PUTTING THE PATIENT FIRST: SELF-CARE APP FOR HEART FAILURE
Qualitative Data Collection For Development Of An Electronic Application To Promote Home-Based Self-Care In Older Heart Failure Patients: Patient And Informal Caregiver Perspectives

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

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TITLE: Qualitative data collection for development of an electronic application to promote home-based self-care in older heart failure patients: patient and informal caregiver perspectives

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Lay Abstract

Heart failure (HF) is one of the leading causes of hospitalization and re-hospitalization in older adults. If patients are able to take care of themselves (self-care) at home they will be less likely to be readmitted to the hospital. However, many patients find self-care difficult, so they do not manage their symptoms.

To assist patients in understanding or following their treatment, various mobile health applications have been developed. Unfortunately, older patients do not commonly use these applications because of their complicated design.

In this study, we interviewed patients and their informal caregivers to help design our HF self-care app. We gathered information on features they may perceive to be helpful. Our goal was to use their feedback to make the app simpler and more user-oriented, which will make self-care easier.
Abstract

Heart failure (HF) affects many older Canadians with recurrent hospitalizations despite post-discharge strategies to prevent readmission. Self-care is key to the management of HF in the home setting and can potentially lead to better clinical outcomes. Proper HF self-care includes tasks such as daily weight and symptom monitoring, as well as adjusting diuretics based on weight. Patients find HF self-care challenging, with less than 50% of patients regularly weighing themselves.

Mobile applications to support self-care have been shown to be effective, however, due to their lack of consideration for barriers such as literacy, numeracy and cognitive impairment within their design, these applications are not usable for many older patients. Previous work supports the use of a paper-based standardized diuretic decision support tool (SDDST) to promote self-care in older individuals with HF. The objective of this study was to use participant (HF patients, informal care-providers) input to convert the paper-based SDDST into a user-centered electronic mobile application.

We recruited 12 patients (male and female, age > 60 years) with a confirmed diagnosis of HF, and 7 informal caregivers from the Heart Function Clinic at the Hamilton Health Sciences General site. HF patients were categorized into three groups, 1) adequate self-care patients (6), 2) inadequate self-care patients without a CP (2) or 3) inadequate self-care patients with a CP (4), based on their self-care abilities measured with the Self-Care Heart Failure Index (SCHFI) where a score of > 70 is considered self-care adequate. We conducted semi-structured interviews with HF patients and CPs using
Persona-Scenarios. Interviews were analyzed using NVivo, version 10, for emerging themes regarding self-care.

Following data analysis, we identified 6 major themes, 1) Usability of technology, 2) Communication, 3) Application customization, 4) Complexity of Self-Care, 5) Usefulness of HF Related Information and 6) Long-Term Use and Cost. Many of the challenges patients and CPs mentioned involved their unfamiliarity with technology. However, by addressing these themes, we were able to develop a series of requirements and modifications to improve the usability of our app design.

Keywords: mHealth, eHealth, Heart Failure, Self-care
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List of Abbreviations and Acronyms

App – Abbreviation for Application

CC-SCHFI – Caregiver Contribution Self Care Heart Failure Index

EHFScBS - European Heart Failure Self-Care Behavior Scale

EMR – Electronic Medical Record

HF – Heart Failure

HFApp – Abbreviation for heart failure self-care application being designed. This refers to the intervention as a whole (app, weight scale, nurse and volunteer assistance)

HHS - Hamilton Health Sciences

HR- Hazard Ratio

mHealth – Mobile Health

PAM -- Patient Activation Measure

PI – Principal Investigator

RCT – Randomized Control Trial

SCHFI – Self Care Heart Failure Index

SDDST – Standard Diuretic Decision Support Tool

UC- Usual Care
UCD – User-Centered Design

WHO – World Health Organization
Declaration of Academic Achievement

The following is a declaration that the work presented in this thesis was completed by Sahr Wali. Guidance at all stages of the research (study design, data collection, data analysis) conducted for this thesis was provided by Dr. Catherine Demers, Dr. Reza Samavi, Dr. Lawrence Mbuagbaw, and Dr. Karim Keshavjee. Sahr Wali was responsible for writing this manuscript. Dr. Catherine Demers, Dr. Reza Samavi, Dr. Lawrence Mbuagbaw, and Dr. Karim Keshavjee contributed to manuscript review and revisions.
Chapter 1: Introduction

1.1 The Problem, Motivation and Objective

Heart failure (HF) currently affects over 1% of Canadians, costing the healthcare system over 2.8 billion/year, with hospital readmissions representing 70% of these costs\(^1\)\(^2\). To reduce readmissions, self-care is key to the management of HF as it can potentially improve clinical outcomes. However, patients view HF self-care as both challenging and intimidating\(^3\)-\(^5\). Moreover, to promote self-care, technology-based interventions showed great promise, as they would be able to automate several difficult steps, yet the same issues continued to arise as the self-care process remained complex.

The motivation for this study focused on how we would be able to simplify the self-care process to promote adherence, instead of burdening patients to go beyond their capabilities. Our primary objective was to obtain feedback from HF patients and their informal caregivers to identify key requirements for the design of our electronic HFApp intervention.

1.2 Research Questions

1) What are the needs of HF patients and informal caregivers to promote self-care within their daily lives?

2) What features would address these needs?

3) How should these features be designed?
1.3 Thesis Structure

Chapter 1: Introduction

Overview regarding the rise in HF and its resultant effects on both patients and the healthcare system, followed by the importance of HF self care and the shortcomings of current self-care interventions.

Chapter 2: Background

In this chapter, a review of previous literature on HF self-care, patient challenges/barriers and current technology-based interventions builds the foundation for our rationale and chosen study design.

Chapter 3: Project Objective, Overview and Hypothesis

A summary of study design outlines how patients and CPs will be interviewed to evaluate effectiveness of HFA pp and determine other design requirements. Hypothesize that this method will lead to a more effective intervention design to promote self-care.

Chapter 4: Methods and Study Design

A detailed version of qualitative study outlines study’s population (both patients and CPs), recruitment, sample size calculation and participant categorization. This leads to description of participant interviews outlining instruments used and use of NVivo for data analysis.

Chapter 5: Results and Major Findings
The study results are presented in three major sections. First, an outline of the participant characteristics is displayed regarding 1) patient baseline characteristics, 2) participant self-care characteristics and 3) patient medication information. The resultant 6 design themes from the discussion session’s thematic analysis are then explained in-text and summarized in Table 4. The final result section identifies the summarized actions and items for the HFApp’s modifications.

Chapter 6: Discussion

The discussion is then separated into 8 major sections and discusses the results in the context of the study’s primary objective. The first 6 sections explain the significance of each of the 6 design themes and how it relates to the design of the HFApp. The final 2 sections outline the strengths and limitations of the overall study.

Chapter 7: Conclusion

The final chapter is an overview of the problem to be addressed and how our study aimed to address it. The results of the study and its significance according to the issue are then summarized, and a series of future steps to apply our findings and improve the intervention are outlined.
Chapter 2: Background and Literature Review

2.1 Prevalence of the Disease and Risk of Readmission

HF has been defined as a global epidemic affecting 26 million individuals worldwide. In North America, HF is the most important cardiovascular condition leading to hospitalization and re-hospitalization in older adults. With the rise in the aging population, these rates are estimated to increase over the next decade, leading to a significant burden on both clinical outcomes and healthcare expenditures. Patients with HF currently have longer hospital stays and up to 50% of them are readmitted within 3-months post-discharge. This leads to HF accounting for 2% of our annual healthcare costs, (2.8 billion/year) with hospital admissions representing approximately 70% of the cost for treatment. Therefore, as the prevalence of the disease continues to rise, the risk of patient readmission, and its resultant economic burden, will increase as well.

2.2 Reasons for Heart Failure Readmission

HF is a complex disease and many factors can lead to patient readmission. Traditionally, HF-related readmission is attributed to worsening symptoms and clinical deterioration. However, to improve patient outcomes it is important to understand various perspectives regarding the reasons leading up to HF readmission. Most studies focus solely on the health care professional’s input, but tend to minimize the important role patients and their informal caregivers (spouse, family, friend) play in the self-care
process. In one study, investigators collected data from patients, informal caregivers, nurses and cardiologists to evaluate the different perspectives regarding the reasons for readmission (8). Worsening HF was categorized as the most frequent factor amongst all 173 participants (8). Nonetheless, other reasons including co-morbid diseases (diabetes, hypertension), knowledge deficits, and poor adherence to medications, diet or fluid restriction were also reported as important contributing factors to patient readmissions (8). Despite all the listed factors, this study indicated that greater than 30% of the readmissions could have been prevented solely if treatment adherence was higher (8). This highlights the importance of managing HF symptoms and the bigger picture that is HF self-care.

2.3 Importance of Heart Failure Self-Care

Self-care is a decision-making process involving behaviors to maintain physiological stability in the face of disease, and an appropriate response to symptoms when they occur (13-16). In HF, self-care combines three main areas that include 1) self-maintenance, 2) self-management and 3) self-confidence (3). Self-maintenance comprises actions associated with treatment adherence (taking medication or following treatment regimens) (15). Self-management includes the recognition and response to changes in symptoms (adjusting diuretics according to weight changes). Finally, self-confidence refers to the individual’s assurance in their decisions during the management process (15). The self-care process can be summarized below in Figure 1.
Figure 1. The Heart Failure Self-Care Process (Adapted from Riegel et al. 2006)

The importance of self-care has been strongly supported in literature indicating that HF readmissions can be reduced if patients are able to recognize and address HF symptoms and signs in the home setting \(^{(17-19)}\). In a systematic review (20 randomized control trials [RCTs], 5624 patients), they compared the use of self-management interventions to usual care (UC) and found decreased HF-related hospitalization (hazard ratio, HR, 0.80; 95% CI, 0.71-0.89) as well as reduced mortality (HR, 0.99, 95% CI 0.97-0.999) in the intervention group \(^{(19)}\). This study showed that the promotion of self-care could lead to reduced hospital readmissions and improved clinical outcomes \(^{(19)}\).
2.4 What Does Heart Failure Self-Care Include?

Proper HF self-care is composed of a series of tasks such as daily weight and symptom monitoring, as well as adjusting diuretics based on patient symptoms (20). Weight control is a pivotal component of HF self-care, as patients often experience weight gain which leads to worsening clinical outcomes and increased risk of readmission (21). To effectively manage weight fluctuations and reduce fluid overload manifested by peripheral edema, loop diuretics, most commonly furosemide, remain the agent of choice for treatment (31). Loop diuretics are a form of central therapy that interferes with the transport of salt and water in the kidneys to increase fluid excretion (22-25). This results in reducing HF patient symptoms such as the shortness of breath and leg swelling (25). The uses of these diuretics are further explained in section 1.4.1.

In the ASCEND-HF RCT they analyzed this relationship between weight and clinical outcomes by examining in-hospital versus post-discharge weight changes and the resultant outcomes among hospitalized patients. They found that increased body weight was independently associated with a worse post-discharge prognosis and a higher risk of 180-day mortality (hazard ratio per kg increase 1.16; 95% CI: 1.09 to 1.23; p < 0.001) (21). With a gain of 2-5lbs the odds of readmission increased by almost 3-fold, and 5-10lbs raises the odds of readmission almost 5-fold (26).

2.4.1 Managing Heart Failure Symptoms: The Use of Loop Diuretics

Loop diuretics have been shown to promptly improve symptoms including dyspnea scores and peripheral edema (27). Nevertheless, the use of these agents also has
side effects, including volume depletion, worsening renal function and potentially dangerous electrolyte disturbances that can precipitate life-threatening arrhythmias \(^{(28-30)}\). If patients are given a higher diuretic dosing during HF hospitalization, this has been shown to lead to increased mortality and poorer 6-month outcomes \(^{(31)}\). Therefore, it is essential that the correct diuretic dosage be carefully adjusted for each patient to optimize volume status without compromising renal function. In the outpatient setting, this adjustment is traditionally carried out by physicians or specialized RNs, according to their clinical judgment. However, as part of HF self-care, patients should be empowered to adjust their own diuretics based on their symptoms and weight in the home setting \(^{(16)}\).

### 2.4.2 Evaluating Patient Self-Care Abilities

Various questionnaires have been developed to help evaluate patients on their ability to manage their care and how it relates to the frequency of exacerbations of their disease \(^{(15,32,33)}\). Specifically, patient activation and self-care are the most common areas included within an evaluation. To further discuss these concepts the patient activation measure (PAM) and the self-care of heart failure index (SCHFI) will be further explained below.

The PAM, developed by Dr. J. Hibbard, is used to reflect an individual’s knowledge, skill and confidence for managing their own health care \(^{(32,34)}\). The PAM is comprised of 13 health-related questions where a patient’s level of activation is then categorized into four stages from low to high. An individual’s relative PAM score indicates their willingness and ability to self-care their health conditions \(^{(32)}\). However, a
The patient’s PAM score does not account for the frequency of disease exacerbations (i.e. condition getting worse), which in turn can result in compromising the reliability of the PAM in predicting disease progression or prognosis. Patient self-care is strongly related to their current clinical condition and state of disease (35). Without consideration of a patient’s on-going condition, the PAM scores cannot give an accurate assessment of their ability to manage their care and how it will affect their clinical stability or future readmissions.

The SCHFI, developed by Dr. B. Riegel, is a validated tool that is used to measure an individual’s naturalistic decision-making process and evaluates their self-care abilities (15). The SCHFI is composed of a set of 22 symptom related questions that are rated on a 5-point scale (15, 36). Patient self-care ability is divided into self-maintenance, self-management and self-confidence, as outlined in Figure 1. Adequacy is then categorized, where a patient score of >70 would be considered self-care sufficient (15, 36). The SCHFI takes greater account of the patient’s condition and how it associates with their ability to self-care. Patient self-care adequacy can then be progressively measured in the SCHFI to continually account for these factors, in comparison to the PAM, which only considers how the patient perceives their own abilities. For this reason, we have decided to use SCHFI to categorize patients on their self-care and not their initial activation.

Similar to the SCHFI, there is also the European Heart Failure Self-Care Behavior Scale (EHFScBS). The EHFScBS, developed by Tina Jaarsma, is a 12-item scale developed to measure HF self-care behaviors (33, 37, 38). The SCHFI and EHFScBS are the only 2 disease specific measures that have undergone psychometric testing in HF.
populations. Both scales demonstrate similarities in their design and evaluative outcomes, however, a review of the psychometric properties in both clinical instruments indicated that SCHFI had a higher level of validity compared to the EHFSceBS, hence it's use in this study.

2.5 Challenges Associated with Patent Self-Care

Studies indicate that readmissions can be reduced if patients are able to self-care at home, however, many older adults find self-care challenging, with less than 50% of them regular weighing themselves. This is due to factors such as, the absence of an informal care partner (CP), poor economic stability (ability to afford medications), presence of co-morbidities, and limited knowledge regarding signs and symptoms.

Amongst many HF patients, cognitive impairment has also become a rising factor contributing to poor clinical outcomes. Cognitive impairment involves various domains that may interfere with daily functioning and the active decision-making process to maintain health behaviors. In a systematic review (n = 26 studies, 4176 participants), it was found that 43% of older adults with HF showed strong evidence of cognitive impairment (95% confidence interval 30-55). The presence of cognitive impairment was associated with reduced ability to self-care, poor adherence to prescribed medications, lower self-care confidence and increased risk of hospitalization.

These results suggest that without addressing these factors, patients will fail to properly manage their symptoms and delay seeking proper support.

2.6 Promoting Self-Care: Understanding the Patient’s Needs
Several studies have reported that patients with HF can improve their self-care behaviors, however, the optimal method to promote self-care has not been identified (17). In an individual patient data meta-analysis (20 RCTs, 5624 patients), investigators evaluated self-care interventions in HF patients and described that the effectiveness of the intervention varied depending on patient involvement (17).

To understand the patient perspective, systematic reviews examined the personal aspects affecting patient self-care decision-making (39,44,45). They found that patient values were integral to how the patients approached and responded to the severity of their symptoms (39). These values were related to a range of personal and social factors (44). Future interventions cannot assume that patient values are fixed, normative or similar to those held by nurses and other health professionals (44). To improve HF self-care, just providing HF self-care knowledge alone or assuming the complexity of patients’ values is non-contributory will not lead to improvements (44). Instead, to improve self-care adoption, health care professionals should better understand the barriers and facilitators HF patients face, and incorporate strategies tailored to addressing those needs (Figure 2). In a literature review, they specifically identified eight major factors that should be considered to promote self-care, this includes 1) experience and skills, 2) motivation, 3) habits, 4) cultural beliefs and values, 5) functional and cognitive abilities, 6) confidence, 7) support and 8) access to care (Figure 2). Incorporating these into a self-care promotion strategy will help develop an effective self-care promotion strategy.
2.7 The Influence of Others: How Informal Caregivers Can Help

Promote Self-Care

The complexities of self-care may cause many older adults to require greater assistance to manage their condition\(^{(46)}\). Promoting self-care alone may not be enough to improve clinical outcomes, because when HF symptoms worsen, the patient's capacity to perform self-care can be exceeded\(^{(46)}\). Studies have recognized the pivotal role of
informal care providers (CPs), such as a spouse, family member, friend interacting with patient 4 times a week for more than one hour per encounter, in providing on-going care when self-care process becomes too demanding \(^{(46-50)}\). Patients who live alone or lack supportive CP assistance are more vulnerable to poor self-care, social isolation and mortality \(^{(51)}\). A systematic review found that CPs contributed substantively in influencing patient outcomes, increasing adherence and improving overall self-care for patients with HF \(^{(48)}\).

To quantify the role of the CP, similar to the patient SCHFI, the caregiver contribution to self-care of HF index (CC-SCHFI) was developed \(^{(17)}\). The CC-SCHFI is composed of 22 questions and measures the informal caregiver’s contribution to the patient’s self-maintenance, -management and –confidence \(^{(17,52)}\). CPs play a pivotal role in assuring the quality of the patient’s self-care, thus it is important that we are able to identify whether they are effectively performing their role.

CPs often experience complex problems when providing support for the HF patient, which can impact all aspects of their lives \(^{(53)}\). In a literature integrative review, it was found that CPs endure four main problems including, 1) performing multifaceted activities/roles to meet daily HF demands, 2) difficulty in maintaining physical, emotional, social and financial well-being, 3) insufficient CP support and 4) inadequate knowledge to effectively manage patient HF conditions \(^{(53-55)}\). Past studies indicate that CPs are usually absent when patients receive HF information during hospital discharge, making it difficult to reduce these negative CP outcomes \(^{(53,56,57)}\). This is very concerning
for patient outcomes, as patient health conditions can often prevent their ability to understand or retain the information they receive from their health care provider \(^{(57)}\). Therefore, without proper CP support, they are in a vulnerable position \(^{(57)}\).

To maximize the beneficial presence of the CP, they should be well informed and engaged with self-care requirements. One area that has been shown to be effective in achieving this goal is technology-based interventions, as they managed to increase patient self-care while reducing CP burden \(^{(58)}\).

### 2.8 Technology to Support Heart Failure Self-Care

Technology can provide effective solutions for both patients and CPs to manage their HF at home \(^{(59, 60)}\). The initial motivation for self-care technology development was derived from the cost-effectiveness evidence from home-based interventions \(^{(61)}\). This was evident in the “Which Heart Failure Intervention Is Most Cost-Effective & Consumer Friendly in Reducing Hospital Care (WHICH)” study, where they demonstrated how a home-based intervention provided equivalent results in reducing hospitalization as a clinic-based intervention, except the home-based intervention was more cost-effective. \(^{(61)}\). However, these interventions were limited in their supportive ability, due to the patients’ overall treatment burden and potential learning challenges. Thus, to minimize the limitations of home-based interventions and advance their perceived benefits, several health technology vendors have begun developing applications to accommodate patient needs and simplify the self-care process \(^{(62)}\).

#### 2.8.1 Use of Mobile Health Applications to Promote Self-Care
One of the largest areas of technology-based interventions is mobile health (mHealth). In today’s society, mobile phones have reached a high penetration where an estimated 67.7% of adults across different socioeconomic and demographic groups own a smartphone (63). As of 2012, 69% of older adults over the age of 65 owned a mobile phone and this number is estimated to increase substantively with the rise in the aging population (64). The use of mHealth applications (apps) provides individuals with a simple and accessible way to manage their health at the tip of their fingers (65). Both the World Health Organization (WHO) and the American Heart Association have made mHealth technology an area of focus for healthcare, as it promises the opportunity to remotely provide patients with a consistent way to be engaged in their own self-care (66). In support of this promise, several studies have shown that by providing education, influencing health behaviors and promoting treatment adherence, health apps have improved clinical outcomes (67-70).

With respect to HF, there have been a number of studies that have developed and tested the effectiveness of mHealth technologies in improving patient self-care. In a pilot study, investigators tested the use of the “Penn State Heart Assistant” that recorded HF patients’ medication, weight and exercise information, while providing a short educational video (66). They found that patients using the device had an increase in medication adherence and exercise, with no persistent weight gain over 30 days (66). In a systematic review, they evaluated the current mHealth apps available for cardiovascular disease, including HF, and found that patients using mHealth apps had greater treatment adherence compared to UC (Odds ratio, 4.51; 95% CI, 2.38-8.57; P< 0.001) (3). Thus, the
results from both these studies highlight the effectiveness and potential of mHealth technology to support HF self-care.

2.8.2 Barriers to Technology Usage Amongst Older Adults

The increasing popularity of mHealth technology has led to more than 3 billion health app downloads across the two major app stores (Google PlayStore and Apple iTunes App Store) (62). Many health care professionals use mHealth apps on tablets or other mobile devices to assist with patient self-care (71). However, despite the growing hype of mHealth technology, older adults still do not commonly use apps due to the perception that they’re not suited to their needs or capabilities (3, 62, 72, 73).

As previously mentioned, older adults with HF have complex needs due to the presence of co-morbidities, limited knowledge or some degree of cognitive impairment. With respect to technology use, older adults commonly have low levels of health and computer literacy, as well as visual and hearing challenges, all of which contribute to their poor use of technology (72, 74, 75). In a systematic review, it was found that an average of 39% of HF patients had low levels of health literacy, which in turn was related to poor HF self-care knowledge and practice (72). The use of mHealth apps was supposed to increase patient’s ability to access and understand health information, however, there is a large discrepancy between the education provided on apps and the patient’s level of understanding. This discrepancy with the apps’ design, in addition to factors highlighted above, creates a large barrier for older adults to use any source of technology (71-75). Health apps should be created to accommodate these conditions, but unfortunately, app
developers have failed to design according to the patient, leaving the majority of individuals at a disadvantage\(^{43,76}\).

In a literature review, 10 specific factors were identified as the main contributors to the lack of mHealth app uptake amongst older adults. This includes, 1) conflicting information from physicians and app \(^{77}\), 2) complicated language/education \(^{78}\), 3) unfriendly user-interface (e.g. small fonts, lack of visual/hearing considerations)\(^{79}\), 4) required manual data input \(^{80}\), 5) meaningless information, 6) daily use not required \(^{80}\), 7) no incentives for use (cost savings or social approval), 8) data collected not valued by physician \(^{81}\), 9) no way for physicians to use data collected \(^{81}\) and 10) no way to integrate app data into electronic medical record (EMR) for analysis or follow-up \(^{82}\).

To be effective, apps must move from quantity to quality, and this starts by addressing the 10 factors indicated above. We have summarized our recommendations for the design of an effective health app with the inclusion of the following 6 attributes, 1) user-centered design \(^{83-84}\), 2) prescription of the app by the physician as part of treatment plan \(^{85}\), 3) integration of app with EMR for optimal management, 4) designed with evidence that is proven to work in a clinical setting, 5) not require manual data input and 6) required to be used daily. By addressing these attributes and moving forward with a patient-centered design, it is expected that usability for older adults, who may be challenged by technology, will improve \(^{72}\).

**2.8.3 What’s Out There? – Review of Current HF Apps Available**

Previous studies found that there were a limited number of health apps available
to support HF self-care \(^{(86, 87)}\). To further evaluate the current HF-related apps, we conducted a systematic review of apps, using a peer-reviewed mHealth reference architecture, to determine whether they met the 6 outlined criteria for an effective HF self-care app \(^{(88)}\). In accordance with this reference architecture, we developed a list of 25 major functions reflecting the 6 criteria to promote HF self-care \(^{(88)}\) (Appendix A). For an app to be considered effective, all 25 major functions did not have to be met, but instead, app adequacy was determined if it included (1) diagnosis, (2) weight, (3) behavior tracking, (4) self-care and (5) notifications component.

As a result, we identified a total of 74 HF self-care apps, however, none met all the functional criteria and only 23% (17/74 apps) included the key weight management feature. In addition, none of the apps reviewed included any visual or hearing impairment considerations in their design. The HF apps user-interface was judged to be very complex and inadequate for patients with cognitive impairment to use. These findings support the results from previous literature reviews and highlight the need for an effective user-centered HF self-care app.

### 2.9 Designing for the Patient: Technology Development Models

It has become evident that mHealth technology can improve HF self-care and overall quality of life \(^{(72)}\). However, technology-based solutions can be ineffective due to the delivery, engagement and design of the intervention \(^{(66)}\). Studies suggest that if apps are designed in a participatory approach, where patients are engaged throughout the design process, overall effectiveness and usability of the apps will be improved \(^{(66, 72)}\).
This concept involving patients in a participatory approach helps define the framework for user-centered design (UCD). The goal of UCD is to envision the way end-users will utilize the product to ensure it meets their needs, wants and capabilities in the real world \(^{(89)}\). To accomplish this, a series of tests are conducted with users to identify and refine design requirements both pre and post-development. The development process first outlines the need/objective for its development and how it would fit within the environment, then it defines and evaluates more specific components such as features and application flow \(^{(89)}\). By involving users and refining these components according to their feedback this will lead to increased product usefulness and usability, compared to when users are forced to change to accommodate to the product \(^{(89)}\).

### 2.9.1 Co-Designing mHealth Interventions

Co-design is an example of UCD. It is an iterative process where end-users work together to design and develop all aspects of an intervention \(^{(90)}\). This collaborative method allows for an application to be refined based on the needs of its end-users, instead of scientific validation from health care professionals \(^{(91,92)}\). Often times, the hype of innovation overshadows the requirements for adequate usability, leaving a number of apps with lost potential. The use of co-design allows self-care interventions to move from being solely educational to empowering \(^{(65,66)}\). This concept of patient empowerment is a key process that enables individuals to conduct a behavior change with confidence \(^{(90)}\). By obtaining patient input and allowing them directly design the tool; this will help them to use their abilities to be the managers of their own health. Empowerment goes beyond just
engaging with patients, but instead it focuses on how to help them gain control and act on issues in their own lives.

Nevertheless, many mHealth interventions fail to even engage with patients during testing, let alone in the design and usability stages\(^\text{93}\). In a Delphi study, investigators conducted a literature review and found that many innovation studies obtained feedback from patients, but they failed to adjust their design/strategies according to the input obtained\(^\text{94}\). Older adults with HF already face challenges when using technology, thus it is not enough to simply obtain their input, but we must apply their feedback into the app’s design to adapt the technology to their needs\(^\text{94}\). Many researchers would even argue that the most successful interventions are those that address patient challenges in the context of their real life\(^\text{66, 94}\). As previously mentioned, to get to this stage, app developers must identify end-user needs to ensure the intervention is both simple and effective to use. We must move away from expert-driven designs and put the patient back in control of their care. This concept can be summarized as the epitome of the co-design methodology, where it uses patient engagement as the catalyst to accomplish this goal.

A common technique used during app co-design is persona-scenarios. Personas are documents that have been used in the software industry to design and develop user-centric software\(^\text{95-96}\). Each persona describes different types of app users based on their goals, motivations and key behaviours. Scenarios are the situations that the persona may face. In app design, it is used to reflect how certain situations may impact app usage, such
as taking vacations, visiting relatives or forgetting to use the app \cite{95, 97}. The use of persona-scenarios allows developers or researchers to better understand users learning needs, appreciate their goals for using the app, and identify key behaviours that might impact app usage \cite{97}. In most instances, user feedback is coded into NVivo software for thematic analysis \cite{97}. The software helps derive a series of themes to reflect user feedback, which will then be used as a guide to ensure that user expectations are being incorporated into the app design.

Mock-ups are another common technique used within app co-design. Mock-ups are a prototyping tool used to display how features will appear on a screen once the app is fully developed \cite{98}. This method is often used as a visual aid to help identify whether the user-interface is at an adequate usability level before the app is fully developed \cite{99}.

2.9.2 mHealth Co-Design - Don’t Forget About The Informal Caregiver

Previous literature has shown the importance of the CP in supporting HF patient’s self-care. Studies have also indicated that app co-design should not be limited to only patient feedback, but that input from primary care providers (CPs) is vital to the development of an effective self-care app \cite{53, 89}. In a recent RCT, the authors evaluated how mHealth support for the patient and mHealth support for the patient and their CP would impact HF self-care \cite{50}. As a result, they found that mHealth + CP patients showed greater medication adherence (13.8% more, CI 3.7-23.8, \( P < 0.01 \)) and were less likely to report breathing problems or weight gain (\( P < 0.05 \)) \cite{50}. Given the complex roles CPs face with caring for HF patients and the substantial influence they have on improving
outcomes, their feedback during app co-design is crucial \(^{(53)}\). The current lack of fluidity between mHealth development and user input has reduced the effectiveness of each health app. It is only by turning back to the patient and their CP for consultation that mHealth technology may regain its prior potential.

### 2.10 The HFApp – Home-Based Self-Care Application for Older Adults with Heart Failure

The HFApp is an electronic app and community intervention that is designed to promote self-care in HF patients and their CPs in the home setting. We are currently working on designing the HFApp in accordance to the previously highlighted areas for an effective technology-based intervention. The HFApp is based on the results of a previous pilot RCT.

This study tested a multi-component home-based intervention amongst males and females over the age of 60 years old with a primary diagnosis of HF, confirmed by the Boston HF Criteria \(^{(100)}\). Patients were put into the intervention or UC group, and then their SCHFI score was taken at baseline and after 3-month. Within the intervention group, patients received the following components, 1) paper-based Standardized Diuretic Decision Support Tool (SDDST, Appendix B) for self-adjustment of furosemide based on weight, 2) trained HF Nurse support, 3) talking weight scale and 4) Numeracy/literacy sensitive HF education booklet in addition to their UC. The validated SDDST diuretic algorithm was used to help patients adjust their diuretic dosing according to their daily weight measured on the Bluetooth weight scale. The Rapid Response Local Health
Integrated Network (RRLHIN) nurses provided the nursing support in the home setting following hospital discharge. The RRLHIN nurses are a team of registered nurses that provide a variety of intensive in-home services to patients and their families to assist the transition from hospital to home. In this pilot RCT, their role included educating patients using the numeracy/literacy sensitive HF booklet and conducting home-visits to ensure patients were following their self-care regimen. As a result, it was demonstrated that this intervention was safe, feasible, and improved self-management compared to UC (p = 0.005) (101).

The design of the HFApp will incorporate all the previously tested components from the pilot study into the electronic app. This will allow us to automate several cognitively challenging steps that hinder patient self-care, including, 1) reading and graphing the weight from scale (HFApp with Bluetooth scale), 2) determining if the weight measurement requires dosage change, 3) looking up a new dose from the dosage table, 4) and acting on new dose with confidence. Nevertheless, before we begin HFApp development we aim to engage with patients and their CPs to obtain key information regarding the intervention’s potential. This will allow us to personalize the app to the end-user, which in turn should improve its overall effectiveness.

1.11 Chapter Summary

HF is the cardiovascular condition most responsible for hospitalization and re-hospitalization in older adults. Patients able to manage their HF at home are less likely to be readmitted; however, many older adults are unable to care for themselves due to non-
compliance of a treatment, cognitive impairment, or merely limited knowledge regarding signs, symptoms and appropriate care. Therefore, by designing a self-care application tailored to minimize challenges faced by older adults, we can increase self-care adherence among HF patients and ultimately prevent future hospital readmissions.
Chapter 3: Project Objective, Overview and Hypothesis

Study Objective:

The objective of this study is to evaluate the effectiveness of the proposed HFApp intervention and co-design the app requirements by conducting a series of qualitative HF patient and CP interviews.

Project Overview

We plan to use patient and CP feedback from the paper-based HFApp and the persona-scenario methodology to design the electronic HFApp. Feedback from participants might include features users perceive to be helpful, and how best to integrate the mHealth app into their daily lives. We hope to show that by using HF patient and CP feedback, it is possible to design a simpler, more user-oriented self-care application compared to current applications available.

Hypothesis:

We hypothesize that by using a user-centered approach, we will be able to design a reliable mHealth tool to promote self-care in older adults.
Chapter 4: Methods and Study Design

4.1. Study Design

This is a qualitative study that consisted of data collection with a series of usability and design interviews. The study moved forward in an experience-based design. An experience-based design is when participants work together with staff (Study team) to help make changes to improve their care.

We chose to use methodology as it was aligned with the criteria for UCD, which allowed us to maximize the patient engagement for the development of the electronic version of the HFApp. Participants were able to share their self-care experiences, specifically the challenges they face, which gave us a better understanding on the requirements for an effective solution. In this study, participants were surveyed on their experience with the paper-based HFApp to address whether it would be an effective tool for their daily lives.

4.2. Population

The patient study population included males and females aged ≥ 60. Patients with a primary diagnosis of HF confirmed by Chart review (Boston HF criteria, probable or definite diagnosis) were considered eligible for participation. Both inpatients and outpatients were considered for the study, as it allowed us to approach a wider range for each category during recruitment. Participant categorization will be further explained in
the section below.

The CPs in the study population consisted of males and females aged 18 years or more. The CPs were defined as the main person other than a healthcare, social work or voluntary care provider, who cares for the patient on an on-going basis. This can include a spouse, family or friend that is assisting with the patient’s healthcare. However, to be considered a CP, they must interact with the patient at least 4 times a week for a minimum of 1 hour per encounter.

4.3 Recruitment

We based our recruitment framework on the basis that the all HF patients are at different levels of self-care adequacy; therefore to move forward in a UCD we must recruit patients at these various levels.

To accomplish this, we approached patients from the Heart Function Clinic at the General site of Hamilton Health Sciences (HHS), from Dr. Demers' ongoing patients at her medical practice, and HF patients in-hospital at the General site of HHS. A pre-screening method was used to categorize potential patients. This consisted of a recruitment strategy where patients were categorized into group A, not re-admitted within past 6 months or group B, re-admitted more than once within past 6 months. This ensured that a variety of patients were being considered, before contacting them to participate in the study. Dr. Demers (Principal Investigator/PI) conducted the pre-screening for her own patients. Following pre-screening, patients were asked if they would like to participate in the study, if they said “yes”, Sahr Wali (Study Coordinator/Interviewer) contacted them.
via telephone (Appendix C) to expand on the research project and confirm participation with consent. (Appendix D). Following participant confirmation, patients were screened once more for eligibility and were then categorized into one of the three patient groups described below.

Following approval and consent from HF patients, the CPs of the participating HF patients in the study, were asked to participate in the study. CPs were contacted in-person or via telephone by Sahr Wali to confirm their participation. Once participation was confirmed, CP consent was obtained.

4.4 Sample Size

We planned to approach a maximum of 20 individuals to participate in the study, consisting of 15 HF patients (five within each of the three patient groups) and five CPs, or until data saturation was reached.

We established the baseline sample size using Malterud et al. (2015) five component guideline evaluating, 1) study aim, 2) sample specificity, 3) use of established theory, 4) quality of dialogue, and 5) analysis strategy. This study had a relatively narrow objective of using patient feedback for the development of an electronic self-care application. The sample specificity was high, as the study population included participants who had direct experience with HF or caring for HF patients. There is no specific established theory developed to determine self-care application usability, however strong case-specific dialogue was used throughout the project to offset the lack of known knowledge on the topic. Therefore, due to the narrow study aim, dense sample
specificity, strong dialogue and case analysis it is estimated that a large sample size is not needed to reach data saturation.

This indicated that our sample size of 20 participants fell within the theoretical range to meet data saturation. Nevertheless, as the interview process continued, we also reviewed the analysis of the interview transcripts to ensure there were no new emerging themes.

4.5. Participant Categorization

Participants were categorized into four primary groups for this study. The first three groups consisted of HF patients, and the fourth group consisted of CPs.

The patients in the first three groups were categorized based on their self-care maintenance, management and confidence, in accordance with the SCHFI. HF patients were listed as 1) adequate self-care patients, 2) inadequate self-care patients without a CP or 3) inadequate self-care patients with a CP. The level of adequacy was based on patients overall SCHFI scale scores (maintenance, management and confidence), where an average score of 70 or higher were labeled as self-care adequate.

The CPs were all categorized into one group. However, they were also asked to complete the CC-SCHFI, for future data analysis within the CP group.

4.6. Persona-Scenario Discussion Sessions
Throughout this study, patients and their CPs were asked to participate in a persona-scenario discussion. The discussion sessions were held separately for each participant at the Hamilton General hospital site of Hamilton Health Sciences for approximately 2 hours. As per mode of convenience for patients and their CPs (e.g. travel burden, age, etc), interviews with each CP were held together with the patient. The student researcher of the study, Sahr Wali (eHealth, MSc), conducted each discussion session.

At the start of the discussion session, the student researcher reviewed the interview agenda and obtained consent from the participant(s). Following participant consent, the student researcher began providing a detailed explanation of the HFApp, regarding how the tool was used and what the tool can assist with (Appendix E). This included information on weight/medication management, and the role of LHIN HFRR nurse visits. Afterward, the participant was given a handout with a tailored discussion guide equipped with the major components of the program, as well as a list of different personas and scenarios for the discussion (Appendix F). A paper-based prototype of the HFApp, as well as a series of mock-up designs (Appendix G) was used throughout the sessions for the participants to engage with. The participant was then asked to review one of the listed personas and evaluate whether the HFApp would be an effective tool with respect to the different scenarios. A list of discussion questions was provided to help the participants during their evaluation (Appendix H). Once evaluations were complete, each participant was then asked to come up with ideas on how they would improve the tool. Feedback and suggestions were recorded and transcribed verbatim for analysis.
At the end of the session, participants were asked to complete a final feedback interview regarding their experience with the persona-scenario discussion session (Appendix I). 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 interview was recorded using a digital recorder and later transcribed for analysis.

4.7. Data Analysis

Verbatim transcriptions of the discussion sessions were coded using the NVivo, Version 10 software for data analysis. The student researcher was the primary investigator identifying the codes, categories and themes for the data analysis.

We used the design themes adapted from a similar previously completed study as guideline when capturing this study’s usability themes for data analysis (Appendix J). This study built on previous work by Chiu (2015), however a different approach was taken to further appeal to the user-centered approach. Specifically, Chiu (2015) made use of the participants to develop personas to evaluate the HFApp, however, we used pre-designed persona-scenarios and a paper-prototype to ease the process of each evaluation. In addition to Chiu (2015) adapted themes, Braun and Clarke’s deductive thematic analysis approach was used to analyze, identify, reflect and refine emerging themes from the discussion sessions. Braun and Clarke’s six-step method required the coder (SW) to 1) familiarize herself with the transcripts, and 2) generate initial codes into meaningful groups. Step three involved searching for the actual themes and identifying possible
candidates. These candidate themes were then reviewed and organized in step four. By step five the themes were defined, named and refined. In the final step, a report was generated for the fully worked-out themes.

Our analysis followed Braun and Clarke’s six steps, except two researchers (Sahr Wali and Linda Nguyen) then reviewed the design themes independently (investigator triangulation) to ensure multiple perspectives were incorporated during analysis. A table of ‘actions’ (activities required to actualize the ideas derived from the themes) and ‘items’ (elements to execute the action) was then developed to determine what areas of the intervention needed to be improved and how. Finally, a list outlining the next steps for the intervention was generated.

4.8. Ethics and Confidentiality

Participation in this study was entirely voluntary and did not affect the patients’ medical care. They were free to refuse to participate or withdraw from the study at any time without any penalty. The participant was able to contact the researcher verbally during the meeting or by phone call to withdraw from the study.

All information was stored in a secure manner to respect patient privacy and confidentiality. As this information was identifiable we de-identified it to maintain patient privacy and confidentiality. Information was still used for analysis, but it was only used for research purposes. Participant names were not used on any report generated from this study. A copy of the consent form was left in the patient’s hospital chart, and the participants were also provided with a copy of the consent.
During the study we did not use patient names or any information that would allow them to be identified. Every effort was made to protect their information and privacy. As soon as data was collected, we removed any identifiable information (for example, their name, date of birth, and age), and then transferred the data onto a computer file that is password protected.

The information was stored securely offline in a password-protected personal computer in a password-protected file. Once the study was completed, the data was transferred to and stored in a secure office space occupied by Dr. Demers. This data will be kept for the next 7 years, after this time period the data will be permanently deleted.

This study obtained ethics approval from the Hamilton Integrated Research Ethics Board (Appendix K, Project Number: 2768).
Chapter 5: Results and Major Findings

5.1. Participant Characteristics

A total of 19 participant interviews were conducted. There were 12 HF patients in the study, 7 were male and the mean age amongst all HF patients was 74 years old (Standard Deviation[SD] = 4.3). Seven CPs participated, 3 were male and the mean age amongst all CPs was 66 years old (SD= 15.9).

Within the patient groups, there were 6 patients categorized as adequate self-care patients, 4 patients as inadequate self-care patients with a CP, and 2 patients as inadequate self-care patients without a CP. The patient and CP characteristics are summarized below in Tables 1-3.

Table 1: Patient Baseline Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Patients N= 12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (Male): n (%)</td>
<td>7 (53.84%)</td>
</tr>
<tr>
<td>Age: mean (SD)</td>
<td>74 (4.3)</td>
</tr>
<tr>
<td>Etiology Ischemic: n (%)</td>
<td>3 (25%)</td>
</tr>
<tr>
<td>LVEF: Echocardiogram, mean (SD)</td>
<td>31.5% (15.89 %)</td>
</tr>
<tr>
<td>Blood Pressure: mean (mmHg)</td>
<td>118/67</td>
</tr>
<tr>
<td>Sodium: mean (SD)</td>
<td>136 (6)</td>
</tr>
</tbody>
</table>
### Table 2: Participant Self-Care Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Patients N= 12</th>
<th>Informal Caregiver/CPs N= 7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender: n (%)</td>
<td>Male: 7 (54%)</td>
<td>Male: 3 (43%)</td>
</tr>
<tr>
<td>Age (Mean, SD)</td>
<td>74 (4)</td>
<td>66 (16)</td>
</tr>
<tr>
<td>Self-Care Adequacy (SCHFI and CC-SCHFI)</td>
<td>Adequate with CP: 6, Inadequate with CP: 4, Inadequate without CP: 2</td>
<td>Adequate: 6, Inadequate: 0</td>
</tr>
</tbody>
</table>

(SCHFI: Self Care Heart Failure Index, CC-SCHFI: Caregiver Contribution Self-care Heart Failure Index)

### Table 3: Patient Medication Information

<table>
<thead>
<tr>
<th>Medication(s)</th>
<th>Patients N= 12</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACE inhibitor: n (%)</td>
<td>3 (25%)</td>
</tr>
<tr>
<td>Beta Blocker: n (%)</td>
<td>10 (83%)</td>
</tr>
<tr>
<td>Diuretic (overall): n (%)</td>
<td>9 (75%)</td>
</tr>
<tr>
<td>ARB: n (%)</td>
<td>5 (41.6%)</td>
</tr>
<tr>
<td>Aspirin: n (%)</td>
<td>3 (25%)</td>
</tr>
<tr>
<td>MRA</td>
<td>6 (50%)</td>
</tr>
<tr>
<td>OAC</td>
<td>5 (41.67%)</td>
</tr>
</tbody>
</table>
Hydrazine | 2 (16.67%)  
ISDN       | 2 (16.67%)  
Entresto   | 1 (8.33%)   


5.2. Discussion Sessions

Data from each participant interview was transcribed verbatim and analyzed using NVivo Version 10 (http://www.qsrinternational.com/nvivo). According to patient and CP feedback, a total of 6 major themes were identified, which included 1) usability of technology, 2) communication, 3) application customization, 4) complexity of Self-Care, 5) usefulness of HF related information and 6) cost and Long-term Use. These themes were derived from a series of codes or factors commonly contributing to the major design theme. The result from the thematic analysis is summarized in Table 4.

<table>
<thead>
<tr>
<th>Design Themes</th>
<th>Factors/Elements</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Usability of Technology</td>
<td>1.1 Perception that technology will make self-care more challenging</td>
</tr>
<tr>
<td></td>
<td>1.2 Incentive for technology use not seen</td>
</tr>
<tr>
<td></td>
<td>1.3 Willingness to learn and use app if simple with minimal number of features</td>
</tr>
<tr>
<td>2. Communication</td>
<td>2.1 Use of direct communication (in-person and online) with nurse highly desired</td>
</tr>
<tr>
<td>Section</td>
<td>Description</td>
</tr>
<tr>
<td>---------</td>
<td>-------------</td>
</tr>
<tr>
<td>2.2</td>
<td>Open sharing and access to patient information during communication. Able to improve communication during visits with accurate information.</td>
</tr>
<tr>
<td>3. Application Customization</td>
<td>3.1. Management of medications on one device. 3.2. Addition of notifications at patient’s desired time/manner. 3.3. Customization of audio, visual and format for each individual patient during setup.</td>
</tr>
<tr>
<td>4. Complexity of Self-Care</td>
<td>4.1. Perception that daily management of HF self-care is difficult. 4.2. Difficulty with diuretic adjustment. 4.3. Benefits of nursing support.</td>
</tr>
<tr>
<td>5. Usefulness of HF Related Information</td>
<td>5.1. Provision of information from physician and nurses difficult to understand. 5.2. Interest in information relevant to specific patient.</td>
</tr>
</tbody>
</table>

We further describe each design theme below according to specific patient and CP feedback. Each HF patient is represented through “P”, and “C” represents each CP.

**5.2.1 Design Theme 1 - Usability of Technology**
Perception that technology will make self-care more challenging

Within our patient population, there was a lot of stigma around technology usage. When participants were asked about their current use of technology devices they indicated that they either did not use them or specifically did not use any for HF self-care.

“I don’t like using any technology, it just makes more problems” (P, inadequate with CP)

“I mean I use my IPad, but not for managing this stuff, I just write it on a piece of paper” (P, adequate with CP)

The preset, negative perception around technology, led the majority of older adults to assume that the HFApp would become another added barrier for their HF self-care, before the intervention was even fully described. They felt that they were already unfamiliar with technology, so it would only further complicate their self-care.

“I think he would have a lot of difficulty learning how to use it. He barely knows how to use his phone” (C, adequate)

In addition, patients and CPs indicated that they preferred to speak with a real person to manage their HF, as it gave them a sense of comfort and added a “human-touch” to their care. Thus, with the HFApp, they believed they would lose confidence in their self-care decision-making and create opportunities for future difficulties.

“Why should I have some computer thing tell me what to do… how do I even know if I can trust it… that’s why I just go to my doctor” (P, inadequate with CP)
“I feel a lot better when I can see who’s giving me advice, call me old fashioned but if someone’s gonna check up on me, they should be in the same room as me” (P, inadequate with CP)

Incentive for technology use not seen

Both patients and CPs mentioned how they did not view the use of technology as an added benefit to their current treatment regimen, as they would be completing the same tasks with or without it.

“If I’m already writing out my weight everyday and doing fine, I don’t see a reason for me to stop what I’m doing and learn something new, like what’s the point?” (P, adequate with CP)

“I’m not going to use it, I don’t want to. I barely track my weight, I know I should, but I rather just go to a nursing home where someone can take care of me” (P, inadequate with CP)

“I think we do an ok job with the weight and the salt. I think it would be harder for us to learn how to use the tablet… maybe my grandkids could use it, but I don’t know about me or my wife” (C, adequate)

Willingness to learn and use app if simple with minimal number of features

After the full HFApp intervention (SDDST + Nursing support + Bluetooth weight scale + Numeracy/literacy sensitive education booklet + Trained volunteer assistance) was explained, patients and CPs had a better evaluation of their potential technology
usage. They indicated that if the application were kept simple, as it was displayed in the mock-ups (Appendix G), they would be willing to learn how to use it.

“Oh that doesn’t look to hard to follow” (P, inadequate without CP)

“I could see my wife be able to use this… I might have to help her start but this is easier than what I pictured” (CP, adequate)

Patients were specifically interested in the inclusion of nursing support and trained volunteer assistance. They felt that the nurses would be able to provide the “human-touch” care, while the volunteers would minimize any of their technical issues along the way.

“I really like that. This way I wouldn’t be alone with a computer… The nurse would come to my home and check if I’m alright” (P, inadequate with CP)

“Ya this would be really helpful. I always have to teach my dad how to use things on his phone… that’s smart to add the volunteer part” (C, adequate)

As we moved into the persona-scenario discussion, many patients indicated that they shared the same frustrations as the persona “Diane Lambert”, who was unfamiliar with IPad’s and tablets (Appendix F). They indicated that learning how to use the HFApp would be easier if there were only a few functionalities.

“Yes this is like me, I feel the same way” (P, inadequate with CP)
“I think the app would help Diane, but only if it was really simple. A lot of apps have too many things going on, so I get lost” (P, adequate with CP)

5.2.2 Design Theme 2 - Communication

*Use of direct communication (in-person and online) with nurse highly desired*

One of the greatest benefits seen by patients involved having a direct source of communication with a member of their care team. Patients articulated how difficult it was to reach their physician or nurse when they were at home.

“My doctor even gave me his cell phone number, but I still can’t reach him” (P, inadequate without CP)

“I can’t even schedule an appointment when I need to, forget being able to talk to them” (P, adequate with CP)

During the persona-scenario discussion, both patients and CPs expressed how being able to get extra information from a nurse would make them feel more confident in their self-care decision-making, similar to the persona Christina Williams (Appendix F). They would not have to solely rely on the technology of the HFApp for guidance, which made the use of the entire intervention more comforting.

“My weight is not always consistent, so I would want to talk to someone before I change anything” (P, inadequate with CP)
“Sometimes I don’t have all the answers… Asking the nurse for help would really make me feel better about the whole thing” (C, adequate)

Open sharing and access to patient information during communication

Participants also emphasized how the intervention’s ability to give nurses and physicians access to their patient’s HFApp information, with consent, allowed for greater accuracy during diagnosis. This aspect of the HFApp was strongly appealing since often time’s patients felt that there was a gap in their quality of care because their health care provider did not understand their updated condition.

“The worst is when they think their right, but they don’t understand that my symptoms are not the same as before” (P, adequate with CP)

“Yes, I think that’s great! Makes life so much easier when everyone is up to speed” (CP, adequate)

Able to improve communication during visits with accurate information

One of the greatest challenges patients and CPs indicated involved having to explain their self-care measurements during their physician appointments. They found that it was difficult to provide accurate information, as they were not able to remember all their symptoms and did not always record their weight. In addition, patients commonly specified how they did not want to consistently re-explain their HF management but would rather have the app summarize it for them.
“I barely remember what I weighed this morning… I usually just say my weight is the same” (P, inadequate without CP)

“I try to record my weight, but when my cardiologist asks me questions I don’t know what to say… I think having the app track it would be really good for me cause I get lazy” (P, inadequate with CP)

“I think this would be the best part of the app, I know my wife records her weight but then she forgets to bring it to her appointment” (C, adequate)

The accurate information within the HFApp was also deemed beneficial for patients who were able to adequately self-care, as they would be able to display how their HF symptoms worsened even when they were adherent. Patients expressed how this would allow physicians to have a deeper understanding of their condition, which in turn would improve the accuracy of their diagnosis.

“I weigh myself and follow everything the doc tells me, but here I am. It’s tough. I don’t know what to do cause they don’t even know what to do” (P, adequate with CP)

“I can see how this can help my dad cause the doctor tells us the same thing. But he doesn’t get that we did that and it didn’t work… So obviously there must be something else going on… maybe this can be our proof or something like that” (C, adequate)

5.2.3 Design Theme 3: Application Customization
When participants were asked about using the HFApp, the concept of customization was a major factor. Patients indicated that being able to tailor the tool to their needs would increase the app’s appeal and overall usability.

Management of medications on one device

One area that patients were disappointed with involved the inability to manage multiple medications within the HFApp. As HF patients take many medications, they believed being able to track all of them in one place would have made their self-care easier.

“I have diabetes too, so why wouldn’t I be able to manage both? I could have like a separate space for it…I think it would be really helpful” (P, adequate with CP)

“I need to track my blood pressure and my water pills. It would be neat if this app could put both of them in it” (P, inadequate with CP)

Addition of notifications at patient’s desired time/manner

Patients and CPs stressed the need for notifications and reminders to be integrated within the HFApp. They stated that it is difficult to maintain their daily treatment routine, due to a number of factors, but mainly because it is very easy to forget.

“I always forget to do it. If you don’t tell me I won’t do it. So, if you want me to use this thing, you better buzz me until I do it… For me, I would make sure it kept buzzing me until I got onto that scale” (P, inadequate without CP)
“Sometimes I forget if I weighed myself, then I’ll just move on and forget about it again. This happens a lot” (P, inadequate with CP)

“I think if I have one reminder in the morning, like when I’m brushing my teeth then I would be good to go” (P, adequate with CP)

**Customization of audio, visual and format for each individual patient during setup**

Many older adults with HF may have visual or hearing impairment. Thus, to optimize the app potential, participants suggested that these conditions be accommodated for during the HFApp set up.

“I know my dad’s vision is getting worse. He’s too stubborn to admit it, but I think maybe if the app could repeat each thing out loud when you click it that would really help. Or just use really big fonts and bright colors” (C, adequate)

“I don’t like looking at screens. It hurts my eyes. I only look when it’s dim. My son usually fixes that for me, but maybe the doctor can do it” (P, adequate with CP)

**5. 2. 4 Design Theme 4: Complexity of Self-Care**

**Perception that daily management of HF self-care is difficult**

Throughout the persona-scenario discussions, participants had varying attitudes regarding HF self-care, however, the majority of HF patients agreed that they found the process to be difficult. They specifically indicated that the daily management was overwhelming, especially in the case when patients had multiple co-morbidities.
“There’s too many things to remember and I have diabetes so I mix those up too” (P, inadequate with CP)

They viewed the management of HF as a burden for their daily routine. Patients even indicated that they consciously decided not to perform self-care tasks because they felt if they were unable to adequately perform all the tasks, one would not make a difference. According to our SCHFI scores recorded, only 50% patients interviewed even weighed themselves.

“I don’t weigh myself all the time, it’s just too much work… The only time I pay attention is when I start to lose my breath, but even then I rather see my doctor” (P, inadequate without CP)

“Once I went to check up on my dad and he’s a big guy so you can’t tell if he really gained any weight… So I forced him to go on the scale, and guess what, his weight was up by 7 pounds! I asked him “why don’t you weigh yourself every day?” and he just tells me it that it won’t help him any way” (C, adequate)

**Difficulty with diuretic adjustment**

One of the most common areas patients had difficulty with involved adjusting their diuretic dosing. Both patients and CPs expressed their fear in changing the dosage incorrectly and potentially worsening the patients’ symptoms.

“I weigh myself and if it doesn’t look normal, I still take my regular water pill… I’m afraid something might happen” (P, inadequate with CP)
“My wife asks me to help her, but I don’t know if I’m doing it right either. Every morning I hope her weight is the same, so I don’t have to think about it again” (C, adequate)

This fear of diuretic adjustment was further exhibited when reviewing the persona of Christina Williams. Due to their lack of confidence in changing their diuretic dosage, patients had expressed the same concern as the persona. Most participants have thus indicated that they continue to take their regular dosage to prevent any further complications, regardless of whether their weight had changed.

“I rather just keep taking the same dose. Maybe it was a fluke… I don’t know. I just take the same old thing its easier” (CP, adequate with CP)

**Benefits of nursing support**

Participants had established their view on the complexity of self-care and their difficulty to manage their symptoms. When the inclusion of the nurse home-visits was explained, both patients and CPs agreed on the undeniable benefits of their presence.

“Yeah, I would love that. Just to come and make sure I’m alright… This beats having to wait for an appointment” (P, inadequate with CP)

“I can see this working for a lot people, personally, I don’t think I need it, but for a person like my dad this would be the icing on the cake” (P, adequate with CP)

5.2.5 Design Theme 5: Usefulness of HF Related Information

**Provision of information from physician and nurses difficult to understand**
Throughout the discussion sessions, participants expressed the lack of clarity in the information provided to them by both nurses and physicians. Patients specifically expressed how they either did not understand or would simply forget about the information after their appointment.

“They keep talking and repeating stuff, but I don’t understand… I just nod my head because I don’t want to disappoint them” (P, inadequate with CP)

“They speak too fast a lot. It’s hard to remember everything when they go through it like a race… And if I don’t get it, you can bet my wife has no clue either” (C, adequate)

**Interest in information relevant to specific patient**

Both CPs and patients felt that they were consistently being given generic information regarding their HF self-care. CPs were very concerned about this issue as they felt that the advice from their physician should be held at a higher degree.

“They ask me about my weight, fluid, salt and whatever, but it’s more than just that… I don’t know how to tell them because they’re the doctor” (P, inadequate with CP)

“My husband is good with managing his weight. He still gets short of breath. I don’t know how to help, but I told his doctor, and they don’t seem to get him either” (C, adequate)

When the participants went through the persona-scenario of “Christina Williams” (Appendix F), a few adequate self-care patients connected with her situation. They agreed on the frustration of following their regimen, but still having worsening symptoms.
Nonetheless, they came up with a similar conclusion on how the HFApp provided specific information relevant to the patient and how their physician can use this as a reference during their appointments. One patient even indicated the interest of integrating their electronic medical record (EMR) information within the app, this way their prescriptions would be up to date as well.

“I’m like Christina… what if I could have my doctor use this info on the app when he talks to me. So he has a better idea of what’s going on” (P, adequate with CP)

“I think what would be even better would be like if they could take my prescription information and put it on the app, like right when it changes, so when I go home its already updated. Could it do that?” (P, inadequate with CP)

5.2.6 Design Theme 6: Long-Term Use and Costs

Concerns with potential dependence on HFApp intervention and future costs

After the HFApp explanation was completed, participants were very intrigued with the interventions implementation; however, they also had concerns on the longevity of its use. The HFApp was described as a service free of charge for the patient, but patients and CPs expressed their fear on potentially becoming dependent on its use and then having to pay for it later.

“Who’s paying for it? Like this sounds all great and stuff. But how do I know it will be free forever?” (P, inadequate without CP)
“So you’re giving me a tablet and a scale and having people come to my home to help. This sounds too good to be true. Will I have to pay monthly or something, like cable? C, adequate)

The lack of upfront costs was very appealing to all participants, but they felt that they needed a source of assurance that they would not be misled into volunteering for unexpected costs in the future.

“Is the government going to pay for it? Like forever? I don’t know what the government even does with their money, so they should pay for it…I think we need something to tell us that hey you won’t be charged later, and if you are you get a refund or something” (P, inadequate with CP)

Integration with current device for long-term use and reduce cost

While the discussion of cost and long-term use was being discussed, a few participants recommended possibly combining the app on current devices (tablet, smartphone, IPad) for patients who feel confident in doing so. They felt that by integrating the intervention with current devices this would reduce the cost for the stakeholder/funder and improve the usability of the app as a whole.

“I already have one of those IPad things, so I don’t really need another one. I can just put your app on my IPad. This way you don’t have to pay or I don’t have to pay now or later, whatever you decide… Either way more bang for your buck” (P, inadequate with CP)
“If I could connect it to my phone, then I wouldn’t have to have another thing to think about. I think it be easier for me because I have it with me all the time anyway” (P, adequate with CP)

5.2.7 Identifying What’s Next – Summarized Actions and Items

To determine what areas of the HFApp intervention needed to be changed and how, a table outlining each design theme factor with the corresponding action and item was created (Table 5).

Table 5: Design Theme Analysis Outlining Actions and Items to Improve HFApp Intervention

<table>
<thead>
<tr>
<th>Factors/Elements</th>
<th>Quote</th>
<th>Action</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Design Theme 1: Usability of Technology</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.1 Perception that technology will make self-care more challenging</td>
<td>“I don’t like using any technology, it just makes more problems”</td>
<td>Ensure patients and CPs are comfortable with HFApp use</td>
<td>- Simple, literacy and numeracy sensitive instruction manual on HFApp use for patient and/or CP</td>
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<tr>
<td></td>
<td>“I think he would have a lot of difficulty learning how to use it. He barely knows how to use his phone”</td>
<td>Nurse provides step-by-step instructions on HFApp use during initial visit</td>
<td>- Schedule first nurse visit</td>
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<td></td>
<td></td>
<td>Volunteers provide technical assistance (as needed)</td>
<td>- Training program for nurses on HF self-care, HFApp and tablet use</td>
</tr>
<tr>
<td>1.2 Incentive for technology use not seen</td>
<td>“If I’m already writing out my weight everyday and doing fine, I don’t see a reason for me to stop what I’m doing and learn something new,”</td>
<td>Nurse outlines benefits associated with HFApp over long-term</td>
<td>- Training program for volunteers on HFApp and tablet use</td>
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<tr>
<td></td>
<td></td>
<td>Nurse outlines</td>
<td>- Summary for patients on how HFApp reduces self-care challenges (literacy and numeracy sensitive)</td>
</tr>
<tr>
<td>1.3 Willingness to learn and use app if simple with minimal number of features</td>
<td>“I think the app would help Diane, but only if it was really simple. A lot of apps have too many things going on, so I get lost”</td>
<td>Simplify user-interface of HFApp and automation of steps</td>
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<tr>
<td>Ya this would be really helpful. I always have to teach my dad how to use things on his phone… that’s smart to add the volunteer part”</td>
<td>Provide volunteer assistance (in-person and via phone) for technical issues</td>
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<td></td>
<td>- User-interface guideline for older adults</td>
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<td></td>
<td>- Secure application with mechanism to contact volunteers</td>
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<td>- Volunteer training program</td>
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<td></td>
<td>- Schedule for volunteer visits</td>
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</table>

**Table: Design Theme 2: Communication**

<p>| 2.1 Use of direct communication (in-person and online) with nurse highly desired | “My doctor even gave me his cell phone number, but I still can’t reach him” | Provide direct communication with nurse via HFApp |
| “My weight is not always consistent, so I would want to talk to someone before I change anything” | Nurses help with patient self-care using HFApp |
| Volunteers help optimize HFApp use (weight scale calibration, Internet connection) | - Secure system to contact nurses |
| - Schedule nurse and/or volunteer home visits (as needed) |
| 2.2 Open sharing and access to patient information during communication | “The worst is when they think their right, but they don’t understand that my symptoms are not the same as before” | Provide nurses and physicians ability to access patient information on HFApp |
| “Yes, I think that’s great! Makes life so...” | - Secure mechanism for nurses and physicians to access HFApp |</p>
<table>
<thead>
<tr>
<th><strong>2.3. Able to improve communication during visits with accurate information</strong></th>
<th>“I try to record my weight, but when my cardiologist asks me questions I don’t know what to say… I think having the app track it would be really good for me cause I get lazy”</th>
<th>Physicians access patient information on HFApp during patient consults</th>
<th>- Secure mechanism for physicians to access HFApp during appointment</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>Physician follows regular appointment routine in parallel with content obtained from HFApp</td>
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</table>

**Design Theme 3: Application Customization**

<table>
<thead>
<tr>
<th><strong>3.1. Management of medications on one device</strong></th>
<th>“I need to track my blood pressure and my water pills. It would be neat if this app could put both of them in it”</th>
<th>Introduce HFApp solely for diuretic adjustment</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>Patients manage diuretics according to weight</td>
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<td></td>
<td></td>
<td>Nurses determine if patient needs are being met and self-care is being improved during ongoing home-visits (via SCHFI)</td>
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<td></td>
<td></td>
<td>Determine suitable duration SCHFI to be conducted over trial period</td>
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<tr>
<td></td>
<td></td>
<td>- Tablet</td>
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<tr>
<td></td>
<td></td>
<td>- Bluetooth scale</td>
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<tr>
<td></td>
<td></td>
<td>- Simple, literacy and numeracy sensitive instruction manual on HFApp use for patient and/or CP</td>
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<tr>
<td></td>
<td></td>
<td>- Nurses to use SCHFI questionnaire for self-care evaluation</td>
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<td></td>
<td></td>
<td>- Schedule for SCHFI evaluations</td>
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</tbody>
</table>

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<tr>
<th><strong>3.2. Addition of notifications at patient’s desired time/manner</strong></th>
<th>“I always forget to do it. If you don’t tell me I won’t do it. So, if you want me to use this”</th>
<th>Integrate notification option within HFApp profile settings</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>- Mechanism to add and adjust notification settings on HFApp</td>
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</tbody>
</table>
thing, you better buzz me until I do it... For me, I would make sure it kept buzzing me until I got onto that scale”

“I think if I have one reminder in the morning, like when I’m brushing my teeth then I would be good to go”

Patient and/or CP can alter notification preferences on HFApp as needed

3.3. Customization of audio, visual and format for each individual patient during setup

“I know my dad’s vision is getting worse. He’s too stubborn to admit it, but I think maybe if the app could repeat each thing out loud when you click it that would really help. Or just use really big fonts and bright colors”

“I don’t like looking at screens. It hurts my eyes. I only look when it’s dim. My son usually fixes that for me, but maybe the doctor can do it”

Develop audio and user interface/ screen customization feature (font, color, contrast adjustment) within HFApp

Nurse sets up audio and user interface preferences during first initial visit during HFApp explanation

Patient and/or CP can alter audio and user interface according to preferences (as needed)

- Mechanism to add/adjust audio and visual settings on HFApp

**Design Theme 4: Complexity of Self-Care**

4.1. Perception that daily management of HF self-care is difficult

“I don’t weigh myself all the time, it’s just too much work... The only time I pay attention is when I start to lose my breath, but even then I rather see my doctor”

Determine self-care concerns specific to each patient and CP

Nurse provides education to outline benefits associated with self-care and

- Scheduled discussion of patient and caregiver needs

- Summary of results for improved self-care with HFApp
### Design Theme 5: Usefulness of HF Related Information

| Provision of information from physician and nurses difficult to understand | “They keep talking and repeating stuff, but I don’t understand…I just nod my head cause I don’t want to disappoint them” | Patient and/or CP is able to access simplified summary of HF information on HFApp | - Simple, literacy and numeracy sensitive summary on general HF related information |
| 4.2. Difficulty with diuretic adjustment | “I weigh myself and if it doesn’t look normal, I still take my regular water pill… I’m afraid something might happen” | Nurse provides education on SDDST benefits | - Secure system to contact nurses through HFApp |
| 4.3. Benefits of nursing support | “Ya I would love that. Just to come and make sure I’m alright… This beats having to wait for an appointment” | Nurse organizes schedule for patient home visits | - Mechanism for HFApp information to integrate into subset of EMR |
| 5.1. Provision of information from physician and nurses difficult to understand | “I’m like Christina… what if I could have my doctor use this info on the app when he talks to” | Integrate patient information on EMR specific for self-care management onto | - Simple, literacy and numeracy sensitive instructions on HFApp use |
| 5.2. Interest in information relevant to specific patient | | - Summary for patients on how HFApp reduces diuretic adjustment challenges (literacy and numeracy sensitive) | |
Design Theme 6: Long-Term Use and Costs

<table>
<thead>
<tr>
<th>6.1. Concerns with potential dependence on HFApp intervention and future costs</th>
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<tr>
<td><strong>“Who’s paying for it? Like this sounds all great and stuff. But how do I know it will be free forever?”</strong></td>
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<tr>
<td>Create financial guideline/budget for HFApp implementation</td>
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<tr>
<td>Outline cost-benefit analysis for intervention implementation</td>
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<tr>
<td>Determine primary stakeholder to fund HFApp implementation</td>
</tr>
<tr>
<td>- Report on costs for HFApp intervention (tablet, Bluetooth scale, nursing/volunteer support)</td>
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<tr>
<td>- Cost-benefit analysis of readmissions/improved self-care vs. intervention</td>
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</table>

<table>
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<tr>
<th>6.2. Integration with current device for long-term use and reduce cost</th>
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<tbody>
<tr>
<td><strong>“If I could connect it to my phone, then I wouldn’t have to have another thing to think about. I think it be easier for me cause I have it with me all the time anyway”</strong></td>
</tr>
<tr>
<td>Introduce HFApp on tablet for sole use of self-care</td>
</tr>
<tr>
<td>Determine effectiveness of HFApp on tablet via SCHFI scores across study period</td>
</tr>
<tr>
<td>- Tablet</td>
</tr>
<tr>
<td>- Bluetooth Scale</td>
</tr>
<tr>
<td>- Summary of patient SCHFI scores across study period</td>
</tr>
<tr>
<td>- Summary of patient PAM scores at end</td>
</tr>
<tr>
<td>Evaluate patients willingness to self-care with HFApp on tablet alone vs on other devices at end of study via PAM</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------------------------------------------</td>
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<tr>
<td>Compare patient SCHFI and PAM scores</td>
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Chapter 6: Discussion

The primary aim of this study was to work collaboratively with patients and their CPs to identify their self-care challenges and evaluate the usability of the HFApp intervention. Consistent with findings from previous publications, we found that there was a large gap between patient self-care capabilities and electronic application usability. This gap has driven older adults away from app usage, when they were initially willing to adopt a technology-based intervention providing that it was suited to their needs and capabilities\(^\text{(104)}\).

Technology, like all interventions, is simply a tool and will only be as effective as the person using it\(^\text{(105)}\). Therefore, with the results of this study we were able to identify 6 major design themes to reflect the app specifications deemed necessary by participants, to improve the usability of the HFApp intervention (Table 4).

6. 1. Usability of Technology – Will I be Able to Use It?

The usability of technology was a concept that emerged related to the lack of comfort many participants had when using electronic devices. Throughout the interview discussion, it became evident that patients had varying experiences with using technology, however, patients with an inadequate self-care score, felt that it would create more challenges than benefits. CPs of both adequate and inadequate patients had also expressed their concern with incorporating an additional component to managing their self-care, as their unfamiliarity with technology could jeopardize their current condition.
This feedback made it clear that the incentive for using the HFApp intervention was absent, as any source of technology was seen as burdensome.

Past studies have indicated that to ensure patients are more comfortable with using technology to self-care, providing education is one of the best modes of action \(^{106, 107}\). However, as many patients with HF have low literacy and numeracy levels, the educational information provided must be created in a patient-friendly format \(^{108, 109}\). Thus, as part of the HFApp intervention, we aim to create a simple, literacy and numeracy sensitive summary regarding the benefits of the app and automation, as well as an instruction manual to ease the operation of its use.

Another aspect involving patients’ resistance to using technology, involved their preference of working with a “real-person” to maintain the human touch associated with their care. Nevertheless, this barrier became less significant once the full HFApp intervention (SDDST + Nursing support + Bluetooth weight scale + Numeracy/literacy sensitive education booklet + Trained volunteer assistance) was explained, and as a result patients and CPs were more willing to use the app. The nursing and trained volunteer support were the key factors that led patients and CPs to improve their comfort and confidence levels.

During the persona-scenario discussions, patients had also indicated the need for simplicity to be incorporated within the app’s design to ensure its overall usability. When working with older adults the statement ‘less is more’ is often key, as their adoption of technology is focused greater on the value, support and confidence obtained from it \(^{109}\).
110. For this intervention, we displayed our mock-up designs, and its simplicity led patients and CPs to agree regarding its user-friendliness (Appendix G). As an added bonus, patients and CPs indicated that having trained volunteers available to provide technical assistance increased the continuity of app activity for patients who are less tech-savvy.

6. 2. Communication – Can I Get a Hold of Others?

One of the on-going issues patients and CPs stressed with their current care was their inability to contact and obtain input from their physician when their symptoms began to worsen. In most cases, patients were able to contact their physician, but the physician was unable to respond fast enough to prevent an emergency visit or hospitalization, due to their demanding workload. This lack of communication currently present led participants to suggest the HFApp become a source for direct communication. The HFApp intervention currently incorporates a community home-based nurse and trained volunteer support, as well as a feature to phone them through the app. Participants highlighted that this extra support would give them more comfort in using the technology and would also provide them with the ‘human-touch’ that they greatly desired.

Nevertheless, some patients preferred to speak solely to their physician. However, by increasing any sort of workload for physicians, this would steer the intervention to become less feasible. The paper-based tool was already tested and proven to be effective without physician guidance, and as the HFApp’s purpose is to promote self-care, the
inclusion of direct physician guidance would decrease their potential to independently make self-care decisions. Instead, we found that when informing patients that physicians and nurses could have access to their app information with their consent, this was a beneficial compromise. Most of the patients and CPs simply wanted their physician to be up to date with their condition, as they would not be able to recall all their self-care information during appointments. Therefore, by automating the weight-tracking aspect of their self-care and allowing physicians and nurses to view this data, this would reduce the burden and effort required by patients and their CPs. However, with the inclusion of this feature we aim to emphasize that the physician would not be obliged to review their patient data on the HFApp but would simply have it as an additional source of information during appointments. This way we would not be adding to the physician’s current responsibilities and would leave the intervention as a self-care tool not a source of tele-homecare.

6.3. Application Customization – Will it Be Suited for Me?

As we moved forward with each discussion session, patients and CPs became more comfortable with the idea of using technology to self-care. With this, many participants began to outline specific features they would like added to customize the app according to their needs. However, some ideas that were suggested created a discrepancy with the HFApp intervention. Specifically, patients wanted to be able to manage multiple medications for their HF on the HFApp, but we had indicated that the app would solely be for weight monitoring and diuretic adjustment. This was mainly because diuretics are
the only medications that have an impact on patient weight that they would be able to adjust (27, 28). Patients are unable to self-manage other medications for HF self-care due to the risk of incorrect dosing that can lead to a high risk of hypotension, bradycardia, electrolyte imbalances, hyperkalemia etc. Other medications for HF management need to be adjusted solely by physicians. In addition, past studies found that when multiple functions are being used within an app, older adults would have greater difficulty using it (111). The ability of multiple medication management is appealing in conversation, but often times its execution is very difficult. Thus, to ensure that the patient’s self-care regimen remains safe, simple and efficient we wanted the app to be limited in its functionality.

To promote technology use, another aspect of customization patients strongly desired involved the addition of notifications within the HFApp. The use of notifications would be similar to a ‘nudge’ to guide patient behavior. The nudge theory, developed by American economist Richard Thaler, discusses this concept where the nudge would serve as a mode of reinforcement or indirect suggestion to promote positive decision-making (112). Often times, patients fail to take their medication or weigh themselves simply because they forget. Therefore, the addition of notifications would be beneficial for patients in need of a reminder.

However, as patients have different schedules and preferences, notifications would need to be tailored to each of the patient’s preferences to increase its effectiveness and prevent the possibility of ‘nudge fatigue’. A few CPs also expressed interest in having these notifications forwarded to them if the patient fails to follow their treatment
regimen. This way every patient would still be responsible for his or her own self-care, but if they begin to fall behind, their CPs would be able to catch them before their symptoms worsened. This aspect of notification forwarding would be active only with patient consent, if they are comfortable with having their CPs being constantly informed.

One of the greatest areas of concern for patients and their CPs involved how they would be able to interact with the app. In section 5.1, ‘Usability of Technology’, participants highlighted the aspect of simplicity and minimalism to increase the usability of the HFApp. Furthermore, as patients may have visual or hearing impairment, a mechanism to adjust the audio and visual settings on the HFApp was crucial to be added (113). One patient also indicated that they did not have any visual or hearing issues, but simply preferred to have a larger font with bigger icons, as it made using the tablet easier. Therefore, the addition of audio and visual settings would not only benefit patients needing the accommodation, but it would also help personalize the app to increase their comfort with the technology.

6.4. Complexity of Self-Care – Does it Make Things Easier?

The difficulties associated with daily HF self-care were strongly emphasized by both patients and CPs. As a result, participants indicated that this perceived self-care burden was the main factor for their low treatment adherence. With these concerns, they did not see any benefit to using technology, as it would be an added component to their already complex treatment regimen. Nevertheless, patients and CPs were intrigued by the unique characteristics of the HFApp, as it would ease the process of weight management
and diuretic adjustment. Patients indicated that one of the greatest challenges associated with their self-care involved adjusting their diuretics with confidence, thus with the automation of the SDDST this would no longer be an issue. In addition, during the persona-scenario discussion, the nursing support was highlighted as a key incentive for the technology-based intervention, as it would reduce their self-care burden. Patients would be able to have proper support on a scheduled basis, to not only ensure the HFApp is being used adequately, but if they have any concerns or challenges with their care. This could prevent patients’ symptoms from worsening and reduce their perceived complexity of self-care.

6.5. Usefulness of HF Related Information – Will I Understand?

As previously mentioned, education is one of the greatest facilitators to promote self-care. However, both patients and CPs expressed that the information provided from physicians or nurses was often not understood or not applicable to their condition. To properly obtain the benefits associated with education, the information must be simple to understand and specific to the patient (88, 109). Past studies have even indicated that individualized education is key to help patients gain the skills needed for adequate self-care, as it accommodates to their learning style and level of health literacy (109, 114). Thus, the previously mentioned HF summary in section 5.1 must reflect these conditions to be effective in promoting self-care.

Interestingly, one patient also proposed the idea of having their EMR information connected to the app. This would help both patients and physicians, as it would increase
the accuracy of their diuretic dosage at home, and their diagnosis in the clinic. Nevertheless, as many hospitals utilize various EMR platforms, the compatibility of patient data to the app may be difficult to resolve, and the approval for its use may be challenging to obtain -. These two issues are common limiting factors for EMR integration within Canada, but we aim to tackle it as we move forward with the HFAApp design process.

6. 6. Long-Term Use and Costs – Can I Afford It?

Towards the end of the persona-discussion, participants had a growing concern regarding the cost of the intervention. The potential dependency that could arise from continual use of the HFAApp could jeopardize their condition if unaffordable costs appeared in the future. Therefore, a source of long-term funding was needed to solidify patient support. We are currently in the process of evaluating sources for the intervention’s long-term use. We suggest that in alignment with the 6 attributes for an effective self-care app outlined in section 1.8.2, by prescribing the HFAApp intervention a mode of treatment, we would potentially be able to cover the associated costs through OHIP and regulate its implementation via Health Canada. Nevertheless, this would need to be further investigated as the development and design of the intervention proceeds.

During discussion, some participants recommended the integration of the HFAApp on their own personal devices (tablet, smartphone, IPad). They claimed that this could reduce any upfront costs associated with the tools in the intervention. Patients may be left with only a monthly subscription, but this cost would not be as significant. Nevertheless,
the issue with integrating the HFApp on personal devices is similar to the issue involving multiple medication management in section 5.3 “Application Customization”. The HFApp is supposed to be used on a tablet solely for HF self-care, with the addition of other functionalities on the device this would complicate the tool and reduce its overall usability (111). More functions create a higher possibility for error or misuse, thus to improve the effectiveness of the HFApp it is more beneficial for older adults to have the tablet for one purpose, at least initially, until the usage conditions for the HFApp were worked out.

6. 7 Study Strengths

This study conducted a series of individual interviews with participants. This allowed for them to have an open conversation without the concern that others would be judging their feedback. Many studies use focus groups more often than individual interviews. However, often times, in focus groups older adults feel threatened due to the pressure of a group setting (116). The use of one-on-one interviews allows participants to create a deeper connection during discussion and ultimately leads to obtaining more insightful feedback.

We also made use of persona-scenarios and mock-ups as modes of user-centered design techniques. This created a series of visual aids that allowed patients and CPs to better understand the intervention, and in turn led to increased feedback. Participants did not have to imagine what the tool would look like or how it would apply to their lives, but they would have a template to evaluate.
Finally, this is one of the first qualitative studies, to our knowledge, to specifically recruit and categorize patients of different self-care adequacy levels according to a validated tool (SCHFI). We wanted to ensure that feedback from different types of patients was obtained to determine whether they faced the same or similar challenges. Many qualitative or usability studies do not take these factors in consideration, which leads to biasing their results and blunting the effectiveness of their intervention \(^{(71)}\).

### 6.8 Study Limitations

Throughout the persona-scenario discussion sessions patients and CPs were limited in their ability to interact with the intervention, as we did not have a developed prototype. The focus of this study was to obtain feedback on participant challenges and HFApp usability; however, they were unable to effectively evaluate its usability because they were only provided with mock-ups and the intervention description. This may have skewed the feedback obtained, thus once the app prototype is fully developed, usability testing must be conducted.

In addition, we aimed to include patients of varying self-care adequacy levels to prevent bias in our evaluation and ensure that we would obtain feedback from a range of patients. However, during recruitment most patients had a CP present at home, and patients who did not were not willing to participate in the study. This limited the number of participants in the inadequate HF patients without a CP group. A larger number of patients with inadequate self-care skills may be required to ensure that design themes created coincide with various groups of patient challenges and needs.
Chapter 7: Conclusion

As the population of older adults continues to rise, the prevalence of HF will continue to increase as well. The promotion of HF self-care can help minimize the readmissions associated with HF, however, the challenges responsible for poor patient self-care have yet to be addressed. Technology has displayed its potential to improve clinical outcomes, but similar to previous interventions, it has failed to address patient challenges within their application designs.

If patients struggle to self-care, there should be a greater focus on how to assist with their treatment regimen to encourage adherence, instead of over-burdening them to go beyond their capabilities. Today, value-based outcomes and patient engagement is key to managing costs, which self-care can help achieve. The HFApp intervention is a multifaceted approach that eases the self-care process and provides the necessary support to ensure the longevity of its use. Our solution appears promising in that it: a) promotes self-care with a literacy/numeracy sensitive education, b) automates diuretic adjustment with a SDDST, d) involves CPs in assisting patients to manage their disease, and e) improves communication with nurses at discharge. However, as innovative solutions are strongly dependent on its design, we directly consulted patients and their CPs regarding their needs, challenges and capabilities. We identified 6 major design themes to reflect a series of requirements to improve the HFApp, but once a prototype has been developed, usability testing will be needed to ensure these findings are coherent with the actual device.
References:


4. Cardiac Care Network Strategy for Community Management of Heart Failure, Feb 2014


doi:10.1097/JCN.0b013e3181b4ba0.


66. Lloyd, Tom, Harleah Buck, Andrew Foy, Sara Black, Antony Pinter, Rosanne Pogash, Bobby Eismann, Eric Balaban, John Chan, Allen Kunselman, Joshua


95. Cooper, A. (2004). The inmates are running the asylum: [Why high-tech products drive us crazy and how to restore the sanity]. Indianapolis, IN, USA: Sams.


Appendix A: List of app features required for an adequate heart failure self-care app

<table>
<thead>
<tr>
<th>App Features</th>
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<tbody>
<tr>
<td>1. Prescribed</td>
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<tr>
<td>2. Diagnosis</td>
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<tr>
<td>3. Patient Demographics</td>
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<tr>
<td>4. Patient socio-cultural</td>
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<tr>
<td>5. Patient Symptoms</td>
</tr>
<tr>
<td>6. Patient Behaviors</td>
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<tr>
<td>7. Patient Physiological Observations</td>
</tr>
<tr>
<td>8. Weight**</td>
</tr>
<tr>
<td>9. Co-Morbidities</td>
</tr>
<tr>
<td>10. Drug-List</td>
</tr>
<tr>
<td>11. Lab Results</td>
</tr>
<tr>
<td>12. Diagnostic Testing</td>
</tr>
<tr>
<td>13. Behavior Tracking</td>
</tr>
<tr>
<td>14. Education/ Recommendations</td>
</tr>
<tr>
<td>15. Self-Care</td>
</tr>
<tr>
<td>16. Health System Utilization</td>
</tr>
<tr>
<td>17. Notifications</td>
</tr>
<tr>
<td>18. Integrations</td>
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<tr>
<td>19. Social Supports</td>
</tr>
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<td>20. PROMS/PREMS</td>
</tr>
<tr>
<td>21. Incentives to Use</td>
</tr>
<tr>
<td>22. Predictive Analytics</td>
</tr>
<tr>
<td>23. Outcomes</td>
</tr>
<tr>
<td>24. Safety Issues</td>
</tr>
<tr>
<td>25. User Interface</td>
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Appendix B: Standardized Diuretic Decision Support Tool

Canadian Copyright Register

Data on copyrights is shown in the official language in which it was submitted. The links on the text provide access to the help file.

Title: Heart Failure Diuretic Decision Support Tool for Patient Self Management
Type: Copyright
Registration Number: 1105713
Status: Registered
Registered: 2013-06-20
Category Of Work: Literary

Interested Parties:

Owner:
Person Name: Catherine Demers
Original Address: 1061 North Shore Boulevard East Burlington
Ontario L7T 1X9
Canada
Current Address: Same as original address.

Author:
Person Name: Catherine Demers
Original Address: 1061 North Shore Boulevard East Burlington
Ontario L7T 1X9
Canada
Current Address: Same as original address.
Appendix C: Recruitment Telephone Script

Participant Recruitment Telephone Script:

Hello (Participant name),

My name is Sahr Wali. 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, we will ask you to evaluate the tool to see whether it would help you on a day-to-day basis. We will then ask you to come up with ideas on how you would use the tablet tool and whether there are specific features you would want included or excluded. Feedback and suggestions will be recorded for analysis afterwards.

The session will take place at the General Hospital location of Hamilton Health Sciences and will last for about two hours. We will pay for your parking and will provide you with a gift certificate ($20.00/person) 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 D: Patient Consent Form

LETTER OF INFORMATION / CONSENT

Study Title: Qualitative Data Collection to Enhance Heart Failure Self-Care App

Investigators:

Local Principal Investigator:  
Dr. Catherine Demers  
Department of Medicine  
McMaster University  
Hamilton, ON, Canada  
(905) 521-2100 ext. 73324

Student Investigator:  
Ms. Sahr Wali  
Department of Medicine  
McMaster University  
Hamilton, ON, Canada

Purpose of the Study

The purpose of this study is to provide patients like you with a reliable tool that will allow you to follow simple instructions to take care of your heart failure.

You have been diagnosed with heart failure. Heart failure can often cause 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 invited to participate in a research study to evaluate how you would use a new tool that we are developing to help manage your heart failure after being sent home from the hospital. This tool, called the standardized diuretic decision support tool, is a paper tool that helps you collect information on your weight at home. It also helps you and
your family members, or friends, to make decisions about adjusting your water pills for your heart failure.

Our goal is to find out what your needs are in order to change this paper tool into an electronic tool. This electronic tool, also known as an “app”, would have the same features as the paper tool, but you would be able to use it on a tablet or computer at home.

**Procedures involved in the Research**

If you agree to participate in this study, you will be asked to attend one discussion session that will take place at the General hospital site of the Hamilton Health Sciences for approximately 2 hours.

A detailed explanation of the standardized diuretic decision support tool will be given at the beginning of the session. During the discussion session, we will be going over one of the provided pretend stories about an individual with the same health conditions as yourself. After reviewing the story, you will then be asked to provide feedback on how the standardized diuretic decision support tool helps or does not help each pretend person.

After this, we will ask you to come up with ideas on how you would use the tool and whether there are specific features you would want added or removed.

For the purpose of the study, we will also need to review your medical chart to obtain some basic health information, which includes your heart failure medical history, age, other major illnesses, list of medications and admission/discharge dates. This is information will be used solely for research purposes and every effort will be made to protect your information privacy.

**Potential Harms, Risks or Discomforts:**

The risks involved in participating in this study are minimal. You may feel uncomfortable or worry when speaking with others in the group.
However, we will be working hard to make sure that all the participants are welcomed into an open environment.

You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. If you need to stop to take a break you are always free to do so. You are also always given the option to leave the study at any time.

**Potential Benefits**

Your participation will give us a better understanding of how patients, like you, use the tool to manage heart failure and what your needs are. As a result, this study will provide us with information on how to help patients better care for their heart failure, as well as help guide future self-care programs.

**Payment or Reimbursement**

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.

**Confidentiality**

During the study we will not use your name or any information that would allow you to be identified. Every effort will be made to protect your information and privacy. As soon as data is collected, we will remove any identifiable information (for example, your name, age, etc.), and then transfer the data onto a computer file that is protected.

The information will be stored securely offline in a password-protected personal computer in a password-protected file. Once the study has been completed, the data will be transferred to and stored in a secure office space occupied by Dr. Demers for the next 7 years. After 7 years the data will be permanently deleted.

**Participation and Withdrawal**
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.
You may contact the researcher verbally during the meeting or by phone
call to withdraw from the study.

All our information will be stored in a secure manner to respect patient
privacy and confidentiality. As this information is identifiable we will
de-identify it to maintain patient privacy and confidentiality.
Information may still be used for analysis, but it will 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.

**Information about the Study Results**

We expect to have this study completed by June 2018. We will provide
you with a brief summary of the results once the study has been
completed.

**Questions about the Study**

If you have questions or need more information about the study itself,
please contact Dr. Demers’ office at (905) 521-2100 ext. 73324.

This study has been reviewed by the Hamilton Integrated Research
Ethics Board (HiREB). The HiREB is responsible for ensuring that
participants are informed of the risks associated with the research, and
that participants are free to decide if participation is right for them. If
you have any questions about your rights as a research participant,
please call the Office of the Chair, HiREB, at (905) 521-2100 ext. 42013.
CONSENT

I have read the information presented in the information letter about a study being conducted by Dr. Catherine Demers and Sahr Wali of McMaster University.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time. I have been given a signed copy of this form. I agree to participate in the study.

_______________________  ______________  ___________
Name of Participant (Printed)  Signature  Date

_______________________  ______________  ___________
Name of Person Obtaining Consent (Printed)  Signature  Date
Appendix E: HFApp Intervention Outline

This study will be conducting a self-care intervention for patients with heart failure (HF) after hospital discharge. It will be using an online system called the standardized diuretic decision support tool to collect patient monitoring data, help educate patients/ informal caregivers, and to help patients self-manage their diuretic dosage.

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 illnesses while living at home.

The program has four components:

1. Online HF Self-Management Support System: HF App 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. LHIN Rapid Response Teams for patients with HF: This program aims to help us understand how HF App 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, home nursing and volunteer support.

Note: Your evaluations may involve all or some of these four components.
Appendix F: Persona-Scenarios

<table>
<thead>
<tr>
<th>Diane Lambert</th>
<th>Bio</th>
<th>Goals</th>
</tr>
</thead>
</table>
|               | Diane has lived a healthy lifestyle for the majority of her life. She has worked at the post office for the past 29 years. Her time at the post office has gained her some basic computer skills, but she is still unfamiliar with using new technology like tablets, mobile phones or leads. Diane was not concerned with her health until her recent diagnosis with heart failure (HF). She is now concerned about how she will be able to take care of herself, so she spends her weekends at her daughter’s house. Diane would like to be able to keep track of her weight and medication, but she is overwhelmed and tends to forget what she needs to do. | • Learn how to use HF App without assistance  
• Be able to manage her weight and medication on a consistent basis |
|               | Diane was not concerned with her health until her recent diagnosis with heart failure (HF). She is now concerned about how she will be able to take care of herself, so she spends her weekends at her daughter’s house. Diane would like to be able to keep track of her weight and medication, but she is overwhelmed and tends to forget what she needs to do. | Frustrations |
|               | Diane gets very emotional about her HF because she feels she is no longer in control. She fears that she will not be able to take care of herself and she will result in getting worse. Her daughter uses her fear to motivate her to use the HF App, so it can help her manage her conditions. Diane is hesitant at first, but she is willing to try for her daughter. | • Unfamiliar with using ipads or tablets- She must learn from scratch  
• New to self-care regimen - Feels unable to take care of herself  
• Diane wants to use HF App but loses faith in herself when she comes across any troubleshooting issues |

<table>
<thead>
<tr>
<th>Attitude</th>
<th>Friendly</th>
<th>Forgetful</th>
<th>Dependent on Others</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Needs</th>
<th>Behavior</th>
</tr>
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<tbody>
<tr>
<td>Diane has her scale set up at her house, but on Saturday she takes it with her to her daughter’s house. She tries to measure her weight the next morning, the scale does not send link to the HF App. The HF App is physically connected to the scale, and Diane had set it up as it was in her home, but she still has trouble measuring her weight.</td>
<td>- Technical Assistance/ Support</td>
<td>Diane opens the HF App to the “Measure my Weight” option and then clicks the “Help” option. She clicks “technical assistance” and then gets connected to a nurse/volunteer via phone. Diane is told to unplug the device, but it still does not work. She ends up having to schedule a visit from the nurse/volunteer to come in to her daughter’s home.</td>
</tr>
</tbody>
</table>
Scenario
Since Christina has used the HF App she has noticed her weight has become more stable. However, this morning her weight had gone up and the HF App recommended a change in her water pill dosage. Christina does not feel confident in the dosage change.

Needs
- Additional medication information

Behavior
Christina opens the HF App to “Take My Medication” and then to the “Why” option. She does not feel the extra information is sufficient, so she gets connected to a nurse/volunteer. She then directly asks to speak to a physician, as she is more comfortable.
Mark is at the office and he gets a notification on his phone stating that his wife has not weighed herself this morning.

- Additional information regarding wife’s condition

Mark calls his wife but she does not answer the phone. He is overwhelmed because he does not have access to the HF App, so he cannot check if anything serious has occurred. He leaves work and goes home. Mark sees that his wife is simply sleeping. He checks the HF App and everything seems to be in line.
### Scenario
Sarah gets a call from her father and he says that the scale is not working.

### Needs
- **Technical Assistance**

### Behavior
Sarah comes home and checks the scale. She finds that the wireless scale is not connecting, so she connects the scale physically with a cable. The scale then connects and her father is able to weigh himself. She asks her father why he didn’t contact the volunteer/nurse and he said he didn’t know how. She contacts the volunteers and schedules an in-home visit so they can help her father understand how to better use the HF App.
Appendix G: HFApp Mock-Up Designs

Welcome to the Heart Success App!

Hello John Doe & Welcome Back!

Heart Success App
John Doe’s Ideal Weight: 
John Doe’s Weight Today: 

Measure My Weight
Take My Medication
See My History

Measure My Weight
Please Step on the Scale
Kg or Lb

Re-Do
Accept

Not You? Logout
Appendix H: Discussion Session Questions

HFApp Discussion Session Guide:

Based on your knowledge and experience as a patient, evaluate the following patient personas and the “scenarios” for each “persona” interacting with the self-care intervention program.

**Note: If you have any questions feel free to ask the discussion leader or the volunteers**

**STEP 1: Evaluate the Persona**

Questions to Consider:

1. Does the self-care program help the patient’s situation?
2. Is the self-care program practical for the patients’ scenario(s)?
3. Does the patient feel comfortable with the self-care program?
4. What information do they need to help manage HF and patient communication?
5. How do they use the HF App or how do they interact with the self-care program?
6. How are the self-care program components interacting with the patient? 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]?
7. What happens after the interaction?
8. What are the results/outcomes of this interaction?
9. Are there any important areas the self-care program does not help with?

**STEP 2. Come up with ideas on how to improve the tool**

Note: This will be recorded for later review.
Appendix I: Informal Feedback Questions

1. What did you like about the discussion today?
2. What didn’t you like about the discussion today?
3. Was it easy to complete the study?
4. Is there any way that you would want us to improve on the discussion style?
5. Did you like how we ran the discussion (having it in pairs and then the larger group)?
6. Overall, did you find the HF App useful?
7. If you could change anything with the HF App, what would you change?
8. Is there anything else you would like to share about your experience today?
## Appendix J: Design Themes from Previous Study

<table>
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<tbody>
<tr>
<td>1. Comfort in using technology</td>
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<tr>
<td>2. Willingness or interest in HF self-care</td>
</tr>
<tr>
<td>3. Provision of Knowledge</td>
</tr>
<tr>
<td>4. Support and Security</td>
</tr>
<tr>
<td>5. Connection to formal and informal caregivers, family members or health care providers to assist in HF self-care</td>
</tr>
<tr>
<td>6. Tailoring the self-care intervention based on the needs of patients, informal and formal caregivers and families</td>
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Appendix K: HiREB Ethics Approval

May 18 2017

Project Number: 2768

Project Title: Qualitative Data Collection for Development of an Electronic Application to Promote Home-Based Self-Care in Older Heart Failure (HF) Patients: Patient and Informal Caregiver Perspectives

Student Principal Investigator: Ms Sahr Wali

Local Principal Investigator: Dr Catherine Demers

We have completed our review of your study and are pleased to issue our final approval. You may now begin your study.

The following documents have been approved on both ethical and scientific grounds:

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<td>May-09-2017</td>
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<td>Feb-13-2017</td>
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Any changes to this study must be submitted with an Amendment Request Form before they can be implemented.

This approval is effective for 12 months from the date of this letter. Upon completion of your study please submit a Study Completion Form. If you require more time to complete your study, you must request an extension in writing before this approval expires. Please submit an Annual Review Form with your request.

PLEASE QUOTE THE ABOVE REFERENCED PROJECT NUMBER ON ALL FUTURE CORRESPONDENCE

Good luck with your research,

Kristina Trim, PhD, RSW
Chair, HiREB Student Research Committee
McMaster University