of a computer was inconvenient and that noises made by the computer often disrupted their resting schedule⁸⁰. Telephone-based interventions

were not available to long-term care patients because they did not have access to a telephone⁸¹. The issues of portability and accessibility to long-term care patients can be solved by using mobile devices for intervention delivery. However, none of the interventions mentioned in existing reviews were delivered to patients with HF by mobile phone or mobile tablet.

A separate search was conducted to find any existing tablet-based or mobile phone based technology for HF self-care. The search terms used were “self-care”, “technology”, “heart failure”, “intervention”, “self-management”, “eHealth”, “tablet”, “smartphone”, and “mobile phone”. A recent Swedish study evaluated a tablet-based home intervention system wirelessly connected to a weight scale and designed to assist monitoring of weight and symptoms, adjust diuretics and provide HF information⁸². The study found that the intervention was able to improve self-care, improve health-related quality of life, and decrease HF-related days in the hospital in patients with HF (mean age = 75 years)⁸². Another study looked at the needs of patients with HF for a tablet-based interactive technology in the hospital setting that promoted physical activity and medication adherence⁸³. Some of the patient needs identified from the results included empathic content, interactive learning, and support from caregivers such as family, friends, or nurses⁸³.

Randomized controlled trials of mobile-phone-based telemonitoring interventions have also been reported in the literature, but with mixed results. One study’s 6-month intervention had patients recording daily weight, blood pressure and ECGs and answering daily questions about symptoms on a mobile phone⁸⁴. This study was conducted with a patient participant group that had a mean age of 53.5 years, was 79% male, and 72% Caucasian. The patient’s phone received instructions and a cardiologist’s phone received alerts if needed. Results showed that the intervention was associated with a greater positive change in quality of life and higher levels of

self-care maintenance after the study. This study did not provide information on levels of hospitalization or emergency room visits⁸⁴. Another study (mean patient age = 66.9 years, 81% male) that also evaluated mobile-phone based telemonitoring found no change in hospitalization⁸⁵. Finally, one study (mean patient age = 66 years, 71% male) had a mobile-phone telemonitoring intervention that required patients with HF to enter information on the phone's internet browser, a task that patients found too difficult⁸⁶. This study highlighted the importance of intervention design for older patients with HF.

There are few limited functionality HF self-care apps available in the Apple and Android mobile app stores. These include: exercise adherence apps that do not target patients with HF, general blood pressure managers, or apps with general information guides about heart disease. To our knowledge, there is one mobile smartphone app, called WOW ME 2000mg© App, that can be used to assist patients with HF with learning and performing daily self-care tasks to help manage their HF condition. The app was designed to complement the patient's regular medical care and helps the patient identify early signs of HF decompensation, while helping them maximize their overall wellbeing. Some of the app's functionalities include recording daily weight, output/input monitoring of fluid and salt consumption, monitor walking steps, and HF symptom evaluation. The app is currently free and available to iOS and Android users⁸⁷. No studies have been conducted on any effects the app might have on HF outcomes or HF self-care.

Older Adults and Use of Technology to Support Self-Care

Older people with chronic diseases often experience deterioration in eyesight, hearing, cognitive function including executive function, working memory, physical coordination^{88,89}, and health literacy⁹⁰. Individuals with low health literacy have a higher chance of having low levels of HF-related knowledge⁹¹ and find it more difficult to navigate and search the Internet for

information^{92,93}. Changes in physical coordination can affect an older individual's ability to interact with technology (e.g. using a mouse or holding a tablet)⁹⁴. Moreover, decreased capacity in memory (working memory) and goal maintenance (executive function) results in technology learning time that is approximately twice as long as the learning time for younger individuals⁹⁵. As a result, the older population requires that technology be adapted to their specific needs in addition to allocating more time and technical assistance to learn technology skills^{96,97}. However, individuals who design health technology for older individuals do not necessarily take into account these specific needs, potentially resulting in lower acceptance and adoption among this population⁹⁸. This issue can be resolved by designing technology that caters to these age-related specifications. This process should include four phases, which are: 1) analyze and understand the requirements and limitations of older individuals, 2) study and implement methods to make health technologies accessible, 3) model and integrate preferences, and 4) evaluate outcomes⁹⁹(e.g., level of self-care, technology acceptance). Research shows that involving older individuals in all these phases (user-driven innovation) results in higher acceptance, usefulness, information quality and utilization by the end-user population^{100,101}.

While older individuals are often perceived to be opposed to technology¹⁰², they are actually willing to accept new technologies. However, one of the issues most often associated with adoption and acceptance of technology is that these individuals are more likely to judge the proposed technology as not being useful and they may be afraid of failing when using it⁹⁹.

HFApp – An Online Self-Care App and Community Intervention

Currently, we are working on designing an online self-care app and community intervention for patients with HF in the home setting, called HFApp. The work in this thesis will focus on this intervention. The goal of HFApp is to promote self-care in older patients with HF

recently discharged from hospital in the home setting with their informal caregivers. HFApp will also give users access to community care by connecting them with Community Care Access Centre Rapid Response Nurses (CCAC RR Nurses) and local volunteers (recruited from community groups and the local university). Elements of this intervention may include: 1) a tablet with HFApp installed 2) a Bluetooth weight scale that will be connected wirelessly to HFApp 3) a standardized diuretic decision support tool (SDDST) within HFApp 4) education related to the purpose of and how to use HFApp 5) HF-related information within HFApp such as recognition of HF symptoms, diet, or exercise and 6) potential visits by CCAC RR Nurses and trained volunteers who will visit between nursing visits. This intervention aims to promote all aspects of HF self-care presented in Figure 1.

Personas and Scenarios

User-Centered Design (UCD) involves users to determine their needs and is key in determining usefulness and usability¹⁰³. Information about user behavior and experiences are analyzed and translated into requirements for the design process. In contrast to expert-driven design, characterized by scientific validation or rules and regulations^{104,105}, a design process driven by users has been shown to result in higher user satisfaction. Moreover, usability problems that arise from an expert-driven design can be diminished in user-centered design. Although usability problems may still exist in a user-centered design, they do not inhibit effective and efficient user performance¹⁰⁵ that would otherwise be present in expert-driven design.

User personas and scenarios are examples of UCD techniques that aim to capture a user profile that consists of user expectations, prior experiences, and anticipated behaviors⁹⁹. The

profile is used to understand how the users think, feel and behave¹⁰⁶. These techniques allow co-designing of the product between the users and the designer.

A persona is a fictitious, but authentic person created to represent the intended user. The purpose of the persona is to allow the designer to understand user points of view, and their needs and demands of the technology by “entering the life” of the user⁹⁹. An effective persona characterizes major user groups, provides insight into user expectations and needs, predicts how users will use the technology, and assists in identifying features and functions of the technology¹⁰⁷. Constructing a persona requires character traits, present emotions, needs and goals that are related to personal, professional and technical backgrounds^{99,107}.

Scenarios are used as an aid for developing design ideas¹⁰⁸. They are created with existing personas to figure out the needs the persona would have when using the technology and the types of situations the persona might be in. Scenarios are typically creative and have a storytelling-like structure⁹⁹. They highlight the possible interactions that a user could have with a technology¹⁰⁹.

Aim and Objective

In a previous feasibility clinical trial, HFApp was tested for usability in older patients with a diagnosis of HF following hospital discharge using a paper-based format¹¹⁰. This trial also provided important information on acceptability, implementation, practicality, and integration. The intervention was found to be safe which leads to the development of a digital version of the intervention. What is not known is the opinions and preferences of the intended users (patients with HF and their informal caregivers) for a digital HFApp. Therefore, the purpose of this research study was to co-design a digital HFApp with patients and their informal caregivers. This

study pursued a user-driven qualitative research technique, persona-scenarios, that can be used to understand how users would react to new online self-care intervention. In order to build an effective intervention, persona scenarios were used to highlight the main interactions between users and HFApp and identify user needs and preferences.

Although persona-scenarios have gained widespread use in the design community of several industries, it is a relatively new concept being applied to healthcare consumer technologies⁹⁹. This study aims to conduct the persona-scenarios discussion sessions as a pilot study with a small sample size. Working with a smaller group allows the study to highlight any challenges that can be faced when designing related healthcare technologies. Being aware of these challenges helps future larger persona-scenario studies (for HFApp or other eHealth technologies) tackle them more efficiently.

The primary objective of this study is to develop user personas and their interactions (scenarios) when using this tool. These might include: (1) how they learn about the tool, (2) how they might access the tool, (3) where they are when they use the tool, (4) who might help them with the tool, and (5) how often they use the tool. The secondary objective is to apply these findings to identify user needs and develop a suitable design for HFApp.

The research questions that will be addressed in this thesis are: Using persona-scenarios, how do the intended users of HFApp, patients with HF and their informal caregivers, envision their use and interaction of HFApp? What are some user needs and/or preferences that can be identified from the persona-scenarios?

Methods

Personas and Scenarios

This study pursues a user-centered research technique, persona-scenarios, that allows the design of an intervention together with the users (patients and their informal caregivers).

Persona-scenarios are a structured discussion session that asks participants to create a fictitious “persona” that will then experience various “scenarios” associated with HFApp¹¹¹. For example, a persona would be a fictitious person with HF, and participants would create a suitable name, age, education, etc. To create scenarios, participants would answer questions about how the persona experiences HFApp such as “How does the persona find out about HFApp?” or “Who helps the persona use HFApp?” or “How do they use HFApp in their home environment?”.

By creating these persona-scenarios, the final goals are to show how users would interact with HFApp, what features users perceive to be useful, and how best to integrate the intervention into the daily lives of users. This is experienced-based design, which differs from traditional design strategies such as focus groups, patient forums and attitude surveys^{112,113}. Experienced-based design is based on storytelling, a way to get “a special kind of knowledge acquired from close and direct personal observation or contact”^{114,115}. Using this knowledge, we will be able to design the intervention in a way that provides better service and better experience for its users.

Population Selection

Patients who attended the Heart Function Clinic at the Hamilton General Hospital were screened for eligibility for participation in this study. Eligible patients were aged 60 years and older, had a confirmed diagnosis of HF by an experienced cardiologist based on chart review for at least the previous 6 months, and had an informal caregiver. Using a telephone script

(Appendix A), a research assistant called eligible individuals. Patients with documented dementia and minimum English speaking ability were not approached.

Persona-Scenario Discussion Sessions

Persona-scenario discussion sessions were held separately for each participant type; one for the group of patients with HF and one for their informal caregivers. These sessions took place in separate meeting rooms in the hospital outpatient area of the Hamilton General Hospital. There was a trained leader for each discussion session whose role was to explain the purpose of the discussion session, facilitate the participant creation of personas and scenarios, and conduct a feedback survey at the end of the session. The role of the leaders was assumed by two researchers for this study, S.C. and L.N. Taking into consideration that patients and their informal caregivers might have MCI and have difficulty creating personas and scenarios, we estimated that two hours should be enough time for the sessions before patients would experience fatigue and lose focus.

Each leader began the discussion session by explaining HFApp to their group. Participants were divided into pairs by selecting partners who were most similar to each other, using factors such as age, experience, and health condition. Each participant pair was given a handout with the tailored discussion guide (Appendix B) to help them create personas and scenarios, as well as pen and paper to take notes. Pairs were asked to create authentic personas – fictitious people who represented their participant type. Persona characteristics were determined such as age, weight, education and health condition. Next, the pairs created detailed scenarios related to the persona's adoption and use of HFApp. At the end of the session, all pairs took turns presenting their personas and scenarios to the whole group. These presentations were audio recorded, transcribed verbatim and used for analysis.

An informal oral feedback discussion (Appendix C) was conducted to gather the participants' opinions about the entire persona-scenario discussion session. Participants were asked what they liked or disliked about the discussion sessions, if there were any parts of the session they found difficult or easy, and if there was anything they would change about the way the study was conducted. The feedback discussion was also audio recorded.

Analysis

Verbatim transcriptions of the discussion sessions were coded into NVivo, Version 10 (Registered) for analysis. One researcher (S.C.) coded the transcriptions into design themes, which were then reviewed independently by a second researcher (L.N). The ideas were combined and the list of themes was converted into an Excel table. These themes were used to identify the necessary actions and items related to the design of the app. Actions are defined as what is required to actualize the themes and items are defined as what is required to complete the actions¹. The table of actions and items were then reviewed by all project stakeholders. A To-Do list was developed using the final actions and items to determine the next steps of app design and development.

Ethical Issues

A detailed Research Ethics Board Amendment application with all the supporting documents was submitted to the Hamilton Integrated Research Ethics Board (HIREB) for ethics review and approval. This study is an amendment to another project about enhanced caregiver support for managing older patients with HF at hospital discharge. The application received a Full Research Ethics Board level of Review and the amendment was approved as submitted. A copy of the REB letter can be found in Appendix D.

Prior to the persona-scenario discussion sessions, consent forms were reviewed and signed by all participants. A copy of the consent form can be found in Appendix E. Copies of the signed forms were provided to all participants. Parking fees were reimbursed and participation was compensated by Shoppers Drug Mart gift certificates (approved by the REB).

Discussion transcriptions and all related data were all anonymized by using randomly assigned numbers to represent participants and session leaders. All participant personal information was kept confidential and only known by the two discussion leaders, S.C. and L.N. The information will be stored securely offline in S.C. and L.N.'s password-protected personal computers in a password-protected file. At the completion of this thesis, all data will be transferred to and stored in a secure office space used by Dr. Demers' research unit for safety reasons.

Results

Data were collected from two persona-scenario discussion sessions with eight participants in total (n=8). These eight participants were invited to participate in four pairs of patient and informal caregiver. Pairs were split into two separate groups of four patients and four informal caregivers and one discussion session was held for each participant type. Although each discussion session was predicted to last at most two hours, both sessions went overtime and lasted approximately 2 ½ hours. Creating a persona was predicted to take 10 minutes and creating scenarios was predicted to take 20-25 minutes. Both sections went over the predicted time.

Baseline Demographics

Patient and informal caregiver demographic information is summarized in Table 1.

Table 1: Characteristics of Study Participants Overall (n=8)

Characteristic	n(%)
Gender	
Female	4 (50)
Male	4 (50)
Age (> 60 years)	8 (100)
	Mean patient age: 78 years Standard deviation (Patient): 0 years Mean informal caregiver age: 76.5 years Standard deviation (Informal caregiver): 4.7 years
Caregiver Type	
Spousal	8 (100)
Education	
High School (Grade 12 or below)	5 (62.5)
College or University (Higher than Grade 12)	3 (37.5)

Design Themes

Personas and scenarios created by participants are highlighted in Appendix F. The resultant coding scheme in NVivo 10 included 16 themes based on the participants' descriptions of their persona and scenarios that related to the topics in the discussion guide provided in the persona-scenario discussion sessions. These themes were grouped into six categories. One theme

was unrelated to all other themes and was placed in its own category (Category 1). The breakdown of the themes into their categories is shown in Table 2.

Table 2: Breakdown of Themes into 6 Categories based on Patient and Informal Caregiver

Results

Category	Themes
1. Comfort in using technology	1.1 Comfort in using technological devices (i.e. computers, tablets) by patients or informal caregivers
2. Willingness or interest in HF self-care	2.1 Willingness or interest in HF self-care
	2.2 Potential long-term use of HFApp
	2.3 Patients' willingness to monitor weight on a daily basis, and recording weight on HFApp
3. Provision of Knowledge	3.1 Use of the intervention as a medium for HF related information
	3.2 Information from CCAC RR nurses on self-care strategies
	3.3 Sharing of patient's health information with informal caregivers, family, and health care providers
4. Support and Security	4.1 Use of HFApp by 2 or more people
	4.2 Scheduled regular nurse or volunteer visits

	4.3 Presence of volunteers to relieve caregiver burden
	4.4 Assistance from visiting nurses and volunteers towards HFApp or related topics
	4.5 Operation of HFApp online
5. Connection to formal and informal caregivers, family members or health care providers to assist in HF self-care	5.1 Open communication and connection to healthcare professionals and others using digital support tools
	5.2 Establishment of trust from other users with access (e.g. informal caregiver, close family members) to HFApp
6. Tailoring the self-care intervention based on the needs of patients, informal and formal caregivers, and families	6.1 Use of the self-care intervention program based on the needs of patients, informal and formal caregivers, and families
	6.2 Introduction of HFApp by family physicians

Each design theme is presented below with its supporting quotations. In some quotations, “L” represents the session leader and Px or Cx represents the patient or informal caregiver, respectively.

Category 1: Comfort in Using Technology

Theme 1.1 Comfort in using technological devices (i.e. computers, tablets) by patients or informal caregivers

In the ‘Create a Persona’ section of the discussion guide, one of the guiding questions asked patients to discuss their persona’s comfort and experience with technology. Both personas created in the patient discussion session had either access to a computer or ownership of one at home. These personas were described to have medium comfort and experience with a computer since the usage of the computer was only occasional for simple tasks such as reading the news or checking sports information.

“P1: It’s a family computer, at this point. And, he uses that occasionally

P2: for sports information

P1: Yeah, for work related. Occasionally, for sports information. “

"He is willing to use the app on the house computer."

"We have four, two laptops and two desktops."

For the caregiver’s personas, they were described to also have access to the computer and also being comfortable using one. Overall, these personas suggested that both patients and informal caregivers would normally have a computer to use and are comfortable using it.

"The patient and caregiver, to be able to access the computer, and also the family members."

Because HFApp will be designed to operate on a tablet, it is important to analyze whether or not the users are willing to use a tablet. None of the personas were described as owning or using a tablet or any type of mobile technology. One participant pair did mention that their

persona was willing to use a tablet if needed. They felt slightly familiar with it already since the persona's children own a tablet. Other participant pairs mentioned that they would feel comfortable enough with technology that they could adopt using a tablet.

"Yes, he would be willing to use a tablet, if need be. Because the children in the house already have tablets and he's already familiar with that."

"...if somebody is more computer [literate], like me for example."

Category 2: Willingness or interest in HF self-care

Theme 2.1: Willingness or interest in HF self-care

During the patients' discussion session, each pair had different attitudes towards HF self-care. One pair described their persona as someone who would be open to disease management. Their persona understands the importance of watching for any weight change, watching ankle and hip measurements, and avoidance of salt intake. Moreover, their persona would be willing to learn how to use the new app and fit it into the daily routine. On the contrary, the second pair's persona rejected the idea of managing his own disease and stated that there must be a doctor to manage the disease.

"Larry [the persona] is willing to play the game and is willing to learn. But he is also willing to hold the line. That is, when he feels good, he wants to stay good."

"He also fully realizes that the weight information is absolutely paramount and the water retention control is very important. Watching his ankles and watching his belt, and making sure that the water is not seeping gradually in there. Avoiding salt, as much as possible."

"L: Would [the persona] like to be able to care for himself and his heart failure? How does he feel about managing his own disease?"

P3: No...

P4: Oh, we would have to have a doctor."

Both caregiver pairs mentioned that their personas would like to receive information about how to better look after their patient.

"I would like to have more information on what, like professional information, on what I can do."

Theme 2.2: Potential long-term use of HFApp

One question from the scenario section of the discussion guide asks participants to describe the results and outcomes of using HFApp. One patient pair predicted that their persona would be willing to use the intervention over a (unspecified) long period of time, provided that the intervention was easy enough to use.

"L: Finally, what are the results and outcomes of this interaction? Would the patient use it over time? Would they continually use it if they found it easy enough?"

P4: Yes, I think so. "

Theme 2.3: Patients' willingness to monitor weight on a daily basis and recording weight on HFApp

The intervention's ability to automatically receive the patient's daily weight via a Bluetooth scale was described to the patients. Both patients created personas that had positive attitudes and were willing to weigh themselves daily. One pair described the daily routine of their persona and how they imagine being able to fit the daily weighing into their routine.

"Yes, and he would use or go to the app right after breakfast, making it a routine. So you get up, you go to the washroom, do what you have to do, step on the scale, get down, get dressed, you go down, you eat your breakfast, and right after breakfast you go to your app. After that, the day is yours."

"Yes, oh yes. What you've described so far is something that you step on the scale and it automatically goes on the tablet."

Category 3: Provision of Knowledge

Theme 3.1: Use of HFApp as a medium for HF related information

One of the goals of this app is to promote self-care amongst the patients to improve their HF outcomes. In order for patients to properly care for themselves, they require more information on their condition, including symptoms and signs.

Patients expressed a desire to understand what is happening to them and realized that the more they know, the more it would help them.

"He's concerned about his health, but he takes little bit of information that he can get, even from the pharmacist."

"So basically, he is following the app. Guidance for him. And he is trying to understand it and trying to make it as clearly as possible. But he is willing to absorb the new knowledge."

"So he's very happy if somebody can help him really understand what really happened with his heart failure."

Both patient and caregiver personas were described as expressing interest towards receiving information about their condition and related topics (e.g., diet, blood pressure).

"We would like to have answers through concerns, diet, blood pressure, general health."

"I think the more information we get, the more it helps the patient."

Theme 3.2: Information from CCAC RR nurses on self-care strategies

During the discussion sessions, patients and informal caregivers were asked what roles, if any, the CCAC nurses would have during their persona's use of HFApp. In addition to receiving information about their condition, patients and informal caregivers believed that the CCAC nurses would be able to provide additional helpful information about self-care strategies (e.g., reacting to weight gain by changing diuretic dose, appropriate exercises, and following a low sodium diet).

"We would like to have answers through concerns, diet, blood pressure, general health."

One patient pair mentioned that they did not know much about their diuretic medication and they would prefer the CCAC nurse to come visit the house.

"L: So if you don't know much about diuretics, would you want a nurse or volunteer to come to your house?"

P3: The nurse. CCAC"

One caregiver pair suggested that the nurse could visit every month. Knowing that the nurse was coming at this scheduled time, their persona would be able to collect and gather their questions and present them to the nurse during the visit.

"The nurse helps answer the questions that you have and every month, when she comes, you know she's coming. So you collect all the questions, you write them down. And when she comes, you ask those questions."

Theme 3.3: Sharing of patient's health information

One patient pair suggested that key people should be aware of information about the patient's condition. The pair did not suggest who these key people would be, but they are likely informal caregivers, health care providers or other family members. The pair wanted the information to be shared among these "key people" because if the caregiver is unable to attend the patient, another must take his or her place.

"It helps to have everyone on the same page and don't have withhold information."

"There is also awareness from key people. The info must circulate. That is, when somebody is sick, and information is gathered, that information must not be secret, like a nuclear secret. It has to be out there, and somebody has to know."

However, the patient pair preferred that, during HFApp usage, a maximum of two people should be using it. This would be the patient and someone close to the patient, such as spouse, caregiver or another family member. This may be different from what the patient pair mentioned above, as the patient pair may believe that only two people should be *inputting* information into HFApp. In contrast, the information and advice that can be read from HFApp can be shared among the “key people”.

"He thinks that two person should deal with the app. There should not be any more people playing with it."

Category 4: Support and Security

Theme 4.1: Use of HFApp by 2 or more people (patient with HF and informal caregiver or close family member)

One of the patient pairs preferred that only two people should be able to use HFApp. However, the other patient pair suggested that HFApp could be open to everyone, such as nurses, volunteers, and others provided that this would be helpful to these additional people.

"He thinks that two person should deal with the app. There should not be any more people playing with it. The two person would be the wife or a close person, the caregiver, another member of the family, or somebody close enough"

"P4: I think so, yeah.

L: So would the app be open to everyone, such as nurses, volunteers...everybody?

P3: Yeah. If it helps somebody else, then that's great. "

Moreover, one caregiver pair suggested that when it is the first time using HFApp, having a nurse or volunteer present would be helpful for both the caregiver and patient to understand how to proceed with using the intervention.

"I think the first time to the program, having the nurse coming is great help for both the caretaker and patient, to understand what is going on."

Theme 4.2 Assistance from visiting nurses and volunteers towards HFApp or related topics

Participants were asked how nurses and volunteers would be involved in the program. One patient pair described their persona as someone who already gained information from previous visits (from other nurses). The persona would be willing to get more visits to ensure that his current HF state is stable and that “things that have to be done will be done”.

"Well yeah, Larry already had some visits earlier. And he was happy that he got a lot of information but he's quite willing to get some more visits to recap and to make sure things that have to be done will be done."

As previously mentioned, the other patient pair's persona is someone who would prefer a nurse to be present to explain to them their diuretic medication.

"L: So if you don't know much about diuretics, would you want a nurse or volunteer to come to your house?"

P3: The nurse. CCAC"

One caregiver pair said that, while their persona is still new to using the SDDST portion of HFApp, a nurse would be helpful for guidance with the unfamiliarity of the intervention. They suggested that a volunteer could provide step-by-step instructions on the program.

"I think the first time to the program, having the nurse coming is great help for both the caretaker and patient, to understand what is going on"

"[The volunteer can] help the caregiver with step-by-step instructions of the program."

Theme 4.3: Presence of volunteers to relieve caregiving burden

Volunteers were viewed as a way to relieve a part of the caregiving burden from both patients and informal caregivers. One patient pair suggested that it would be good if a volunteer could visit to check that there is nothing to be concerned about the patient's condition

*"So he is willing, and he think it would be great if somebody could come in, and tell him that
"Yeah. He is in line and he's doing okay."*

"...if something becomes critical, another person has to pick up the slack."

An informal caregiver pair mentioned that volunteers could help with technology, computer skills, or stay with the patient if the caregiver has other commitments. Moreover, the pair suggested that because some patients are not very mobile, volunteers could help with transportation.

"Volunteers that could help with technology, computer skills, stay with the patient is the caregiver has to go out and help the caregiver with step-by-step instructions of the program."

"I think it would be good to have it on a schedule, personally, to give the caretaker a chance to even go have a cup of coffee with a friend, it's like a treat."

"I think the volunteers are very important because some people are not so mobile, and if they are not so mobile, they need volunteers to transport them somewhere."

Theme 4.4: Scheduled regular nurse or volunteer visits

When asked about potential roles for nurses and volunteers, both patient and informal caregiver groups mentioned that there would be scheduled visits by either or both nurses and volunteers throughout their time using HFApp. One patient pair preferred if a nurse was present to explain the use of diuretic medication and would visit once a week.

"L: How often?"

P3: Once a week, every Thursday."

One informal caregiver pair mentioned that once a nurse is aware of patient and informal caregiver needs, the nurse will be able to determine how often to visit.

"Once the nurse knows what capacity you have to connect with all the other parts of the medication or the medical field, then she can decide if she wants to stay on this program or if she has enough visit or visits, or maybe every 2-3 months instead of every month."

"...think that if you had a schedule, with the caretaker, with the volunteer, and the volunteer knows that she's coming to you every morning or maybe Monday morning from 2-3 and maybe another hour on the Friday, you could also plan things better, with a volunteer."

Theme 4.5: Operation of HFApp online

One patient pair mentioned that their persona would operate the app online.

"I: Would the tool be online?"

P3: Yeah."

Category 5: Connection to formal and informal caregivers, family members or health care providers to assist in HF self-care

Theme 5.1: Open communication and connection to healthcare professionals and others using digital support tools

During the discussion sessions, participant comments suggested that HFApp could serve as a connection to a secondary person to assist in their HF self-care. One patient pair described their persona as someone who is always willing to receive new information about their HF and how to care for it. The easiest way for him to receive this information is when he has contact with his doctor (either family physician or cardiac specialist).

"Yes, and doctor's. Whatever convenient, whenever he has contact with his people"

The other patient pair also mentioned that the HFApp could be used to contact family and friends.

"L: Would the tool be used to contact family and friends?"

P3: Yeah."

The caregiver pairs supported this further by mentioning that it would be helpful to be able to contact a specialist through the app program. This would be able to provide a better

understanding of care and disease management for those who are involved in caring for the patient.

"The ability to connect to a specialist through the computer, through the HFApp when required."

"Everyone would have a better understanding to meds, effects, and what kind of responses would be best. And the care and management of disease would be easier."

Theme 5.2: Establishment of trust from other users with access (e.g. informal caregiver, close family members) to HFApp

One patient pair mentioned that although HFApp might be able to connect the user with external people, it is important to restrict HFApp use to those whom the patient trusts. This concern was mentioned by the patient likely because the app would contain personal information that the patient does not want to share freely to everyone.

"The two person would be the wife or a close person, the caregiver, another member of the family, or somebody close enough. A person that he trusts, and a person that can really deal with the app, understand what is going on and report what should be reported, and realize the danger zone if there is one."

Category 6: Tailoring the self-care intervention based on the needs of patients, informal and formal caregivers, and families

Theme 6.1: Tailoring the self-care intervention based on the needs of patients, informal and formal caregivers, and families

One informal caregiver pair mentioned that they felt that it was important that parts of the intervention could be tailored to the patient and informal caregivers based on their individual needs. As an example, they suggested that visits from a medical practitioner or a nurse could be arranged based on what their needs are.

"Not everybody might need, it depends... of each person. Each person is different, right? That's why we say that we may need a visit from the medical practitioner or the nurse, depending on individual needs."

"Also the ability of a visiting nurse according to personal needs would be helpful."

Theme 6.2: Introduction of HFApp by family physicians

One patient pair mentioned that their persona would find out about HFApp from their HF physician.

"L: So how does [the persona] find out about the program?"

P4: The family doctor."

Actions and Items

An Excel table (Table 3) was created with the design categories, their respective themes, and their supportive quotations extracted from the persona-scenario discussion sessions. Actions and items were identified for each theme and added to the same table. Actions are defined as activities required to execute ideas from the themes and items are defined as elements required to carry out the actions¹¹¹.

<p>"L: Finally, what are the results and outcomes of this interaction? Would the patient use it over time? Would they continually use it ..if they found it easy enough ? P4: Yes, I think so. "</p>	<p>2.2 Potential long-term use of HFApp</p>	<p>App keeps a long-term record of weight and medication change</p>	<p>Application with record keeping tools with the possibility of being able to graph/manipulate data</p>
<p>"Yes, and he would use or go to the app right after breakfast, making it a routine. So you get up, you go to the washroom, do what you have to do, step on the scale, get down, get dressed, you go down, you eat your breakfast, and right after breakfast you go to your app. After that, the day is yours." "Yes, oh yes. What you've described so far is something that you step on the scale and it automatically goes on the tablet."</p>	<p>2.3 Patients' willingness to monitor weight on a daily basis, and recording weight on HFApp</p>	<p>Scale records weight and automatically transfers it to the app</p>	<p>Bluetooth scale Mechanism on app to receive the information via bluetooth Tablet that can connect with the scale through Bluetooth Spreadsheet to collect weight values</p>
<p>Category 3: Provision of Knowledge</p>			
<p>"I think the more information we get, the more it helps the patient. " "We would like to have answers through concerns, diet, blood pressure, general health." "He's concerned about his health, but he takes little bit of information that he can get, even from the pharmacist." "So he's very happy if somebody can help him really understand what really happened with his heart failure."</p>	<p>3.1 Use of the intervention as a medium for HF related information</p>	<p>Patient is able to read about HF related information through the app Patient is able to search for HF information</p>	<p>Separate section in app providing general HF related information Information section is divided in categories (diet, BP, general health) Search bar in app</p>

<p>"So basically, he is following the app. Guidance for him. And He is trying to understand it and trying to make it as clearly as possible. But he is willing to absorb the new knowledge."</p>			
<p>"We would like to have answers through concerns, diet, blood pressure, general health."</p> <p>"The nurse helps answer the questions that you have and every month, when she comes, you know she's coming. So you collect all the questions, you write them down. And when she comes, you ask those questions."</p> <p>"L: So if you don't know much about diuretics, would you want a nurse or volunteer to come to your house? P3: The nurse. CCAC"</p>	<p>3.2 Information from CCAC RR nurses on self-care strategies</p>	<p>Nurses answer questions that patients and caregivers might have and suggest self-care management strategies</p>	<p>Mechanism to provide information to patients and caregivers about self-care management (poster/pamphlet)</p>
<p>"It's help to have everyone on the same page and don't have withhold information."</p> <p>"There is also awareness from key people. The info must circulate. That is, when somebody is sick, and information is gathered, that information must not be secret, like a nuclear secret. It has to be out there, and somebody has to know."</p> <p>"He thinks that two person should deal with the app. There should not be any more people playing with it."</p>	<p>3.3 Sharing of patient's health information with aregivers, family, and health care providers</p>	<p>Information is gathered and sent to key people</p> <p>Only two people (maximum) can access the patient's health information</p>	<p>Secure system to transfer health information</p> <p>Mechanism to ensure proper access to patient health information</p>

Category 4: Support and Security			
<p>"The two person would be the wife or a close person, the caregiver, another member of the family, or somebody close enough"</p> <p>"I think the first time to the program, having the nurse coming is great help for both the caretaker and patient, to understand what is going on."</p> <p>"P4: I think so, yeah. L: So would the app be open to everyone, such as nurses, volunteers...everybody? P3: Yeah. If it helps somebody else, then that's great. "</p>	<p>4.1 Use of HFApp by 2 or more people</p>	<p>Caregiver uses app alongside patient</p> <p>Nurses teach patient how to use app the first time</p> <p>Patient, caregiver, nurses, volunteers are all able to access the app</p>	<p>Training/teaching caregivers to use app</p> <p>Scheduled first time visit for nurse</p> <p>Training program for nurses</p> <p>Training program for all types of users</p> <p>Mechanism on app to distinguish between users (maybe?)</p>
<p>"Once the nurse what capacity you have to connect with all the other parts of the medication or the medical field, then she can decide if she wants to stay on this program or if she has enough visit or visits, or maybe every 2-3 months instead of every month."</p> <p>"...think that if you had a schedule, with the caretaker, with the volunteer, and the volunteer knows that she's coming to you every morning or maybe Monday morning from 2-3 and maybe another hour on the Friday, you could also plan things better, with a volunteer."</p> <p>"I think it would be good to have it on a schedule, personally, to give the caretaker a chance to even go have a cup of coffee with a friend, it's like a treat."</p>	<p>4.2 Scheduled regular nurse or volunteer visits</p>	<p>Nurse and/or volunteer discusses with the patient the best schedule for visits</p> <p>Nurse and/or volunteer visits patient at pre-determined scheduled times</p>	<p>Planned meeting to discuss a schedule for visits</p> <p>Schedule for nurse/volunteer visits</p>

<p>" Yes. She (nurse) gives the caretaker a feel of relief"</p> <p>"So he is willing, and he think it would be great if somebody could come in, and tell him that "Yeah. He is in line and he's doing okay."</p> <p>"Volunteers that could help with technology, computer skills, stay with the patient is the caregiver has to go out and help the caregiver with step-by-step instructions of the program."</p> <p>"I think the volunteers are very important because some people are not so mobile, and if they are not so mobile, they need volunteers to transport them somewhere."</p> <p>"if something becomes critical, another person has to pick up the slack."</p>	<p>4.3 Presence of volunteers to relieve caregiving burden</p>	<p>Nurses help patient with whatever needs they have</p> <p>Volunteers support any technical problems the patient might have</p> <p>Volunteers help patients with their general needs</p> <p>Nurses and/or volunteers are able to respond to an emergency</p>	<p>Mechanism to ensure volunteer's high level of comfort with technology and app</p> <p>Training program for volunteers</p>
<p>"Well yeah, Larry [the persona] already had some visits earlier. And he was happy that he got a lot of information but he's quite willing to get some more visits to recap and to make sure things that have to be done will be done."</p> <p>"...think the first time to the program, having the nurse coming is great help for both the caretaker and patient, to understand what is going on"</p> <p>"...help the caregiver with step-by-step instructions of the program."</p>	<p>4.4 Assistance from visiting nurses and volunteers towards the HFApp or related topics</p>	<p>Nurses and volunteers ensure the app is used correctly</p> <p>Nurses and Volunteers give step-by-step instructions if required</p>	<p>Instruction Manual for app</p>

<p>"So if you don't know much about diuretics, would you want a nurse or volunteer to come to your house?" P3: The nurse. CCAC"</p>		<p>Nurses and Volunteers explain the reasoning behind the weight and medications used in app</p>	
<p>"L: Would the tool be online?" P3: Yeah."</p>	<p>4.5 Operation of HFApp online</p>	<p>App connects to other sources via Wifi</p>	<p>Mechanism to make the tool available online</p>
<p>Category 5: Connection to formal and informal caregivers, family members or health care providers to assist in HF self-care</p>			
<p>"The ability to connect to a specialist through the computer, through the HFApps when required," " Everyone would have a better understanding to meds, effects, and what kind of responses would be best. And the care and management of disease would be easier " "Yes, and doctor's. Whatever convenient, whenever he has contact with his people" "L: Would the tool be used to contact family and friends?" P3: Yeah."</p>	<p>5.1 Open communication and connection to healthcare professionals and others using digital support tools</p>	<p>App connects with physician or other health care provider User is able to send relevant information to physician or other health care provider Patient uses app to contact family and friends</p>	<p>Mechanism for asynchronous communication between health care provider and app user Mechanism to securely send information Follow up/Assessment of information from health care provider Mechanism to connect app with other devices</p>
<p>"The two person would be the wife or a close person, the caregiver, another member of the family, or somebody close enough. A person that he trusts, and a person that can really deal with the app, understand what is going on and report what should be reported, and realize the danger zone if there is one."</p>	<p>5.2 Establishment of trust from other users with access (e.g. informal caregiver, close family members) to HFApp</p>	<p>Someone whom the patient trusts and is knowledgeable gains access to the app</p>	<p>Mechanism to ensure only trusted users have app access</p>

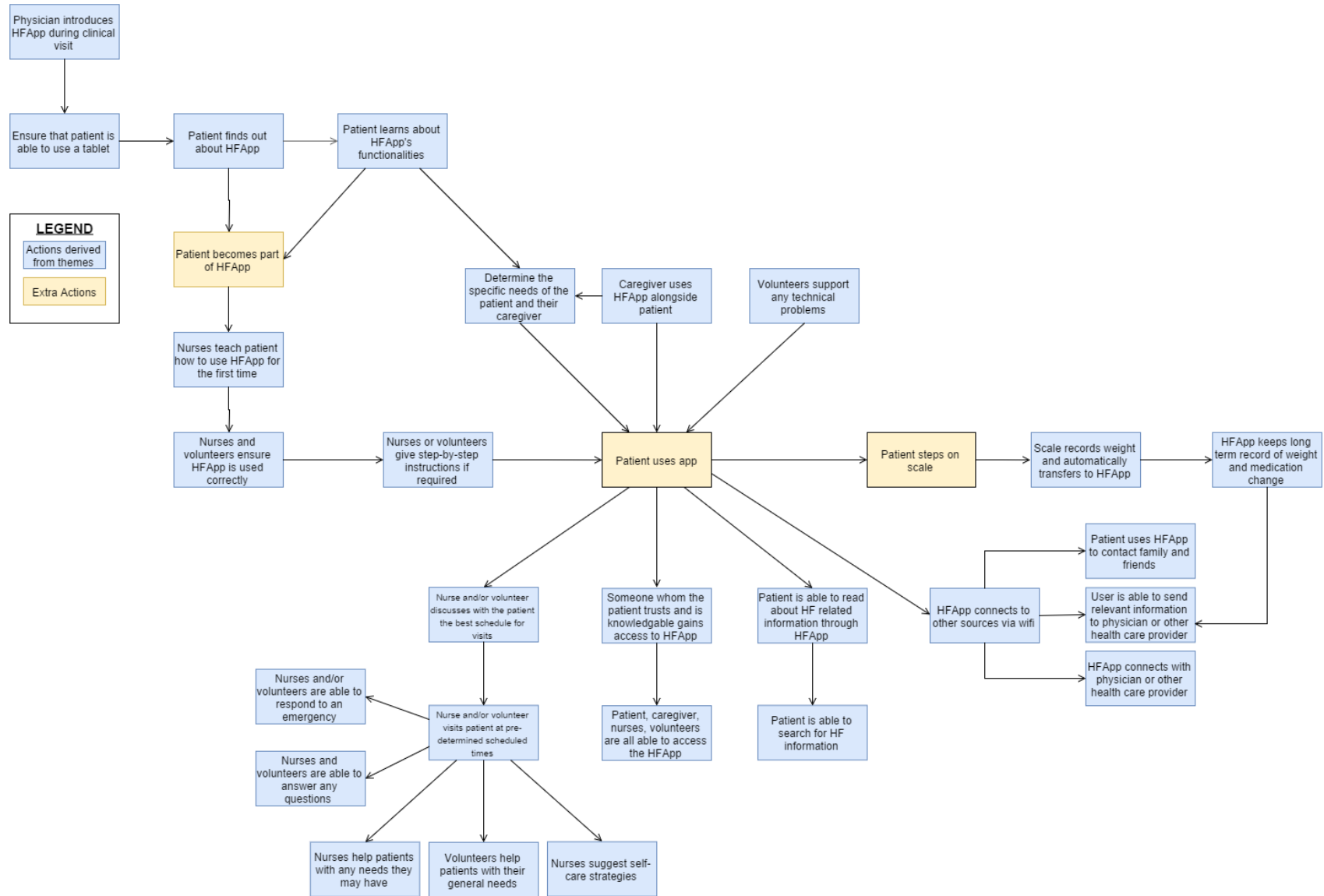
Category 6: Tailoring the self-care intervention based on the needs of patients, informal and formal caregivers, and families			
<p>"Not everybody might need, it depends... of each person. Each person is different, right? That's why we say that we may need a visit from the medical practitioner or the nurse, depending on individual needs."</p> <p>"also the ability of a visiting nurse according to personal needs would be helpful."</p>	<p>6.1 Use of the self-care intervention program based on the needs of patients, informal and formal caregivers, and families</p>	<p>Determine the specific needs of the patient and their caregiver</p>	<p>Scheduled discussion of patient and caregiver needs</p> <p>Mechanism to translate this information over to the nurse</p>
<p>"So how does [the persona] find out about the program? P4: The family doctor."</p> <p>"L: Where does he [the patient] find out about it? P4: Well, he [the doctor] recommended that I come here [to find out about it]. "</p>	<p>6.2 Introduction of HFApp from physicians</p>	<p>Physician introduces app during clinical visit</p>	

The actions and the items form the basis of developing the design for HFApp. For example, the first node, ‘Comfort in using technological devices (i.e., computers, tablets) by patients or informal caregivers’, resulted in one required action and item. The required action is to ensure that the patient is able to use a tablet. The associated item required to complete the action is a set of instructions about general tablet use that is provided to the patient.

Specifications for the Design of HFApp

Using the actions and items specifications, a design specification list was generated to assist with moving forward the HFApp design and development. The actions and items were translated into basic requirements for HFApp. After analyzing patient and caregiver interactions with the program, we were able to reinforce the importance of existing features of the program as well as to identify novel components that users felt were needed. Figure 1 shows a visual representation of the different components that would be required for HFApp. A separate list includes the items that would be required for the components in Figure 1.

Figure 2: Required Actions in HFApp



A list of items required for HFApp are outlined below.

1. Mechanism to introduce HFApp to patient (e.g. physician, poster, pamphlet)
2. Mechanism to explain HFApp functionalities to patient
3. Tablet
4. Tablet that can connect with the scale through Bluetooth
5. Instructions about general tablet use
6. Bluetooth scale
7. Mechanism on HFApp to receive the information via Bluetooth
8. Instruction Manual for HFApp
9. Training/teaching informal caregivers to use HFApp
10. Training program for nurses
11. Training program for volunteers
12. Planned meeting to discuss a schedule for visits
13. Scheduled discussion of patient and caregiver needs and mechanism to translate this information over to the nurse
14. Scheduled first time visit for nurse
15. Schedule for nurse/volunteer visits
16. Mechanism to ensure volunteer's high level of comfort with technology and HFApp
17. Separate section in HFApp providing general HF related information
18. Information section is divided in categories (diet, BP, general health)
19. Mechanism to provide information to patients and informal caregivers about self-care (poster/pamphlet)
20. Search bar in HFApp
21. Application with record keeping tools with the possibility of being able to graph/manipulate data

22. Spreadsheet (or similar collection tool analysis tool) to collect weight values
23. Mechanism to make the tool available online
24. Mechanism to connect app with other devices
25. Secure system to transfer health information
26. Mechanism for asynchronous communication between health care provider and app user
27. Mechanism on HFApp to distinguish between users
28. Mechanism to ensure proper access to patient health information (e.g. weight recordings, medication administration history)
29. Mechanism to ensure only trusted users have HFApp access

Discussion

This study identified the potential interactions older patients with HF and their informal caregivers would have with HFApp. This was used to determine their needs and requirements as design specifications for the intervention. It is important to assess potential user interactions with HFApp in order to prevent designing an intervention that would risk low adoption by the intended users. How these users would potentially interact with HFApp was presented through findings from persona-scenario discussion sessions.

The common belief is that older individuals are resistant against accepting and using new technology. In contrast, it may be the case that older individuals are actually willing to accept new technology¹¹⁶. When HFApp was explained to participants during the persona-scenario discussion sessions, participants did not express any negative attitudes towards the intervention. Instead, they were able to help identify the six main design themes for HFApp that would affect how patients and informal caregivers would find HFApp useful and acceptable. The six themes are:

- 1) Comfort in using technological devices (e.g., computers, tablets) by patients and informal caregivers
- 2) Willingness or interest in HF self-care
- 3) Provision of knowledge
- 4) Support and security
- 5) Connection to a secondary person to assist in HF self-care
- 6) Tailoring the self-care intervention based on the needs of patients and informal caregivers

Older individuals have a different acceptance of technology compared to younger technology users that involve 1) whether or not they find the technology potentially useful and 2) the chance of failure associated with using the technology¹¹⁶. These six design themes address the two above mentioned barriers against technology acceptance by the elderly.

Most of the personas created in this study expressed interest in HF self-care. This can be translated into the fact that the participants, both patient and caregiver type, had the required knowledge and motivation to adopt self-care in their daily life. Thus, HFApp, which helps the user assess when a different diuretic dose is required for symptom (weight) change, could be deemed as useful for both patients and informal caregivers.

Research also shows that education to promote self-care is associated with better adoption of self-care^{74,117}. Informal caregivers often lack the information and knowledge on how to manage HF^{44,52,53} and usually do not receive the same amount of information as the patient from the health care providers^{54,55}. Under the “Provision of Knowledge” theme, there are two user needs that can also be deemed as useful. These needs include ability to obtain HF-related information from HFApp and learning self-care strategies from CCAC nurses. Research shows that the optimal way to effectively provide HF-related knowledge is through repetitive education sessions or follow-ups (as opposed to one-time education session)¹¹⁸. Designers and developers for HFApp should ensure there will be a mechanism to provide consistent, continuous education for users including patients and their informal caregivers.

The possibility of failure when using technology can be related to low user confidence. Some of the design categories including “Provision of Knowledge”, “Support and Security”, “Connection to a Secondary Person to assist in HF Self-Care”, if implemented in HFApp in the future, can improve self-care confidence and potentially reduce the chance of failure. There are

several themes under these categories that are consistent with results from other studies^{69,71,117} such as scheduled visits from nurses or volunteers who can provide assistance about HFAPP or related topics, using the tool for HF-related information, and open communication with health care professionals.

A number of user requirements or preferences identified in this study did not agree with the original HFApp concept or found to be unfeasible for HFApp design. These included: 1) Introduction of HFApp to patients with HF and their informal caregivers by their family physicians 2) open communication with health care professionals, 3) volunteers helping to transport less mobile patients with HF or informal caregivers, and 4) informal caregivers receiving respite care from local volunteers.

A participant pair had suggested in their scenario that HFApp would be introduced by the family physician. However, in the original conceptualization of HFApp, patients with HF are referred to CCAC and assigned to HFApp through CCAC. CCAC nurses often have early contact (compared to family physicians) with patients after discharge from the hospital. This time is also when patients with HF are most vulnerable to being readmitted to the hospital. Introducing HFApp at the CCAC level would encourage an earlier start to self-care that could potentially prevent hospital readmissions.

Many participants mentioned that they would prefer being able to use HFApp as a medium for open communication with health care professionals or family and friends. This feature could lead to medicolegal issues related to “responsibility” of the health care providers for response in a timely fashion to any changes in patient signs and symptoms. It may also cause information overload for physicians or nurses as they would have to constantly review messages sent over by the users^{119,120}. Moreover, in the previous feasibility clinical trial for HFApp, it was

shown that patients with HF can safely self-care¹¹⁰. One of the main objectives of HFApp is to promote self-care. Thus, if HFApp introduced the ability for patients to connect “online” with their healthcare providers, patients may not develop a sense of independence to make decisions on their own.

An interesting finding that we came across was that a participant mentioned that volunteers could be present to help with patient transportation (e.g., helping them with their walker or getting into the car) in addition to assisting with use of HFApp. Volunteers are known to many as people who perform unpaid activities to help another person. These activities include “more commitment than spontaneous assistance but narrower in scope than the care provided by family and friends”¹²¹. Thus, patients and informal caregivers may believe that volunteers can help with anything they need, such as transportation. However, for the intervention that we will be developing, the roles of the volunteers will be defined to only assist with the intervention and answer any questions related to HFApp, their condition or HF self-care. It can be up to the volunteer to help with more, but users will be informed that volunteers are not there to perform other chores for them.

Themes identified from the informal caregiver discussion sessions suggested that a possible role for HFApp volunteers is to provide respite care. Respite care, defined as short-term breaks to temporarily restore energy and relieve caregiving burden¹²², has been shown in the literature to potentially increase informal caregivers’ quality of life and overall wellbeing^{123,124}. To support this, participants in this study mentioned that scheduled regular visits by volunteers can be helpful if informal caregivers have other commitments to attend to. However, the adequate amount of resources to provide respite care training that would be required for volunteers is not accounted for in the original design of HFApp. If additional research was conducted and found

that many patients with HF and their informal caregivers feel that respite care or other services (such as help with transportation) are required, HFApp may need to work with local volunteer agencies to address these needs.

Outlying user requirements or preferences, such as the ones listed above, are to be expected when conducting user-centered design approaches like persona-scenarios. A possible reason that these features would not agree with the study's original HFApp design is because participants did not fully understand the concept of HFApp. During the discussion sessions, the session leaders explained HFApp once and answered any questions the participants might have about HFApp. The discussion sessions did not have a physical demo to show to the participants. Because a demo was not readily available, it could have been helpful to use infographics to assist in explaining HFApp. Infographics are defined as “any graphically rendered combination of text, pictures, and data visualizations in a manner that tells a complete story”¹²⁵. They have been shown to improve comprehension of concepts, enhance ability to relate ideas, and higher retention and recall of information¹²⁶. Using infographics to complement a verbal explanation of HFApp may help study participants understand HFApp better.

To address features that were found to be unfeasible for HFApp, conducting a larger persona-scenario study would be helpful to validate the importance of these features. If a certain feature is a reoccurring preference suggested by potential users, a re-design of HFApp may be required. Other HFApp stakeholders, such as CCAC nurses, family physicians, or volunteer representatives may need to be involved to re-evaluate the concept of HFApp.

In addition to defining the user requirements for the development of HFApp, it is also important to consider other design issues, such as usability^{127–129}. As older patients with HF more often present some degree of MCI combined with deterioration of eyesight, memory, and coordination, it is important to develop an interface that is suitable for these individuals and their informal caregivers. Some of the results from this study provide a preliminary idea of certain usability problems that can be tackled early on in the design process of HFApp.

None of the study participants created a persona that was comfortable using mobile tablets. This suggests that the patients and informal caregivers themselves have little experience with these types of devices. It would be necessary to implement some sort of instructional mechanism in the app program to teach and familiarize the users about how to use a tablet. A previous Australian study also showed that older patients found tablets too heavy to hold¹³⁰. Ensuring that patients are strong enough to hold the tablet or have a convenient place to store the tablet would be necessary. One part of the app program that participants suggested would improve usability was the Bluetooth scale. Patients found it helpful that the scale would be able to automatically transfer their weight information to the app on its own.

Although we can address these usability problems during the design of HFApp, there will likely still be usability problems following the HFApp's deployment. One of the main design themes identified in our results was support and security, with one of its subthemes being scheduled volunteer visits. Volunteers can help diminish any usability problems that users might experience while they use HFApp.

The method used in this thesis is an adaptation of personas and scenarios that are typically conducted by IT specialists¹⁰⁸: Patients and informal caregivers are put in charge of the development of the personas and scenarios. During the feedback survey, all participants from

both discussion groups mentioned that the discussion guide was too long and too difficult to read. Although the discussion guide was written with the intention that it could be read by a grade 5 student, the participants still found that the guide had poor readability. The participants found the font to be too small and the sentences were too long. Attention should be paid to these comments when designing the part of HFApp that provides HF-related information to the users. This information should be presented to the users in bigger text font and in bullet point format as requested by study participants and also follow plain language guidelines for lay audiences and older adults¹³¹⁻¹³³.

Challenges

In this study, several challenges presented themselves that were not anticipated during the design of this study. During the discussion session, the leader explained to all participants the concept of creating a fictitious persona that would experience numerous different scenarios related to using HFApp. In the patient session, the first patient pair was able to understand the concept and complete the exercise without difficulty. The second pair was unable to understand the concept and required the session leader to sit with them throughout the entire session. The pair had difficulty focusing on a ‘persona’ and their answers often reverted to a first-person point of view (i.e. what the patient themselves would experience). The session leader needed to repeat the idea of ‘creating a fake person and telling a story’ multiple times. As a result, the second pair created a persona and scenarios for part of the discussion session, but other answers were based more on their personal experiences. More time was required by the second pair to complete the study and contributed to the session going overtime. The caregiver discussion session experienced the same problem. The first caregiver pair created a complete persona and scenarios, while the second caregiver pair required more time and had some answers based on their

personal experiences. Other studies have shown similar results in which older participants had difficulty engaging in UCD to design to new technologies^{134,135}.

It is possible that the participants' ability to grasp the concept of persona-scenarios was related to their education and work experience. When pairs were asked to create their persona, one of the questions from the discussion guide asks the pairs to describe the persona's education and work experience. In each discussion session, there was a noticeable education difference between the two pairs' personas. One patient pair described their persona as having a college education, completed extra academic studies, and climbed the corporate ladder throughout his career. The other patient pair's persona obtained a high school diploma and went on to become a carpenter. In the informal caregivers' session, one caregiver pair also created a persona that received a college education and was self-employed while the other caregiver pair's persona finished Grade 11 and worked as a telephone support for a communication company. Pairs that created personas with post-secondary education consisted of participants that went to university or college in reality. In contrast, pairs that consisted of high school educated participants also created personas that reflected this demographic. Both pairs that created personas with university or college education were able to create their persona and scenarios without difficulty while the remaining pairs with lower persona educations required the session leader to guide them through the entire discussion. Therefore, it is likely that the participants who had a better understanding of the persona-scenario concept also had higher education and work experience.

Maintaining focus and structure is a challenge when conducting a UCD session with older participants¹¹⁶. Many older participants perceive UCD sessions as a means for socializing with other participants¹³⁶. Going off topic and conversing about their own personal lives were issues faced during our discussion sessions. To tackle this issue, one study suggested that

technology designers should plan UCD sessions as more exciting social events¹¹⁶. This way, both the designer and the older users will be able to talk about their opinions comfortably to each other¹³⁷. Studies show that a friendly atmosphere¹¹⁶ and group interaction is valuable in helping participants collaborate and help each other to produce quality answers^{138,139}.

At the end of the discussion sessions, pairs were asked to summarize and present their personas and scenarios to the rest of the participants in their session. Although session leaders took down notes for participant pairs during the discussion, sessions leaders noticed that participants did not present all aspects of their persona-scenario creation during this summary session (e.g., missed persona characteristics, missed scenarios). MCI, common in patients with HF³⁵, is associated with lower attention and memory capacity¹⁴⁰, and may be one of the reasons behind participants forgetting parts of their persona and scenarios.

Another challenge experienced during the discussion sessions was time. The sessions took about 2 ½ hours, which was longer than the predicted 2 hour session. Participants began to feel fatigue and lose focus near the end of the session, both of which could have been caused by being forced to talk about HFApp for a long period of time¹¹⁶. However, it would be difficult to compromise time in discussion sessions, as participants could have MCI¹⁴¹, and would require a longer period of time to create the persona and scenarios. Instead, as mentioned previously, persona-scenario discussion session that involved socializing aspects may prevent loss of focus or interest.

Study Limitations

Persona-Scenarios was the UCD method of choice in this study and has some of its own limitations. First off, some of the participants in this study had difficulty and took longer than

predicted to create personas and scenarios. The discussion guide consisted of open-ended questions that suggested participants to answer in a creative manner. Participants, who were older individuals that are more likely to be cognitively impaired, were given only a general description of HFApp, and thus, the persona-scenario creation task may have been challenging for them. In the end, resulting personas and scenarios may lack detail due to difficulty of the task.

Another limitation of using persona-scenarios for this study is that the results focused on user experiences, needs and preferences. What is not assessed in this study is attitudes (positive or negative) or opinions of the user about HFApp. For example, participants were asked of what roles they perceive visiting CCAC nurses and volunteers to have in the intervention. However, they were not asked how they felt about CCAC nurses or volunteers visiting them in their home or if they would prefer another individual to visit instead. Focus groups, in contrast, is another UCD method defined as a guided discussion about a particular topic and focuses more on users attitudes towards a service or product^{139,142,143}. For the design of HFApp or other healthcare technologies, it might be helpful to incorporate both findings on experiences and attitudes to determine the most optimal design.

Conflicting user needs or preferences cannot be addressed by using the persona-scenario UCD method. For example, participants in this study had varying scenarios regarding how often CCAC nurses or local volunteers would come visit the patient's home (e.g. once a week vs. once every few weeks). Another UCD method, Delphi surveys, can be used to help reach consensus for conflicting preferences or requirements¹⁴⁴. Just like focus groups, Delphi surveys can be used in conjunction with persona-scenarios to support the design process.

Lastly, this study had a small study sample. The needs and requirements of the participants from this study for HFApp could not be generalized to all patients with HF and their informal

caregivers. Another study conducted a similar persona-scenario exercise to co-design a health care intervention, and found data saturation after a higher number of sessions¹¹¹. Therefore, while it might be the case that a small number of sessions and participants is sufficient to identify some design requirements for HFApp¹¹¹, a larger study with more discussion sessions would be required to determine the less common design requirements. Moreover, participants expressed conflicting opinions on some of the themes (e.g., how many people should be using the intervention, interest in self-management). Conducting a larger discussion session with a bigger study sample can also help provide insight on which opinions on these topics are more popular.

Additional Work

The next step in this research would be to conduct the persona-scenario discussion sessions with a larger study sample. However, because participants in this study struggled with the creative aspect of the persona-scenarios, a larger study could consider using a different study design. In contrast to this study, a different design could involve the designer or researcher inventing the personas and scenarios^{145–147}. These could be loosely based on the persona-scenarios already created from this study. Once the persona-scenarios are ready, they can be presented to the group of potential users to generate opinions, feedback, or revisions. Similar to this study, participants can be divided into multiple smaller groups by participant type (i.e., patients and informal caregivers). The personas that were created in this study can serve as a detailed user profile and be used as a basis for selecting new participants for the larger study. This method could have some advantages; 1) Participants will not be fatigued by the creation process 2) Interacting with the designer/researcher or group members to provide feedback on an already created persona-scenario can provide a sense of a social event to the participants 3) Some participants in our study often reverted back to talking about their scenarios in a first-person

point of view. In this design, participants will be able to apply their own personal experiences to generate feedback.

Information gathered from a larger study sample can then be used to facilitate determining almost all user needs and preferences for HFApp. Overall, the larger study would aim to accomplish three research goals: (1) Validate the design requirements determined in this study; (2) Resolve any conflicting requirements determined in this study; and (3) Identify any new design requirements not mentioned by participants in this study. Once the requirement list is refined, a detailed feasibility assessment is necessary to determine if these features are viable in terms of time, budget, and resources. If the development progresses to a testing and evaluation phase^{148,149}, information from the persona-scenario studies can be used to help identify any issues behind adoption and acceptability of the intervention. In these phases, study personas can be used to identify appropriate test users who can test HFApp in various situations that were adapted from study scenarios.

Based on observations, challenges, and results from this study, a list of guiding tips and suggestions was created for conducting future persona-scenario discussion sessions.

Table 4: Tips and Suggestions for using the Persona-Scenario Technique

<p style="text-align: center;">Tips and Suggestions for Conducting Persona-Scenarios During the Co-Design of a Healthcare Technology with Older Participants</p> <ul style="list-style-type: none">• Consider having the researcher or designer create several personas and scenarios instead. This can save time and energy for older participants. Once created, present the persona-scenarios to participants for feedback.• One discussion leader per participant pair or group instead of only one session leader<ul style="list-style-type: none">○ Discussion leader will record detailed notes to assist participants in remembering ideas, connecting ideas, or generating new ideas• Train all discussion leaders (e.g. conduct a training session prior to presenting persona-scenarios). Some topics to train could be:<ul style="list-style-type: none">○ Concept of HFApp and self-care○ Ensure an adequate level of comfort with technology○ How to interact with older individuals with MCI• Participant pairing criteria<ul style="list-style-type: none">○ Important to pair participants according to their health condition (more difficult for newly diagnosed patients to relate to a patient who has had HF for a longer time)• Simplify the discussion guide<ul style="list-style-type: none">○ Lay language, bullet point format, large font, short statements, understandable by a Grade 5 student

- Consider social aspect: allow participants some time to socialize with each other
- Scheduling a break in the middle
 - Allows participants to socialize and then regain focus after the break. This way, the 2 hours will seem less long
 - Allows a bathroom break (especially for HF who are already taking diuretic medications)
 - Allows participants a cognitive break, instead of focusing on persona-scenarios for two hours straight causing fatigue
- Prepare infographics to help explain the concept of HFApp or persona-scenarios to participants

Conclusion

The prevalence of HF is on the rise, especially in older individuals over 60 years of age. As the population's proportion of seniors also continues to increase, HF-related hospitalizations will greatly contribute to health care system costs. HF self-care behaviors have been shown in research to reduce the number of HF-related hospital readmissions.

HFApp was conceptualized to provide patients with HF and their informal caregivers the support to promote HF self-care in the home setting and access to community support from CCAC RR nurses and local volunteers. A user-centered research technique was conducted to co-design HFApp with users and determine their needs and preferences for HFApp. Six categories of design themes were identified which were used to develop a list of user requirements for HFApp. Some of these requirements support older users perceive HFApp to be more useful and give users a sense of self-care confidence. However, some requirements may be excluded due to low feasibility. It is recommended that a larger persona-scenario group session be conducted in the future in order to validate the requirements gathered in this study as well as identify any new requirements.

References

1. Ross H, Howlett J, Arnold JMO, et al. Treating the right patient at the right time: access to heart failure care. *Can J Cardiol.* 2006;22(9):749-754.
<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2560514&tool=pmcentrez&rendertype=abstract>. Accessed October 27, 2015.
2. Blair JE a, Huffman M, Shah SJ. Heart failure in North America. *Curr Cardiol Rev.* 2013;9(2):128-146. doi:10.2174/1573403X11309020006.
3. Dickstein K, Cohen-Solal A, Filippatos G, et al. ESC guidelines for the diagnosis and treatment of acute and chronic heart failure 2008: the Task Force for the diagnosis and treatment of acute and chronic heart failure 2008 of the European Society of Cardiology. Developed in collaboration with the Heart. *Eur J Heart Fail.* 2008;10(10):933-989. doi:10.1016/j.ejheart.2008.08.005.
4. Ditewig JB, Blok H, Havers J, van Veenendaal H. Effectiveness of self-management interventions on mortality, hospital readmissions, chronic heart failure hospitalization rate and quality of life in patients with chronic heart failure: A systematic review. *Patient Educ Couns.* 2010;78(3):297-315. doi:10.1016/j.pec.2010.01.016.
5. Johansen H, Strauss B, Arnold JMO, Moe G, Liu P. On the rise: The current and projected future burden of congestive heart failure hospitalization in Canada. *Can J Cardiol.* 2003;19(4):430-435. doi:<http://www.ncbi.nlm.nih.gov/pubmed/12704491>.

6. Massie BM, Shah NB. Evolving trends in the epidemiologic factors of heart failure: Rationale for preventive strategies and comprehensive disease management. *Am Heart J.* 1997;133:703-712. doi:10.1016/S0002-8703(97)70173-X.
7. Cleland JG, Swedberg K, Poole-Wilson PA. Successes and failures of current treatment of heart failure. *Lancet (London, England).* 1998;352 Suppl :SI19-SI28.
<http://www.ncbi.nlm.nih.gov/pubmed/9736476>. Accessed November 5, 2015.
8. Jerant a F, Azari R, Nesbitt TS. Reducing the cost of frequent hospital admissions for congestive heart failure: a randomized trial of a home telecare intervention. *Med Care.* 2001;39(11):1234-1245. doi:10.1097/00005650-200111000-00010.
9. Azad N, Lemay G. Management of chronic heart failure in the older population. *J Geriatr Cardiol.* 2014;11(2):329-337. doi:10.11909/j.issn.1671-5411.2014.04.008.
10. Berry C, Murdoch DR, McMurray JJ. Economics of chronic heart failure. *Eur J Heart Fail.* 2001;3(3):283-291. <http://www.ncbi.nlm.nih.gov/pubmed/11377998>.
11. Braunschweig F, Cowie MR, Auricchio A. What are the costs of heart failure? *Europace.* 2011;13(SUPPL. 2):13-17. doi:10.1093/europace/eur081.
12. McMurray JJ V. Systolic Heart Failure. *N Engl J Med.* 2010;362(3):228-238.
doi:10.1056/NEJMcp0909392.
13. Dai S, Walsh P, Wielgosz A, Gurevich Y, Bancej C, Morrison H. Comorbidities and mortality associated with hospitalized heart failure in Canada. *Can J Cardiol.* 2012;28(1):74-79. doi:10.1016/j.cjca.2011.05.002.

14. Burns RB, McCarthy EP, Moskowitz MA, Ash A, Kane RL, Finch M. Outcomes for older men and women with congestive heart failure. *J Am Geriatr Soc.* 1997;45(3):276-280.
<http://www.ncbi.nlm.nih.gov/pubmed/9063271>.
15. Krumholz HM, Parent EM, Tu N, et al. Readmission after hospitalization for congestive heart failure among Medicare beneficiaries. *Arch Intern Med.* 1997;157(1):99-104.
doi:10.1001/archinte.1997.00440220103013.
16. Lee DS, Johansen H, Gong Y, Hall RE, Tu J V, Cox JL. Regional outcomes of heart failure in Canada. *Can J Cardiol.* 2004;20(6):599-607.
<http://europepmc.org/abstract/med/15152289>. Accessed September 24, 2015.
17. Michalsen A, König G, Thimme W. Preventable causative factors leading to hospital admission with decompensated heart failure. *Heart.* 1998;80(5):437-441.
<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1728853&tool=pmcentrez&rendertype=abstract>. Accessed September 29, 2015.
18. Strömberg A. The crucial role of patient education in heart failure. *Eur J Heart Fail.* 2005;7(3):363-369. doi:10.1016/j.ejheart.2005.01.002.
19. Hernandez AF, Greiner M a, Fonarow GC, et al. Relationship between early physician follow-up and 30-day readmission among Medicare beneficiaries hospitalized for heart failure. *JAMA.* 2010;303(17):1716-1722. doi:10.1016/S0735-1097(10)61205-3.
20. Assareh AR, Alasti M, Beigi S, Fayyazi S. Effect of Discharge Education on Quality of Life and Hospital Readmission in Patients with Heart Failure: Is It Effective? *J Tehran*

Univ Hear Cent. 2008;3(1).

http://www.researchgate.net/publication/242617864_Effect_of_Discharge_Education_on_Quality_of_Life_and_Hospital_Readmission_in_Patients_with_Heart_Failure_Is_It_Effective. Accessed November 5, 2015.

21. Cline CM, Israelsson BY, Willenheimer RB, Broms K, Erhardt LR. Cost effective management programme for heart failure reduces hospitalisation. *Heart.* 1998;80(5):442-446.
22. Riegel B, Carlson B, Moser DK, Sebern M, Hicks FD, Roland V. Psychometric testing of the self-care of heart failure index. *J Card Fail.* 2004;10(4):350-360. doi:10.1016/j.cardfail.2003.12.001.
23. Riegel B, Moser DK, Anker SD, et al. State of the science: Promoting self-care in persons with heart failure: A scientific statement from the american heart association. *Circulation.* 2009;120(12):1141-1163. doi:10.1161/CIRCULATIONAHA.109.192628.
24. Riegel B, Lee CS, Dickson VV, Carlson B. An update on the self-care of heart failure index. *J Cardiovasc Nurs.* 2010;24(6):485-497. doi:10.1097/JCN.0b013e3181b4baa0.
25. Atienza F, Anguita M, Martinez-Alzamora N, et al. Multicenter randomized trial of a comprehensive hospital discharge and outpatient heart failure management program. *Eur J Heart Fail.* 2004;6(5):643-652. doi:10.1016/j.ejheart.2003.11.023.

26. Giordano a., Scalvini S, Zanelli E, et al. Multicenter randomised trial on home-based telemanagement to prevent hospital readmission of patients with chronic heart failure. *Int J Cardiol.* 2009;131(2):192-199. doi:10.1016/j.ijcard.2007.10.027.
27. Seto E, Leonard KJ, Cafazzo J a., Masino C, Barnsley J, Ross HJ. Self-care and Quality of Life of Heart Failure Patients at a Multidisciplinary Heart Function Clinic. *J Cardiovasc Nurs.* 2011;26(5):377-385. doi:10.1097/JCN.0b013e31820612b8.
28. De la Porte PWFB-A, Lok DJA, van Veldhuisen DJ, et al. Added value of a physician-and-nurse-directed heart failure clinic: results from the Deventer-Alkmaar heart failure study. *Heart.* 2007;93(7):819-825. doi:10.1136/hrt.2006.095810.
29. Del Sindaco D, Pulignano G, Minardi G, et al. Two-year outcome of a prospective, controlled study of a disease management programme for elderly patients with heart failure. *J Cardiovasc Med.* 2007;8(5):324-329. doi:10.2459/JCM.0b013e32801164cb.
30. Evangelista LS, Doering L V, Dracup K, Westlake C, Hamilton M, Fonarow GC. Compliance behaviors of elderly patients with advanced heart failure. *J Cardiovasc Nurs.* 2003;18(3):197-208.
<http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=2003106751&site=ehost-live>.
31. Doughty RN, Wright SP, Pearl a, et al. Randomized, controlled trial of integrated heart failure management: The Auckland Heart Failure Management Study. *Eur Heart J.* 2002;23(2):139-146. doi:10.1053/euhj.2001.2712.

32. Carlson B, Riegel B, Moser DK. Self-care abilities of patients with heart failure. *Hear Lung J Acute Crit Care*. 2001;30(5):351-359. doi:10.1067/mhl.2001.118611.
33. Evangelista LS, Shinnick MA. What do we know about adherence and self-care? *J Cardiovasc Nurs*. 2008;23(3):250-257. doi:10.1097/01.JCN.0000317428.98844.4d.
34. Jerant AF, von Friederichs-Fitzwater MM, Moore M. Patients' perceived barriers to active self-management of chronic conditions. *Patient Educ Couns*. 2005;57(3):300-307. doi:10.1016/j.pec.2004.08.004.
35. McLennan SN, Pearson S a., Cameron J, Stewart S. Prognostic importance of cognitive impairment in chronic heart failure patients: Does specialist management make a difference? *Eur J Heart Fail*. 2006;8:494-501. doi:10.1016/j.ejheart.2005.11.013.
36. Dickson V V, Tkacs N, Riegel B. Cognitive influences on self-care decision making in persons with heart failure. *Am Heart J*. 2007;154(3):424-431. doi:10.1016/j.ahj.2007.04.058.
37. Cameron J, Worrall-Carter L, Page K, Riegel B, Lo SK, Stewart S. Does cognitive impairment predict poor self-care in patients with heart failure? *Eur J Heart Fail*. 2010;12(5):508-515. doi:10.1093/eurjhf/hfq042.
38. Riegel B, Dickson VV. A situation-specific theory of heart failure self-care. *J Cardiovasc Nurs*. 2008;23(3):190-196. doi:10.1097/01.JCN.0000305091.35259.85.

39. Riegel B, Carlson B, Glaser D, Romero T. Randomized Controlled Trial of Telephone Case Management in Hispanics of Mexican Origin With Heart Failure. *J Card Fail.* 2006;12(3):211-219. doi:10.1016/j.cardfail.2006.01.005.
40. Feijó M, Biolo A, Ruschel K, Orlandin L, Aliti G, Rabelo-Silva E. Effect of a diuretic adjustment algorithm and nonpharmacologic management in patients with heart failure: study protocol for a randomized controlled trial. *Trials.* 2015;16(1):44. doi:10.1186/s13063-015-0559-7.
41. McDonagh TA, Blue L, Clark AL, et al. European Society of Cardiology Heart Failure Association Standards for delivering heart failure care. *Eur J Heart Fail.* 2011;13(3):235-241. doi:10.1093/eurjhf/hfq221.
42. Arno PS, Levine C, Memmott MM. The economic value of informal caregiving. *Health Aff.* 1999;18(2):182-188. doi:10.1377/hlthaff.18.2.182.
43. Fargo N. *Informal Caregivers: 2002 Outreach Survey.* Itle.; 2003.
44. Aldred H, Gott M, Gariballa S. Advanced heart failure: Impact on older patients and informal carers. *J Adv Nurs.* 2005;49(2):116-124. doi:10.1111/j.1365-2648.2004.03271.x.
45. Brännström M, Ekman I, Boman K, Strandberg G. Narratives of a man with severe chronic heart failure and his wife in palliative advanced home care over a 4.5-year period. *Contemp Nurse.* 2007;27(1):10-22. doi:10.5555/conu.2007.27.1.10.

46. Davidson PM, MacDonald P, Moser DK, et al. Cultural diversity in heart failure management: Findings from the DISCOVER study (part 2). *Contemp Nurse*. 2007;25(1-2):50-62. doi:10.5172/conu.2007.25.1-2.50.
47. Clark AM, Reid ME, Morrison CE, Capewell S, Murdoch DL, McMurray JJ. The complex nature of informal care in home-based heart failure management. *J Adv Nurs*. 2008;61(4):373-383. doi:10.1111/j.1365-2648.2007.04527.x.
48. Gusdal AK, Josefsson K, Adolfsson ET, Martin L. Informal Caregivers' Experiences and Needs When Caring for a Relative With Heart Failure. *J Cardiovasc Nurs*. 2014;00(0):1. doi:10.1097/JCN.0000000000000210.
49. Dunbar SB, Clark PC, Quinn C, Gary RA, J KN. Family Influences on Heart Failure Self-care and Outcomes. *J Cardiovasc Nurs*. 2008;23(3):258-265. doi:10.1097/01.JCN.0000305093.20012.b8.Family.
50. Reid M, Clark A, Murdoch DL, Morrison C, Capewell S, McMurray J. Patients strategies for managing medication for chronic heart failure. *Int J Cardiol*. 2006;109(1):66-73. doi:10.1016/j.ijcard.2005.05.051.
51. Chin MH, Goldman L. Factors contributing to the hospitalization of patients with congestive heart failure. *Am J Public Health*. 1997;87(4):643-648. doi:10.2105/AJPH.87.4.643.

52. Scott LD. Caregiving and care receiving among a technologically dependent heart failure population. *ANS Adv Nurs Sci.* 2000;23(2):82-97.
<http://www.ncbi.nlm.nih.gov/pubmed/11104326>.
53. Bakas T, Pressler SJ, Johnson E a, Nauser J a, Shaneyfelt T. Family caregiving in heart failure. *Nurs Res.* 2006;55(3):180-188. doi:10.1097/00006199-200605000-00004.
54. Luttik ML, Blaauwbroek A, Dijker A, Jaarsma T. Living with heart failure: partner perspectives. *J Cardiovasc Nurs.* 22(2):131-137.
<http://www.ncbi.nlm.nih.gov/pubmed/17318039>. Accessed November 5, 2015.
55. Hellesø R, Eines J, Sorensen L, Fagermoen MS. Severity of illness - implications for information management by patients. *Stud Heal Technol Informatics.* 2009;146:373-377.
<http://www.ncbi.nlm.nih.gov/pubmed/19592869>.
56. Hellesø R, Eines J, Fagermoen MS. The significance of informal caregivers in information management from the perspective of heart failure patients. *J Clin Nurs.* 2012;21(3-4):495-503. doi:10.1111/j.1365-2702.2011.03927.x.
57. Schulz R, Ma AL, Martire LM. Technology-Based Caregiver Intervention Research: Current Status and Future Directions. *Gerontechnology.* 2002;2:15-47.
58. Faris RF, Flather M, Purcell H, Poole-Wilson PA, Coats AJ. Diuretics for heart failure (Review). *TheCochrane Libr.* 2012;2012(2):1-44. doi:10.1002/14651858.CD003838.pub3.
59. Basraon J, Deedwani PC. Diuretics in Heart Failure. Practical Considerations. *Med Clin North Am.* 2012;96(5):933-942. doi:10.1016/j.mcna.2012.07.003.

60. Felker GM. Loop diuretics in heart failure. *Heart Fail Rev.* 2012;17:305-311.
doi:10.1007/s10741-011-9245-3.
61. Volz EM, Felker GM. How to use diuretics in heart failure. *Curr Treat Options Cardiovasc Med.* 2009;11(6):426-432. <http://www.ncbi.nlm.nih.gov/pubmed/19930980>.
62. Cooper H a, Dries DL, Davis CE, Shen YL, Domanski MJ. Diuretics and risk of arrhythmic death in patients with left ventricular dysfunction. *Circulation.* 1999;100(12):1311-1315. doi:10.1161/01.CIR.100.12.1311.
63. Ahmed A, Husain A, Love TE, et al. Heart failure, chronic diuretic use, and increase in mortality and hospitalization: An observational study using propensity score methods. *Eur Heart J.* 2006;27(12):1431-1439. doi:10.1093/eurheartj/ehi890.
64. Butler J, Forman DE, Abraham WT, et al. Relationship between heart failure treatment and development of worsening renal function among hospitalized patients. *Am Heart J.* 2004;147(2):331-338. doi:10.1016/j.ahj.2003.08.012.
65. Hasselblad V, Stough WG, Shah MR, et al. Relation between dose of loop diuretics and outcomes in a heart failure population: Results of the ESCAPE Trial. *Eur J Heart Fail.* 2007;9(10):1064-1069. doi:10.1016/j.ejheart.2007.07.011.
66. Jones CD, Holmes GM, Dewalt D a, et al. Is adherence to weight monitoring or weight-based diuretic self-adjustment associated with fewer heart failure-related emergency department visits or hospitalizations? *J Card Fail.* 2012;18(7):576-584.
doi:10.1016/j.cardfail.2012.05.004.

67. Jha AK, Orav EJ, Epstein AM. Public reporting of discharge planning and rates of readmissions. *N Engl J Med.* 2009;361(27):2637-2645. doi:10.1056/NEJMsa0904859.
68. Baker DW, Dewalt DA, Schillinger D, et al. The effect of progressive, reinforcing telephone education and counseling versus brief educational intervention on knowledge, self-care behaviors and heart failure symptoms. *J Card Fail.* 2011;17(10):789-796. doi:10.1016/j.cardfail.2011.06.374.
69. Cené CW, Haymore LB, Dolan-Soto D, et al. Self-care confidence mediates the relationship between perceived social support and self-care maintenance in adults with heart failure. *J Card Fail.* 2013;19(3):202-210. doi:10.1016/j.cardfail.2013.01.009.
70. Jovicic A, Holroyd-Leduc JM, Straus SE. Effects of self-management intervention on health outcomes of patients with heart failure: a systematic review of randomized controlled trials. *BMC Cardiovasc Disord.* 2006;6:43. doi:10.1186/1471-2261-6-43.
71. Barnason S, Zimmerman L, Hertzog M, Schulz P. Pilot testing of a medication self-management transition intervention for heart failure patients. *West J Nurs Res.* 2010;32(7):849-870. doi:10.1177/0193945910371216.
72. Artinian NT, Magnan M, Christian W, Lange MP. What do patients know about their heart failure? *Appl Nurs Res.* 2002;15(4):200-208. doi:10.1053/apnr.2002.35959.
73. Strömberg A, Dahlström U, Fridlund B. Computer-based education for patients with chronic heart failure. A randomised, controlled, multicentre trial of the effects on

- knowledge, compliance and quality of life. *Patient Educ Couns*. 2006;64(1-3):128-135.
doi:10.1016/j.pec.2005.12.007.
74. Brandon AF, Schuessler JB, Ellison KJ, Lazenby RB. The effects of an advanced practice nurse led telephone intervention on outcomes of patients with heart failure. *Appl Nurs Res*. 2009;22(4):e1-e7. doi:10.1016/j.apnr.2009.02.003.
75. Dansky KH, Vasey J, Bowles K. Impact of telehealth on clinical outcomes in patients with heart failure. *Clin Nurs Res*. 2008;17(3):182-199. doi:10.1177/1054773808320837.
76. Shearer NBC, Cisar N, Greenberg E a. A telephone-delivered empowerment intervention with patients diagnosed with heart failure. *Hear Lung J Acute Crit Care*. 2007;36(3):159-169. doi:10.1016/j.hrtlng.2006.08.006.
77. Riley JP, Gabe JP, Cowie MR. Does telemonitoring in heart failure empower patients for self-care? A qualitative study. *J Clin Nurs*. 2013;22(17-18):2444-2455.
doi:10.1111/j.1365-2702.2012.04294.x.
78. Radhakrishnan K, Jacelon C. Impact of Telehealth on Patient Self-management of Heart Failure. A Review of Literature. *J Cardiovasc Nurs*. 2012;27(1):33-43.
doi:10.1097/JCN.0b013e318216a6e9.
79. Barnason S, Zimmerman L, Young L. An integrative review of interventions promoting self-care of patients with heart failure. *J Clin Nurs*. 2012;21(3-4):448-475.
doi:10.1111/j.1365-2702.2011.03907.x.

80. Dansky KH, Vasey J, Bowles K. Use of telehealth by older adults to manage heart failure. *Res Gerontol Nurs*. 2008;1(1):25-32. doi:10.3928/19404921-20080101-01.
81. Koelling TM, Johnson ML, Cody RJ, Aaronson KD. Discharge education improves clinical outcomes in patients with chronic heart failure. *Circulation*. 2005;111(2):179-185. doi:10.1161/01.CIR.0000151811.53450.B8.
82. Hägglund E, Lyngå P, Frie F, et al. Patient-centered home-based management of heart failure : Findings from a randomized clinical trial evaluating a tablet computer for self-care , quality of life and effects on knowledge. *Scand Cardiovasc J*. 2015;7431(October). doi:10.3109/14017431.2015.1035319.
83. Oosterom-Calo R, Abma T a, Visse M a, Stut W, Te Velde SJ, Brug J. An interactive-technology health behavior promotion program for heart failure patients: a pilot study of experiences and needs of patients and nurses in the hospital setting. *JMIR Res Protoc*. 2014;3(2):e32. doi:10.2196/resprot.3188.
84. Seto E, Leonard KJ, Cafazzo J a, Barnsley J, Masino C, Ross HJ. Mobile Phone-Based Telemonitoring for Heart Failure Management: A Randomized Controlled Trial. *J Med Internet Res*. 2012;14(1):e31. doi:10.2196/jmir.1909.
85. Koehler F, Winkler S, Schieber M, et al. Telemedical Interventional Monitoring in Heart Failure (TIM-HF), a randomized, controlled intervention trial investigating the impact of telemedicine on mortality in ambulatory patients with heart failure: Study design. *Eur J Heart Fail*. 2010;12(12):1354-1362. doi:10.1093/eurjhf/hfq199.

86. Scherr D, Kastner P, Kollmann A, et al. Effect of home-based telemonitoring using mobile phone technology on the outcome of heart failure patients after an episode of acute decompensation: randomized controlled trial. *J Med Internet Res*. 2009;11(3):e34. doi:10.2196/jmir.1252.
87. AtlantiCare. WOW ME 2000mg© App. <http://www.atlanticare.org/index.php/community-and-patient-resources/heart-failure-self-management-app>. Accessed October 15, 2015.
88. Harman D. The aging process. *Proc Natl Acad Sci U S A*. 1981;78(11):7124-7128. doi:10.1073/pnas.78.11.7124.
89. Sneha S, Varshney U. Enabling Ubiquitous Patient Monitoring: Model, Decision Protocols, Opportunities and Challenges. *Decis Support Syst*. 2009;46(3):606-619. doi:10.1016/j.dss.2008.11.014.
90. Macabasco-O'Connell A, DeWalt DA, Broucksou KA, et al. Relationship between literacy, knowledge, self-care behaviors, and heart failure-related quality of life among patients with heart failure. *J Gen Intern Med*. 2011;26(9):979-986. doi:10.1007/s11606-011-1668-y.
91. Williams M V, Baker DW, Parker RM, Nurss JR. Relationship of functional health literacy to patients' knowledge of their chronic disease - A study of patients with hypertension and diabetes. *Arch Intern Med*. 1998;158(2):166-172. doi:10.1001/archinte.158.2.166.

92. Birru MS, Monaco VM, Charles L, et al. Internet usage by low-literacy adults seeking health information: An observational analysis. *J Med Internet Res*. 2004;6(3):1-17. doi:10.2196/jmir.6.3.e25.
93. Schprechman JP, Gathright EC, Goldstein CM, et al. Health literacy and global cognitive function predict e-mail but not internet use in heart failure patients. *Nurs Res Pract*. 2013;2013:507910. doi:10.1155/2013/507910.
94. Charness N, Boot WR. Aging and Information Technology Use. Potential and Barriers. *Assoc Psychol Sci*. 2009;18(5):253-258.
95. Charness N, Kelley CL, Bosman E a, Mottram M. Word-processing training and retraining: effects of adult age, experience, and interface. *Psychol Aging*. 2001;16(1):110-127. doi:10.1037/0882-7974.16.1.110.
96. Melenhorst A-S, Rogers W a, Bouwhuis DG. Older adults' motivated choice for technological innovation: evidence for benefit-driven selectivity. *Psychol Aging*. 2006;21(1):190-195. doi:10.1037/0882-7974.21.1.190.
97. Selwyn N. The information aged: A qualitative study of older adults' use of information and communications technology. *J Aging Stud*. 2004;18:369-384. doi:10.1016/j.jaging.2004.06.008.
98. Pan S, Jordan-Marsh M. Internet use intention and adoption among Chinese older adults: From the expanded technology acceptance model perspective. *Comput Human Behav*. 2010;26(5):1111-1119. doi:10.1016/j.chb.2010.03.015.

99. LeRouge C, Ma J, Sneha S, Tolle K. User profiles and personas in the design and development of consumer health technologies. *Int J Med Inform.* 2013;82(11):e251-e268. doi:10.1016/j.ijmedinf.2011.03.006.
100. D. Lewis, G. Eysenbach, R. Kukafka, P.Z. Stavri HBJ. *Consumer Health Informatics.* Springer, New York. 2005:8-21.
101. Roberts D, Berry D, Isensee S, Mullaly J. Designing for the User with OVID: Bridging the Gap Between Software Engineering and User Interface Design. September 1998. <http://dl.acm.org/citation.cfm?id=552267>. Accessed November 5, 2015.
102. Ryan EB, Szechtman B, Bodkin J. Attitudes toward younger and older adults learning to use computers. *J Gerontol.* 1992;47:P96-P101.
103. Mao J-Y, Vredenburg K, Smith PW, Carey T. The state of user-centered design practice. *Commun ACM.* 2005;48(3):105-109. doi:10.1145/1047671.1047677.
104. Verhoeven F, Steehouder MF, Hendrix RMG, Van Gemert-Pijnen JEW. From expert-driven to user-oriented communication of infection control guidelines. *Int J Hum Comput Stud.* 2010;68(6):328-343. doi:10.1016/j.ijhcs.2009.07.003.
105. Kilsdonk E, Peute LW, Riezebos RJ, Kremer LC, Jaspers MWM. From an expert-driven paper guideline to a user-centred decision support system: A usability comparison study. *Artif Intell Med.* 2013;59(1):5-13. doi:10.1016/j.artmed.2013.04.004.

106. Idoughi D, Seffah A, Kolski C. Adding user experience into the interactive service design loop: a persona-based approach. *Behav Inf Technol*. 2012;31(3):287-303.
doi:10.1080/0144929X.2011.563799.
107. Usability.gov. Personas. <http://www.usability.gov/how-to-and-tools/methods/personas.html>.
108. Nielsen L. Engaging Personas and Narrative Scenarios. *A study how a usercentered approach Influ*. 2004;215:353-380. doi:ISSN 1399 – 1779.
109. Carroll JM. Five reasons for scenario-based design. *Interact Comput*. 2000;13(1):43-60.
doi:10.1016/S0953-5438(00)00023-0.
110. Demers C, Patterson C, Archer N, et al. A simple multi-component intervention improves self-management in heart failure. *Can J Cardiol*. 2014;30(S201).
111. Valaitis R, Longaphy J, Nair K, et al. Persona-scenario exercise for codesigning primary care interventions. *Can Fam Physician*. 2014;60:294-296.
112. Bate P, Robert G, Lavis P. *Bringing User Experience to Healthcare Improvement: The Concepts, Methods and Practices of Experience-Based Design: Paul Bate, Glenn Robert, Paula Lavis: 9781846191763: Books - Amazon.ca.; 2007.*
<http://www.amazon.ca/Bringing-User-Experience-Healthcare-Improvement/dp/1846191769>.
113. Russ LR, Phillips J, Brzozowicz K, et al. Experience-based design for integrating the patient care experience into healthcare improvement: Identifying a set of reliable emotion

words. *Healthc (Amsterdam, Netherlands)*. 2013;1(3-4):91-99.

doi:10.1016/j.hjdsi.2013.07.004.

114. Bate P, Robert G. Experience-based design: from redesigning the system around the patient to co-designing services with the patient. *Qual Saf Health Care*. 2006;15(5):307-310. doi:10.1136/qshc.2005.016527.
115. The NHS Institute for Innovation and Improvement. The EBD Approach (Experienced Based Design). 4.
[http://www.institute.nhs.uk/quality_and_value/experienced_based_design/the_ebd_approach_\(experience_based_design\).html](http://www.institute.nhs.uk/quality_and_value/experienced_based_design/the_ebd_approach_(experience_based_design).html).
116. Lindsay S, Jackson D, Schofield G, Olivier P. Engaging older people using participatory design. *Proc 2012 ACM Annu Conf Hum Factors Comput Syst - CHI '12*. 2012:1199.
doi:10.1145/2207676.2208570.
117. DeWalt DA, Malone RM, Bryant ME, et al. A heart failure self-management program for patients of all literacy levels: a randomized, controlled trial [ISRCTN11535170]. *BMC Health Serv Res*. 2006;6:30. doi:10.1186/1472-6963-6-30.
118. DeWalt DA, Broucksou KA, Hawk V, et al. Comparison of a one-time educational intervention to a teach-to-goal educational intervention for self-management of heart failure: design of a randomized controlled trial. *BMC Health Serv Res*. 2009;9:99.
doi:10.1186/1472-6963-9-99.

119. Drummond D. 9 Reasons Physicians Hate EMR - The 2013 Rand Study. 2014:1.
<http://www.thehappyemd.com/blog/bid/351428/9-Reasons-Physicians-Hate-EMR-The-2013-RAND-Study>.
120. Pecci AW. EHR “Information Overload” Plagues Clinic Notes. *Heal Leaders Media*. 2015:1. <http://healthleadersmedia.com/page-1/TEC-320738/EHR-Information-Overload-Plagues-Clinic-Notes>.
121. Wilson J. Volunteering. *Annu Rev Sociol*. 2000;26(1):215-240. doi:10.2307/223443.
122. HelpGuide.org. Respite Care.
123. Lawton MP, Brody EM, Saperstein AR. A Controlled Study of Respite Service for Caregivers of Alzheimer’s Patients. *Gerontologist*. 1989;29(1):8-16.
doi:10.1093/geront/29.1.8.
124. Salin S, Kaunonen M, Astedt-Kurki P. Informal carers of older family members: how they manage and what support they receive from respite care. *J Clin Nurs*. 2009;18(4):492-501.
doi:10.1111/j.1365-2702.2008.02550.x.
125. Krum R. Designing Infographics. In: *Cool Infographics : Effective Communication with Data Visualization and Design*. ; 2013:271-303.
126. Smiciklas M. *The Power of Infographics*.; 2012.
127. Sonderegger A, Schmutz S, Sauer J. The influence of age in usability testing. *Appl Ergon*. 2016;52:291-300. doi:10.1016/j.apergo.2015.06.012.

128. Gregor P, Newell AF, Zajicek M. Designing for dynamic diversity. In: *Proceedings of the Fifth International ACM Conference on Assistive Technologies - Assets '02*. New York, New York, USA: ACM Press; 2002:151. doi:10.1145/638249.638277.
129. Nielsen J. Usability 101: Introduction to Usability. *Nielsen Norman Gr.* 2012. <http://www.nngroup.com/articles/usability-101-introduction-to-usability/>. Accessed November 6, 2015.
130. Waycott J, Vetere F, Pedell S, et al. Older adults as digital content producers. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems - CHI '13*. New York, New York, USA: ACM Press; 2013:39. doi:10.1145/2470654.2470662.
131. U.S. Department of Health and Human Services. PLAIN LANGUAGE: A PROMISING STRATEGY FOR CLEARLY COMMUNICATING HEALTH INFORMATION AND IMPROVING HEALTH LITERACY. <http://health.gov/communication/literacy/plainlanguage/PlainLanguage.htm>.
132. National Institutes of Health. Plain Language at NIH. <http://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/plain-language>.
133. Stableford S, Mettger W. Plain language: a strategic response to the health literacy challenge. *J Public Health Policy*. 2007;28(1):71-93. doi:10.1057/palgrave.jphp.3200102.

134. Lindsay S, Brittain K, Jackson D, Ladha C, Ladha K, Olivier P. Empathy, participatory design and people with dementia. *Proc 2012 ACM Annu Conf Hum Factors Comput Syst - CHI '12*. 2012;521. doi:10.1145/2207676.2207749.
135. Massimi M, Baecker R. Participatory design process with older users. *Proc UbiComp2006 Work Futur* 2006.
<http://www.cs.toronto.edu/~mikem/pubs/MassimiBaecker-Ubicomp2006Workshop.pdf>\nfile:///Users/namb24/Documents/Papers/2006/Massimi/Proc. UbiComp2006 Workshop on future ? 2006 Massimi.pdf\npapers://7913d6b8-5b9d-41de-991e-ab7ef94452e2/Paper/p335.
136. Lines L, Hone KS. Research methods for older adults. *Proc BCS HCI*. 2002.
137. Newell A, Arnott J, Carmichael A, Morgan M. Methodologies for involving older adults in the design process. *Proc HCII 2007 5*. 2007;4554:22-27. doi:10.1007/978-3-540-73279-2_110.
138. Barrett J, Kirk S. Running focus groups with elderly and disabled elderly participants. *Appl Ergon*. 2000;31(June 1999):621-629. doi:10.1016/S0003-6870(00)00031-4.
139. Gibbs A. Focus Groups. *Soc Res Updat*. 1997;Winter(19):6-11.
<http://sru.soc.surrey.ac.uk/SRU19.html>\nAccessed:26/06/2012.
140. Kindermann I, Fischer D, Karbach J, et al. Cognitive function in patients with decompensated heart failure: the Cognitive Impairment in Heart Failure (CogImpair-HF) study. *Eur J Heart Fail*. 2012;14(4):404-413. doi:10.1093/eurjhf/hfs015.

141. Bennett SJ, Sauv  MJ, Shaw RM. A conceptual model of cognitive deficits in chronic heart failure. *J Nurs Scholarsh*. 2005;37(3):222-228. doi:10.1111/j.1547-5069.2005.00039.x.
142. Mayer JM, Zach J. Lessons learned from participatory design with and for people with dementia. *Proc 15th Int Conf Human-computer Interact with Mob devices Serv - MobileHCI '13*. 2013:540. doi:10.1145/2493190.2494436.
143. Usability Body of Knowledge. Focus Group. 2012. Usability Body of Knowledge.
144. Hasson F, Keeney S, McKenna H. Research guidelines for the Delphi survey technique. *J Adv Nurs*. 2000;32(4):1008-1015. <http://www.ncbi.nlm.nih.gov/pubmed/11095242>. Accessed November 3, 2015.
145. Feiner S. What are Use Scenarios and Personas? 2015.:1.
146. Carroll J, Rosson MB, McInerney P. Scenarios in practice. *CHI '03 Ext Abstr Hum factors Comput Syst*. 2003:1046-1047. doi:10.1145/765891.766141.
147. Madsen S, Nielsen L. Exploring persona-scenarios - Using storytelling to create design ideas. *IFIP Adv Inf Commun Technol*. 2010;316:57-66. doi:10.1007/978-3-642-11762-6_5.
148. Cooper A, Reimann R, Cronin D. About Face 3: The Essentials of Interaction Design. 2007. <http://www.amazon.com/About-Face-Essentials-Interaction-Design/dp/0470084111>. Accessed November 6, 2015.

149. Calabria T. An introduction to personas and how to create them. *Step Two Des.* 2004. T.
Calabria, An Introduction to Personas and How to Create Them. Step Two Design, 2004.

For Reporting Qualitative Results

Burnard, P., Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Analysing and presenting qualitative data. *British Dental Journal*, 204(8), 429–32.
<http://doi.org/10.1038/sj.bdj.2008.292>

Appendix A: Participant Recruitment Telephone Script

Hello (Patient name),

My name is L.N. I am a student researcher working with Dr. Catherine Demers at Hamilton General Hospital. I am calling to invite you to participate in our research study to better understand how a tablet tool that we are developing could help manage your heart failure after being discharged from the hospital. This tool helps collect information on your weight, helps make decisions and teaches you and your caregiver (i.e. family member, husband, wife, or partner) about heart failure. We want to know your opinion on how we should develop this tool.

We also want information you see how nurses doing home visit could help you better understand and manage heart failure. We plan to have volunteers helping you also. We would want your ideas or opinion on how they can help you with the tablet tool.

During the discussion session, you will be paired with another patient similar to you. As a pair, you will be asked to come up with a real person “person” that is similar to you, with the same age, gender, and education. After creating this pretend person, we will ask you to come up with ideas on how you would use the tablet tool. The pretend person and what would happen to you will then be presented by each pair to the larger group and recorded for analysis.

The session will take place at Hamilton General Hospital that will last for about two hours. We will pay for your parking and a gift certificate for Shoppers Drug Mart (\$40.00/person) will be provided if you participate in this study.

If you have any questions or comments regarding the study, please do not hesitate to contact Dr. Catherine Demers at 905-521-2100 extension 73324.

Thank you.

Appendix B: Persona-Scenario Discussion Guide (similar one created for informal caregivers)

Persona Development and Discussion Guide (Patients)

This study will be conducting a self-care intervention for patients with heart failure (HF) following hospital discharge. It will be using an online system called HFApp to collect patient monitoring data, to help educate patients and their caregivers about HF and its effects, and to help patients self-manage diuretic dosage to reduce potential risks from fluid buildup.

The aim of this activity is get your assistance in the co-design of the intervention for patients who are self-managing HF and possibly other comorbidities while living at home.

The program has four components:

1. Online HF Self-Management Support System:

HFApp is an online tablet-based system that allows patients to store and access monitored data about their weight, and support their involvement in self-managing their health. Patients are able to share this information with whomever they choose, including health care providers, family members or other selected individuals, for viewing or updating information with their consent.

2. Electronic support tools

A digital tablet with a Standardized Diuretic Decision Support Tool (SDDST) decision aid and automatic weight scales will be provided to patients to assist them in monitoring their weight. The SDDST will also include a tool that helps patients to self-adjust their diuretic dose. In addition, patients will be able to access the Internet and communicate with family and friends in order to combat social isolation. In case their weight gets out of a predetermined safe zone for the patient, she/he will be urged to contact their family physicians and make office appointments to get help. In case of emergencies, patients will be urged to contact EMS immediately.

3. Trained primary health care volunteers:

The program includes trained primary healthcare volunteers as one part of its intervention. These volunteers will visit patients with HF at home and help to train them in the use of their online digital tablets to view information about trends in their weights,

and educational information about HF. Volunteers may also inform patients about community based events that they might wish to attend.

4. CCAC Rapid Response Teams for patients with HF:

This program aims to help us understand how HFApp can be used effectively to meet the needs of patients with HF and comorbidities. This will be done by combining the use of technology, social interactions with friends and family, and home nursing and volunteer support.

Note: your scenario may involve all or some of these four components.

Based on your knowledge and experience as a patient, create a fictitious (but believable) “persona” and at least one “scenario” for each “persona” interacting with the self-care intervention program. Report back to the larger group.

STEP 1: Create a Persona (10 minutes)

Your persona will be a patient with heart failure using HFApp. Give your patient- your “Persona”- some personality. Briefly describe the following:

1. a name
2. age, gender
3. education and employment background
4. desires, attitudes about work
5. years of service with current employer/organization
6. experience with primary health care team members (physicians, nurses, social workers, pharmacists, etc.,)
7. comfort and experience with technology
8. hopes and fears about HF disease management

STEP 2. Create a scenario (or 2) (20- 25 minutes)

Create a scenario (or 2) for your persona who is involved in the Program. Describe the following:

1. How does the patient persona become involved with this self-care program?
2. What are the following people doing in the scenario? (What, where, when, how?)
 - i) Patients (i.e.- In what ways are they using the HFApp?);

- ii) Health care providers (What information do they need to help manage disease and improve communication with patients?);
 - iii) Any other important characters
3. How are the components interacting? That is, how do individuals relate to each other (patients, visiting nurses, volunteers) and to the technologies [Standardized Diuretic Decision Support Tool, online contacts with friends and family]?
 4. What happens when they (all players involved) interact with the program?
 5. What happens after the interaction?
 6. What are the results / outcomes of this interaction? For patients; caregivers?

STEP 3. Report back to larger group a high level summary of your persona and scenario/s. (5 minutes per group). This will be recorded for later review.

Appendix C: Informal Feedback Discussion – Questions Asked

Do you have any feedback for how we ran the discussion today?

What did you like about the discussion today?

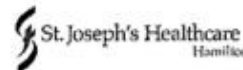
What didn't you like?

Was it easy to complete the study?

Is there any way that you would want us to improve on the discussion style?

Did you like how we ran the discussion (having it in pairs and then the larger group)?

Appendix D: Research Ethics Board Approval Form



Hamilton Integrated Research Ethics Board AMENDMENT REQUEST

REB Project #: 11-638

Principal Investigator: Dr. Catherine Demers

Project Title: Caregiver Enhanced Assistance and Support for the Elderly Heart Patient at Hospital discharge (CEASE-HF)

SUB-STUDY: A randomized controlled trial of a diuretic decision support tool for managing older heart failure patients discharged from hospital

Document(s) Amended with version # and date:

- Administrative Change - Sub-Study: A randomized controlled trial of a diuretic decision support tool for managing older heart failure patients discharged from hospital
- Protocol - Sub-Study Protocol Ver: 1 Dated: 24 June, 2015
- Consent Form - Sub-Study Patient Information/Consent Form Ver: 1 Dated: 12 June, 2015
- Consent Form - Sub-Study Caregiver Information/Consent Form Ver: 1 Dated: 12 June, 2015
- Instruments - Persona Development and Discussion Guide (Patients) Ver: 1 Dated: 24 June, 2015
- Other - PI's Letter dated June 22, 2015 clarifying the amendment

Research Ethics Board Review *(this box to be completed by HIREB Chair only)*

Amendment approved as submitted

Amendment approved conditional on changes noted in "Conditions" section below

New enrolment suspended

Study suspended pending further review

Level of Review:

Full Research Ethics Board

Research Ethics Board Executive

Conditions:

REB Project #: 11-638

Page 2 of 2 Pages

Dr. Catherine Demers

The Hamilton Integrated Research Ethics Board operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practices; Part C Division 5 of the Food and Drug Regulations of Health Canada, and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations; For studies conducted at St. Joseph's Hospital, HIREB complies with the health ethics guide of the Catholic Alliance of Canada.


Suzette Salama PhD., Chair
Raelene Rathbone, MB, BS, MD, PhD, Chair

08 July, 2015
Date of REB Meeting

All Correspondence should be addressed to the HIREB Chair(s) and forwarded to:
HIREB Coordinator
293 Wellington St. N, Suite 102, Hamilton ON L8L 8E7
Tel. 905-521-2100 Ext. 42013 Fax: 905-577-8378

Change in HiREB Process re stamping of Research Study Documents

Effective immediately we will no longer be stamping the Information Sheet/Consent Forms and recruitment materials with the REB approval stamp. This is neither a TCPS2 nor a GCP requirement and going forward with the launch of the eREB system this is the time to implement this change in practice.

We recommend you revise your internal policies and procedures to note that for recruitment/consenting you are using the most recently approved study documents. As you are aware our final approval letters and our amendments reflect the version number and date for all approved study documents.

Thank you,

*Deborah Mazzetti
HiREB Manager*

Appendix E: Persona-Scenario Session Consent Form

(similar one created for informal caregivers)



A Randomized Controlled Trial of a Diuretic Decision Support Tool for Managing Older Heart Failure Patients Discharged from Hospital

CONSENT FORM

Principal Investigator: Dr. Catherine Demers, Cardiologist

Funding: Hamilton Academic Health Sciences Organization (HAHSO) Innovation Fund

You have been diagnosed with heart failure. Heart failure often causes worsening shortness of breath during daily activities and even at rest. You may also have noticed swelling of your ankles, increasing tiredness, and weight gain.

You are being invited to participate in a research study to evaluate how you would interact with a new tool that we are developing to help manage your heart failure after being discharged from the hospital. This tool, called HFApp, helps you collect weight monitoring data, helps makes decisions and educates you and your caregivers about your heart failure.

If you agree to participate in this study, you will be asked to attend a discussion session that will take approximately 2 hours. A detailed explanation of HFApp will be given at the beginning of the session. During the discussion session, you will be paired with another patient similar to you. As a pair, you will be asked to come up with an authentic and realistic persona that resembles yourselves (e.g., a HF patient similar in age, gender and education). After creating a persona, you will be asked to create a scenario regarding how the persona is involved in the HFApp program

(e.g., how do they learn about the program? How do they interact with HFApp?). The persona and scenario will be presented by each pair to the larger group and recorded for further analysis.

The interview will take place at the hospital clinic. A paid parking voucher and a gift certificate (\$20.00) will be provided if you take part in this study.

The interview will be recording using a digital recorder and transcribed.

Your participation in this study is entirely voluntary and will not affect the medical care that you are entitled to. You are free to refuse to participate or withdraw from the study at any time without any penalty. All our information will be stored in a secure manner to respect patient privacy and confidentiality. As this information is anonymous, it may still be used for analysis. All information obtained as part of the study will be kept confidential, and only used for research purposes. Your name will not be used on any report generated from this study. A copy of the consent form will be left in your hospital chart. You will also be provided with a copy of the consent.

If you have any questions regarding the study, please contact Dr. Catherine Demers at 905-521-2100, extension 73324. If you have questions regarding your rights as a research participant, you may contact the Hamilton Health Sciences, Faculty of Health Sciences, Office of the Chair at 905-521-2100, extension 42013.

Patient Consent

This study has been explained to me, and any questions that I had have been answered.

I know that I may leave the study at any time. I agree to take part in this study.

_____	_____	_____
Patients Name (Printed)	Patients Signature	Date

_____	_____	_____
Person Obtaining Consent (Printed)	Person Obtaining Consent (Signature)	Date

_____	_____	_____
Investigator (Printed)	Investigator (Signature)	Date

Appendix F: Personas and Scenarios Created by Patient Participants with HF and their Informal Caregivers

Larry (Patient Persona)

Background: Larry is 56 years old and was diagnosed with HF last year. He has a college education and completed some extra financial studies.

Description: Larry currently has one family computer at home. Larry is concerned about his health. He understands the importance of weight information and water retention control. He is also willing to absorb new HF knowledge.

Scenarios:

Larry was visited by a CCAC nurse after heart surgery and finds out about HFApp. Generally, he is feeling well but he realizes the importance of weight and water retention information and that he must weigh himself.

Larry is comfortable using a tablet because the children in his house already have a tablet and he is familiar with it.

Larry uses the app in order to gain guidance. He is willing to absorb new HF knowledge. He also wants to have medical guidance if something goes wrong.

Larry's wife or companion is also involved in using HFApp. Key people in his life are aware of his HF-related information. If something goes wrong, and the informal caregiver cannot be there to help, another person must be able to take over.

Larry uses HFApp right after breakfast, making it part of his routine. He gets up, goes to the washroom, steps on the scale, gets off, gets dressed, goes down and eats breakfast.

Larry wants to feel good in terms of his health. When he feels good, he also wants to be able to maintain it.

Larry would like to receive visits from CCAC nurses or volunteers to help ensure that he is doing his self-care activities properly. He also would like to have them as somebody to talk to. He thinks that these visits could provide him with more self-care strategies.

Lloyd Gary (Patient Persona)

Background: Lloyd Gary is 78 years old. He completed high school and went on to become a carpenter. Lloyd Gary worked with his employer for over 30 years.

Description: Lloyd Gary is not comfortable conducting his own self-care and believes that a healthcare provider should be present. Lloyd Gary has past experience using a computer.

Scenarios:

Lloyd Gary finds out about HFApp from his family doctor.

Lloyd Gary will be at home when he uses HFApp. He would access HFApp around the afternoon time. The spouse caregiver will be present, and if that is not enough, the child caregiver will also be there.

In order to manage his HF, Lloyd Gary knows that the doctors often check for his pulse and heartbeat. However, he does not know much about his diuretic medication. Lloyd Gary wants a nurse to come visit him weekly at his home to help him with his medication.

Lloyd Gary wants to use HFApp as a tool to contact family and friends, through online communication.

Once Lloyd Gary is comfortable using HFApp and finds it easy enough to use, he sees himself using it over a long period of time.

Personas and Scenarios Created by Informal Caregiver Participants

Phyllis (Informal Caregiver Persona)

Background: Phyllis is 65 years old and was educated up to Grade 11. She works at Bell Telephone and has been there for 35 years.

Description: Phyllis is familiar with healthcare teams and would like to gain as much information from them as possible. Her patient's activity is very low. Her patient has constant signs of dizziness and instability and spends a lot of time sleeping. The patient struggles with depression and frustration on a daily basis. The patient gets along with the healthcare workers but not with family members due to dementia.

Scenarios:

Phyllis wants to have answers regarding concerns, diet, blood pressure, and general health.

Phyllis wants volunteers to help with technology, teach computer skills, provide step-by-step instructions or stay with the patient if she (Phyllis) has to leave the house. Volunteers do not need to be there all the time, and can visit in an on-call manner instead.

Phyllis wants all the people involved in the patient's care to have access to the patient's health information to ensure better understanding of the condition, medications, etc.

Mary (Informal Caregiver Persona)

Background: Mary is 78 years old and has a college education. She was self-employed for over 25 years and is currently retired.

Description: Mary has constant fears and hopes for her patient with HF. She finds it difficult to communicate with the patient. Mary has to remind the patient of daily medications, watch for sodium intake, control potassium intake, and manage food consumption. Mary is reluctant to change her current working habits. Mary has access to a computer at home.

Scenarios:

When Mary uses HFApp for the first time, the nurse will visit to help both the patient with HF and informal caregiver understand the purpose of HFApp. After the first time, further visits will depend on their individual needs. The nurse gives her a feeling of relief and security. For example, subsequent monthly visits from nurses can help answer questions that Mary has collect over the month. Some questions could involve medication effects or how to deal with the patient. Mary believes that it is important to have a third person's input (in addition to the input provided by the patient and herself).

Mary wants volunteers to visit to provide relief from her caregiving duties. For example, if the patient is not very mobile, the volunteers can help with transportation. Mary also wants some free time for herself. If she wants to leave the house for one or two hours, the volunteer will be there to take her place.

Mary has a schedule for times that nurses and volunteers will come to visit. This helps her plans things better in general.

Mary wants to connect to a specialist through HFApp when required.