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Patient Portal Use, Health Information Technology Self-Efficacy, Electronic Health Literacy, and Self-Management among Patients with Heart Failure: A Cross Sectional Study

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PATIENT PORTAL USE, HEALTH INFORMATION TECHNOLOGY SELF-EFFICACY, ELECTRONIC HEALTH LITERACY, AND SELF-MANAGEMENT AMONG PATIENTS WITH HEART FAILURE: A CROSS SECTIONAL STUDY

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By
Pamela S. Kallmerten

August 2021

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By

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Approved July 1, 2021

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ABSTRACT

PATIENT PORTAL USE, HEALTH INFORMATION TECHNOLOGY SELF-EFFICACY, ELECTRONIC HEALTH LITERACY, AND SELF-MANAGEMENT AMONG PATIENTS WITH HEART FAILURE: A CROSS SECTIONAL STUDY

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August 2021

Dissertation supervised by Dr. Melanie T. Turk

Background: By the year 2030, the prevalence of heart failure (HF) is anticipated to rise by 46%, impacting over 8 billion persons. Self-management of HF is key to maintaining a healthy lifestyle and quality of life. Yet many have sub-optimal self-management skills necessitating innovative strategies to enhance self-management. An innovative strategy to support the person with HF is the use of health information technology (HIT) such as a patient portal (PP). Additionally, self-efficacy and health literacy are important to self-management of HF. Further understanding is needed of the relationship between PP use, HIT self-efficacy (HIT SE), electronic health literacy (eHL) and self-management among persons with HF. **Objective:** To describe patient portal use among persons with HF, explore differences in PP use based on demographic characteristics, and examine associations between the key variables of PP use, HIT SE, eHL, and self-management of HF. **Methods:** A cross sectional design with an anonymous electronic survey was used to collect data on: demographics, the Self-Assigned New York Heart Association Classification (SA-NYHA), PP use, HIT SE, eHL, and self-management as measured by the Self-Care Heart Failure Index (SCHFI). Self-report data from a convenience sample from three facilities in the Northeastern United States was explored using descriptive statistical analysis, Chi Square tests of independence, and a Kruskal-Wallis/Jonckheere Terpstra analysis. **Results:** Among persons with an active diagnosis of HF who were registered for their PP (*N=20*), 90% were >60 years, and 95% were diagnosed within the previous decade; 75% classified themselves as Class I/II according to the SA-NYHA. Sufficient HIT SE (M= 23.3, *SD*=4.2) and eHL (M=31.1, *SD=5.4*) was reported. Sixty percent reported using the messaging feature while <40% reported using any other features. Forty percent were categorized as a non-user, with 25% light and 35% active users. There were statistically significant associations between the category of PP user and the site where they received care (x^2 (4)=18.19, p=.001) as well as their SA-NYHA Classification (x^2 (2)=6.59, p=.037). There were no statistically significant relationships between the category of portal user and HIT SE, eHL, or self-management of HF. All SCHFI scores indicated adequate self-care except for the SCHFI for self-care management (M=60.7, *SD*=22.0). **Conclusion:** This small sample reported sufficient HIT SE and eHL, yet only 35% were active PP users, and use of PP features was limited. Finally, there remains an opportunity to support self-management of HF.

DEDICATION

First and foremost, I would like to dedicate this dissertation to my husband, Dan. You always challenge me to be better and stand by my side through good days and bad. Without your love, support, advice and patience during this journey, I would not have endured and enjoyed this transformative process. I would also like to thank my family for their gifts of love, encouragement and laughter.

I would also like to express profound gratitude for my committee chair, Dr. Melanie Turk who readily shares her wisdom as a nurse scientist and educator. Especially impressive is her ability to reassure her students that this is possible even amid a global pandemic. She completely understood when to pause, persist or pivot and helped me to realize my goal.

I am grateful for the support of my committee, Dr. Karen Jakub and Dr. Eun-Shim Nahm, throughout this process and for Dr. James Schreiber's patience with all things statistical. Finally, I am thankful for Dr. Joanne Samuels and Dr. Rebecca Chia for their foundational support as I started this educational journey.

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Finally, I would like to acknowledge the Eta Iota At-Large Chapter of Sigma Theta Tau International for their research award to support this study.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF ABBREVIATIONS

HIT = Health Information Technology

SE = Self-Efficacy

eHL = Electronic Health Literacy

SCHFI = Self-Care Heart Failure Index

HITAM = Health Information Technology Acceptance Model

SA-NYHA = Self-Assigned New York Heart Association

PP = Patient Portal

HF = Heart Failure

Patient Portal Use, Health Information Technology Self- Efficacy, Electronic Health Literacy, and Self-Management among Patients with Heart Failure:

A Cross Sectional Study

Specific Aims

Heart Failure (HF) is a chronic condition affecting nearly 6 million adults in the United States with a 50% five-year survival rate and an economic burden of nearly $31 billion annually (Centers for Disease Control [CDC] 2016). Like many chronic conditions, effective self-management is necessary to improve health outcomes and reduce the cost of care (Benjamin et al., 2017). Yet many with heart failure have sub-optimal self-management skills impacting health outcomes and necessitating costly medical attention. Udlis (2016) defined self-management as the ability to manage the dimensions of resource utilization, active participation in managing the self, and shared decision-making with caregivers. Antecedents include self-efficacy, the ability to access quality information, effective health literacy, support from family, friends and health care providers, intention and mutual investment in the patient-provider relationship (Udlis, 2011). Self-efficacy, or the person's perception of the ability to perform an act, is a major aspect of self-management. Health information technology (HIT) represents the use of electronic systems in health care to store and share health information to improve care (HealthIT.gov, 2013). Combining both concepts, HIT self-efficacy is the individual's perception of the ability to perform a task using HIT (Kim & Park, 2012). In addition, eHealth literacy or the ability to seek, find and appraise health information from an electronic resource is important for optimal use of HIT (Norman & Skinner, 2006b). Meaningful use of HIT such as the patient portal may enhance self-management of heart failure. A patient portal is a secure online personal health record that is tethered to a provider's electronic medical record. Using a patient portal can enhance health knowledge and patient-provider communication and may improve HIT self-efficacy, and eHealth literacy in the service of improving self-management skills.

A review of the literature to explore the use of a patient portal by the heart failure population noted very few studies that examined the relationship between portal use, HIT self-efficacy, ehealth literacy and self-management of heart failure. Therefore, a better understanding of these factors may inform decisions that are to be made regarding the information in and policies for use of a patient portal for the person with heart failure. Increased understanding of these relationships could lead to improved health outcomes and reduced economic burden. The proposed study seeks to examine the relationship between the use of a patient portal, HIT self-efficacy, eHealth literacy and self-management of heart failure.

Maximizing the heart failure patient's efforts for self-management is critical to improve health care outcomes and reduce the cost of care. In preliminary work, barriers and facilitators to patient portal use were explored leading to the identification of an initiative to improve patient portal utilization rates (Kallmerten, 2016). More recently, a qualitative pilot study conducted by the principal investigator elucidated the HIT experiences of the adult with heart failure who had been readmitted to the hospital for exacerbation. Adults with heart failure reported patient portal use either personally or in partnership with a caregiver but reported various usability concerns including difficulty with the login process. This study suggested the need to examine patient portal use, HIT Self-efficacy, and eHealth literacy in the self-management of heart failure.

The proposed study that will examine the relationship between portal use, HIT self-efficacy, and eHealth Literacy in the adult patient with heart failure will help us understand how these concepts impact self-management. A descriptive, cross sectional study will examine associations between patient portal use, HIT self-efficacy, and eHealth literacy, in the self-management of heart failure in a sample of patients in Central New Hampshire. This study will be guided by the Health Information Technology Acceptance Model which describes three zones of beliefs that impact the behavioral intention important in the acceptance of technology: the health zone, the information zone and the technology zone (Kim & Park, 2012). A chronic disease such as heart failure impacts the perceived threat to health in the health zone. HIT Self-efficacy and eHealth literacy are major concepts in the information and technology zones that impact the perception of usefulness and ease of use. Finally, the acceptance of the patient portal can impact the consumers' use of health information technology to improve self-management (Ong, 2016). The specific aims of this study are to:

Aim 1: Describe patient portal use among persons with heart failure to include frequency of use and specific use of features such as the portal messaging system to email their provider or make appointments for routine or follow-up care.

Aim 2: Explore potential differences in patient portal use among patients with heart failure based on gender, age, race, educational background, yearly household income, years since diagnosed and Self-Assigned New York Heart Association (SA-NYHA) Classification.

Aim 3: Examine associations between patient portal use, HIT self-efficacy, and eHealth literacy in the self-management of heart failure.

A deeper understanding of the relationship between patient portal use and the antecedents to self-management may translate into improved health outcomes and reduced cost of care. This research aligns with the strategic plan of the National Institute of Nursing Research and the key theme of Self-Management: Improving Quality of Life for individuals with chronic illness. In addition, it addresses innovation via the use of technology to improve health. Ultimately, this optimized use of HIT may reduce the economic burden and improve overall health and quality of life for patients with heart failure.

Significance

By the year 2030, the prevalence of this condition is projected to increase by 46% affecting more than 8 million people with a projected cost increase by 127% to nearly $70 billion annually (Benjamin et al., 2017). This chronic disease is associated with patient report of outcomes such as fatigue, dyspnea and depression which can interfere with self-management. When a patient is faced with perceived threats to their health, information-seeking behavior is noted in an attempt to enhance knowledge of the disease process, plan of care, and self-management (Udlis, 2011). Prior findings suggest that the consumers' use of a patient portal would be especially beneficial for patients with a chronic condition that required self-management (Ong, 2016).

Yet many patients have sub-optimal self-management skills which can necessitate costly urgent or emergent care such as emergency department visits and hospitalizations. Rates of hospitalizations are increasing for those with heart failure and 83% were hospitalized at least once after diagnosis with over 40% hospitalized at least four times (Benjamin et al, 2017). Innovative strategies are necessary to improve self-management skills and enhance health outcomes for those with heart failure. One such strategy to enhance self-management of heart failure involves the consumers' use of HIT such as the patient portal to manage personal health information. Using a patient portal can provide quality information and support the mutual investment between the patient and the healthcare provider which are important antecedents to self-management (Udlis, 2011).

Patient Portal Use

A review of the literature in patient portal use by persons with heart failure revealed that most define use as registration for the portal and lack of registration as non-use. Most reported access in terms of registration but not use (Holden et al., 2017; Schprechman et al., 2013). Clear definitions of usage to include frequency and type of usage would enhance understanding of use beyond simple registration for portal use. For example, the use of features such as the sending and responding to email messages through the patient portal may suggest more patient engagement. As noted by Udlis (2016) information and support from the healthcare provider are antecedents to effective self-management. A deeper understanding of the relationship between the extent of portal use and self-management will be examined by this study by exploring how a patient uses the technology.

Self-Efficacy

Self-Efficacy, or the belief in one's ability to accomplish a task, has been identified as a crucial antecedent to self-management (Udlis, 2011). Yet only three studies exploring the use of a patient portal by a person with heart failure examined this concept (Dang et al., 2018; Earnest et al., 2004; Ross et al., 2004). Most of the studies identified in the integrative review of the literature examined the general concept of self-efficacy with the general self-efficacy scale. One author identified self-efficacy as the primary variable of interest in a study examining self-management of heart failure with the general self-efficacy scale but no significant differences were noted between patient portal users and non-users (Ross et al., 2004). Dang et al (2018) used an alternative scale, the Self-Efficacy for Managing Chronic Disease but found no significant differences among portal users compared to non-users (Dang et al., 2018). While the concept of general self-efficacy has been explored as a variable impacting self-management, there have been no studies that examined the concept of self-efficacy specific to the use of HIT such as the patient portal. This study will narrow the focus of self-efficacy of the person with heart failure from the broad general self-efficacy to HIT self-efficacy important to self-management.

Health Literacy

Health literacy is the ability to obtain, read, understand and use health information (Norman & Skinner, 2006b). Only two of the studies examined in an integrative review of the literature explored the association between health literacy and patient portal use. One researcher assessed health literacy with the Newest Vital Sign (NVS) instrument and noted that 75% of the participants had adequate general health literacy (Rohani Ghahari et al., 2018). The Medical Term Recognition Test (METER) is a tool for health literacy that showed that higher METER scores predicted e-mail use but not web based patient portal use (Schprechman et al., 2013). While many studies have examined the association between general health literacy and the use of the patient portal, none of the studies examined the association between electronic health literacy (eHL) and patient portal use. Health literacy differs from eHealth literacy which is the ability to use a computer to use and understand health information (Norman & Skinner, 2006b). The proposed study will examine the relationship between eHealth literacy specifically and self-management of heart failure.

Self-Management

A review of the literature suggests that the terms self-management and self-care are often used interchangeably in the heart failure population (Riegel et al., 2016). Self-care is considered a broader term encompassing self-management as specific to symptom response. Self-care is defined as a naturalistic decision-making process that patients use that influences actions to maintain physiological stability (self-care maintenance), perceive symptoms of heart failure (symptom perception), and respond to symptoms when they occur (self-care management) (Riegel et al., 2004; Riegel et al., 2016).

In a concept analysis of self-management, five dimensions were noted including resources, knowledge, adherence to the plan of care, active participation and informed decision making (Udlis, 2011). Self-maintenance was reported as better by those using the technology enhanced care of the patient portal ($p<0.05$) (Brennan et al., 2010). Ross et al (2004) noted that portal users had significantly better general adherence scores ($p=0.01$). Qualitative and usability studies show that usability and acceptance of the electronic PHR can impact medication adherence (Mickelson et al., 2015). In addition, usability in impacted by the time and effort spent in accessing resources on the patient portal. It was also reported that portal use can support recording personal health information and communication with their provider that is reflective of active participation in their care (Ferguson et al., 2010; Wakefield et al., 2017). Rohan Ghahari et al (2017) reported that heart failure patients were reportedly interested in the use of a patient portal to enhance knowledge of their condition and to communicate with their provider to improve self-management.

Theoretical Framework for the Proposed Study

A review of the literature identified many theoretical frameworks in the use of technology to improve patient care in the outpatient setting. The most frequently used framework to describe consumer use of technology is the Technology Acceptance Model (TAM) or one of the many revisions (TAM 2, TAM 3) (Venkatesh & Bala, 2013). Most of these were developed to address the healthcare workers rather than a patient's use of technology and one of the constructs is that of job relevance. Thus, the original TAM and the revised versions were not suitable for this research. The best fit for this research was determined to be the Health

Information Technology Acceptance Model (HITAM) which broadens the focus from the technology realm to include the health status of the person as well as the quality of the information (Kim & Park, 2012).

The Health Information Technology Acceptance Model (HITAM) was developed by Kim and Park (2012) as an extension of TAM that also incorporated constructs from the Theory of Planned Behavior (TPB) and the Health Belief Model (HBM) (See Figure 1). The HITAM categorizes the antecedents to the intention to measure, store, and manage PHI into three domains called the health, information, and the technology zone (Kim & Park, 2012). Within the health zone are constructs from the Theory of Planned Behavior (behavioral beliefs) as well as the Health Belief Model (health status, health belief and concerns and perceived threat). Within the information zone are constructs from the Theory of Planned Behavior (normative beliefs and subjective norm). Lastly, within the technology zone are constructs from the Theory of Planned behavior (efficacy beliefs) and Technology Acceptance Model (HIT reliability and self-efficacy). These antecedents are mediated by the perceived threat to health, perceived usefulness of the information and the technology and the perceived ease of use. These mediating processes can impact the attitudes that generate behavioral intentions and lead to a change in behavior (Kim & Park, 2012).

The proposed study will benefit from the use of the HITAM as a framework guiding the research because it more effectively captures the influencing factors in the use of HIT for behavior change. The population of interest, persons with heart failure, is addressed through this framework within the health zone as the chronic condition impacts their health status, beliefs and concerns that are mediated by a perceived threat to health. The use of the patient portal as an electronic repository of information as well as a mechanism for communication between the patient and their provider is addressed in the information and technology zones. The HIT self-efficacy is a core component of the technology zone impacting the perception of usefulness and ease of portal use. eHealth literacy is a core component of the information and technology zones as well the ability to use the information to address a health problem such as heart failure. Finally, the mediating processes of perceived threat, usefulness and ease of use impact the attitude that leads to an intent to change behavior for enhanced self-management.

Relationship between Patient Portal Use, HIT Self-Efficacy, eHealth Literacy (eHL) and Self-Management

It is important to recognize the opportunities to maximize the self-management efforts of the person with heart failure. One such opportunity is to continue to explore the relationship between patient portal use, HIT self-efficacy, eHL, and self-management in the person with heart failure. To date, patient portal use by the person with heart failure has been restricted to whether or not a person was registered to use the portal and not by examining the granular elements of use suggesting bi-directional communication and engagement. Although studies have explored the association of general self-efficacy with portal use, there have been no studies exploring the association of HIT self-efficacy with portal use by the person with heart failure. Likewise, the association of general health literacy and portal use has been explored but research has not been conducted to explore the relationship between eHealth literacy and portal use by the person with heart failure. Finally, an examination of the associations of patient portal use, HIT self-efficacy, eHealth literacy and self-management of heart failure has not been addressed.

Importance of the Proposed Study to Healthcare and Nursing

Despite heavy investment by organizations, portal utilization remains low. A deeper understanding of the relationships between the antecedents to and consequences of self-management advances the state of the science to better support patient centered care. This new knowledge can be useful to tailor the functionality of the portal so that the use is truly meaningful for the person with heart failure. Additionally, the collaborative effort between the person with heart failure and the healthcare team can enhance the patient-provider relationship and support shared decision making. An understanding of the relationship between portal use, HIT self-efficacy and eHealth literacy in the self-management of heart failure can help providers to leverage the use of the technology to improve self-management.

Innovation

This study is innovative in several ways including expanding the definition of patient portal use beyond that of registration, exploring the relationship between portal use, HIT self-efficacy, and eHealth literacy in self-management, and the use of the HITAM as a theoretical framework.

The Health Information Technology for Economic and Clinical Health (HITECH) Act provided a stimulus for the provision of electronic access to personal health information by consumers as a way to improve patient engagement. Meaningful use of patient portals are expected to improve patient engagement and clinical outcomes (Ong, 2016). Organizations have responded with offering the portal to their patients to meet meaningful use criteria. In the first stage, the number of registrations was a metric satisfying the meaningful use criteria. With the second stage of meaningful use, more emphasis was placed on the use of portal features such as viewing, downloading and transmitting (VDT) of information and communicating with patients via the sending of messages through the patient portal. However, there is a lack of research on an expanded definition of patient portal use by adults with heart failure beyond the first stage of meaningful use. The proposed study will focus on a more robust definition of use rather than access or registration. The person with heart failure will be asked to describe frequency of portal use as well as use of the features such as VDT, sending messages through the portal, requesting referrals and scheduling appointments connoting bi-directional communication that is a noted antecedent to self-management.

Udlis (2011) identified self-efficacy and the ability to use information or health literacy as antecedents to self-management. However, very few studies have explored the relationship between self-efficacy and patient portal use by the adult with heart failure. In addition, while the relationship between the concepts of health literacy and portal use has been explored in these studies, the concept of eHealth Literacy and portal use by the adult with heart failure has not. eHealth Literacy more accurately reflects the concept of using a patient portal to organize personal health information to support self-management.

The most commonly used theoretical framework for guiding HIT research is the Technology Acceptance Model (Venkatesh & Bala, 2013). This framework is limited to a focus on the technology itself and, while important to the adoption and use of HIT, does not capture the full elements leading to the intent to use and actual change in behavior that is captured by the Health Information Technology Acceptance Model (HITAM). The HITAM is an optimal choice to explore not only the technology aspects of portal adoption and use but the health status and information aspects integral to the change in behavior. An understanding of the antecedents and the mediating processes such as the perceived threat, usefulness and ease of use can be useful to leverage the technology to support self-management.

These innovative strategies have the potential to expand our knowledge regarding portal use and the antecedents to self-management that can be utilized to refine patient centered care for the person with heart failure.

Approach

Preliminary Work Exploring the Decision to Use a Patient Portal

Implementation of a healthcare improvement project to improve patient portal use in a local medical group was conducted by the principal investigator (Kallmerten, 2016). The global aim of the two-part research translation project included the promotion of patient engagement by ascertaining the patients' perceptions leading to their decision to use a patient portal and the identification of potential strategies to increase portal use. During phase I of the project, the patients completed a survey adapted from the instrument used in the development of the Health Information Technology Acceptance Model (HITAM) (Kim & Park, 2012). The HITAM model distills the facilitating and barrier factors of acceptance of health information technology (HIT) such as the patient portal into three zones of influence: the health, information and technology zones. In the health zone, the presence of a chronic condition such as heart failure as well as the perception of *general* self-efficacy impacts the perceived threat to health. In the information zone, the quality of the information as well as health literacy or the ability to use the information impacts a perception of usefulness. In the technology zone, the usability and functionality of the patient portal in addition to the *HIT* self-efficacy impacts a perceived ease of use. These perceptions lead to a positive attitude and the intent to use the technology to change behaviors important in self-management (Kim & Park, 2012).

An electronic survey was created which incorporated the HITAM survey as well as an assessment of baseline patient engagement with the *Patient Activation Measure* (PAM®) (Hibbard et al., 2007). When comparing portal users (n=235) to non-users (n=36) differences were noted in the perception of usefulness as well as the related outcomes of attitude and intent to use the technology. In addition, it was noted that if a patient perceived the portal as useful, they were 1.44 times more likely to register and use the portal (Kallmerten, 2016). There were no differences in baseline patient engagement. This information was presented to key stakeholders and used to identify potential strategies to increase portal use in the second phase.

In phase II, an intervention to potentially increase the percentage of patient registration and use of the portal was selected. This intervention, the release of the complete office note through the patient portal is called *Open Notes. Open Notes* is a national initiative to improve the information available through the portal and contribute meaningfully to the patient-provider relationship by facilitating communication and transparency (Delbanco et al., 2012). The patients were surveyed post-implementation regarding their perception of the experience of reading their providers' notes about their office visit. Aggregate survey results were consistent with published findings including most felt more in control of their care and reported improved medication adherence and sharing of personal health information (PHI) with others. A few patients reported that the information was more confusing than helpful and that there were privacy concerns regarding PHI. There were no significant findings regarding an increase in patient portal registrations (Kallmerten, 2016).

More recently, a qualitative mini study was conducted by the doctoral student to describe the lived experience of using HIT by the person with heart failure with repeated hospitalizations. Individual interviews were completed with four adults with heart failure who recently received acute healthcare services. Three initial elements in the overall gestalt were identified including shared self-management in a care partnership model, a sense of loss that motivates behavior to improve self-management, and opportunities to optimize the use of HIT including the patient portal.

From the quality improvement project, the overall barriers and facilitators to portal use was explored with identifiable patient factors as well as technology factors noted (Kallmerten, 2016). The qualitative study explored the perceptions of the specific population of adults with heart failure and that opportunities to facilitate portal use were noted. This preliminary work conducted by the principal investigator is directly applicable to the proposed study to extend the knowledge base regarding the associations between patient portal use, HIT self-efficacy, eHealth literacy, and self-management in the heart failure population.

Research Design

The specific aims of this research include: to describe patient portal use by adults with heart failure (Aim 1); explore potential differences in patient portal use among patients with heart failure based on gender, age, race, educational background, yearly household income, years since diagnosed and Self-Assigned New York Heart Association Classification (Aim 2); and examine associations between portal use and health information technology (HIT) self-efficacy, eHealth literacy, and self-management (Aim 3). A cross sectional design is an ideal choice to describe variables of interest and to examine associations between them (Hulley, 2007). The quantitative data will be collected with a Qualtrics® survey from a target sample of at least 77 participants from a convenience sample of adults with heart failure from two cardiology practices. Following data collection, robust analysis of the association between the explanatory variables of HIT self- efficacy, eHealth literacy, and patient portal use and the outcome variable of self-management can be conducted.

Setting

Data will be collected at Capitol Region Health Care which includes both Concord Hospital Medical Group (CHMG) and Concord Hospital in Merrimack County, New Hampshire.

The Concord Hospital Cardiac Associates of CHMG have two office locations with one on the main campus and a second office in Laconia, New Hampshire. Concord Hospital Cardiac Associates includes 24 providers which represents a panel of patients adequate for representation (Concord Hospital, 2019). The cardiology office layout includes a waiting room, registration desk, private exam and consultation rooms and private offices.

Population

Survey data collected by Advameg, Inc. (2019) reported that 89% of residents of Merrimack County described themselves as white with all other ethnicities under 11% combined. The majority (92%) were educated at the high school or higher level. The median age is 39, with 44% self-described as now married, 33% never married with the remainder as separated, widowed, or divorced. The median household income is nearly $60,000 (Advameg, Inc., 2019). Fifty five percent of patients from Merrimack County with heart failure are discharged home rather than to another healthcare setting which attests to the implications for self-management and care provided by informal caregivers. Merrimack County also has a higher percentage (5.4%) of hospitalized heart failure patients who died before discharge than the state of New Hampshire (5.1%) as well as nationally (4.8%) (CDC, 2015). This suggests that home care may be sub-optimal leading to hospitalization when critical care is necessary.

Sample and Procedures

In collaboration with the chief medical informatics officer of the facility, support for the proposed study will be obtained. A full description of the intended study will be provided to the cardiologists, advance practice registered nurses and staff caring for the potential participants with an opportunity to address any questions and provide clarification if necessary, in addition to securing IRB approval. The principal investigator will complete the CHMG modules regarding privacy and confidentiality prior to recruitment and a certificate of completion will be provided to the office staff and interested participants. Patients will be assured that their participation in the study will have no bearing on the care they receive. It will be made explicit that the principal investigator will not be involved in their health care to address any potential concerns about a conflict of interest.

A convenience sample of the population with be recruited until the target of 77 participants is reached. Inclusion criteria will include a current CHMG consenting adult (over age 18 years) patient with a primary diagnosis of heart failure who has registered for their patient portal in order to understand the perceptions of the population of interest. Exclusion criteria include the inability to read English as well as any significant cognitive disability that would limit comprehension of the survey.

Methods of recruitment will include sending the survey link to those who have enrolled in the patient portal and provided an email address. The link will be sent via email by an honest broker of the organization. A query of the CHMG population to identify persons with heart failure who have registered for the patient portal have identified a sufficient number of potential participants.

The goals of recruitment are to obtain sample representation of a population in sufficient numbers to reduce bias and random error (Hulley, 2007). An A priori power analysis using the program G*Power 3.1.9.2 indicates that for a linear multiple regression: Fixed model with three predictor variables (alpha set to 0.05, power at 0.80 and effect size of 0.15), a total sample size of 77 is required (Faul et al., 2009).

Measures

The data collected will include socio-demographic data, one question representing the SA-NYHA Classification (Holland et al., 2010), six questions regarding patient portal use derived from the Health Information national Trends Survey (HINTS5) (Blake & Moser, 2019), the six item HIT self-efficacy scale (Kim & Park, 2012), the eight item eHealth literacy instrument (Norman & Skinner, 2006a), and the 29 items from the Self-Care of Heart Failure Index (SCHFIv7.2) (Riegel et al., 2019). The predictor variables of patient portal use, HIT self-efficacy, and eHealth literacy will be analyzed for the effect on the outcome variable of self-management. Permissions to use were requested and received for all instruments.

Socio-demographic data. Socio-demographic data will be collected including gender (male/female), age, educational background (some high school, high school diploma or GED, Associate Degree, Bachelor Degree, Master's Degree, Doctoral Degree), annual household income, and estimated years since diagnosis of heart failure using an investigator-designed questionnaire.

Self-Assigned New York Heart Association Classification. The participant will select one description from four choices which best summarizes their ability for physical activity considering shortness of breath, fatigue or having heart palpitations with minimal, light or strenuous activity. This description corresponds with the healthcare provider generated New York Heart Association Classification (Class I-IV) for heart failure. Permission to use the SA-NYHA instrument was obtained by the author with proper citation (Holland et al., 2010).

Patient portal use. A more robust measurement defines a non-user as someone who has not logged in within the past 12 months, a light user as someone who has logged in within the past 12 months but less than 10 times per month and an active user as someone who has logged in at least 10 times in the previous 12 months. The features of the portal that are commonly used include viewing laboratory results, medication and problem lists and immunization status. The key feature of using the portal to schedule appointments and requesting referrals as well as sending or replying to a secure message connotes bi-directional communication and more patient activation. Questions regarding use of the features and frequency will be incorporated into the survey based on the HINTS5 instrument. This variable of portal use is represented in the HITAM framework as the change in behavior reflective of HIT acceptance.

HIT Self-efficacy. The authors of the HITAM noted that *HIT* self-efficacy beliefs were an integral component of the perceived ability to use a patient portal in the technology zone (Kim & Park, 2012). The six items assessing HIT self-efficacy in a Likert-style format were derived from the Technology Acceptance Model version 3 (TAM3) (Venkatesh & Bala, 2013). The definition used in the TAM 3 addressed *computer* self-efficacy as the degree to which an individual perceives that they have the ability to perform a task using the computer (Venkatesh & Bala, 2008). The HITAM authors modified the instrument to include the use of a wider range of technology (desktop, laptop or tablet computers and smartphones) specific to health information and management and noted internal consistency with a Cronbach's Alpha coefficient of 0.88 (Kim & Park, 2012). The participants will be asked to select their response (strongly disagree, disagree, neither agree nor disagree, agree or strongly agree) to the six HIT self-efficacy questions including: I am **good** at using technology (computer, tablet, smart phone, etc.); I think I **excel** compared to others in online access technique or capacity; I am **confident** of my online health information search abilities and health management; I think I can **utilize** online health information and health management; I think it is **interesting** to find online health information and perform health management; and I think it is **useful** to find health information and perform health management (Kim & Park, 2012). Permission for use was obtained from the authors who provided an electronic copy of the original instrument. The six questions were totaled with a range of 6-30. Higher scores are reflective of optimal perceived HIT self-efficacy.

Electronic health literacy. Electronic or eHealth literacy (eHL) is the ability to find, understand and appraise health information from electronic resources and then apply the knowledge gained toward addressing or solving a health problem (Norman & Skinner, 2006a). The eHEALS instrument has been psychometrically tested with many participants with high reliability Cronbach's Alpha coefficients ranging from 0.89 to 0.94 (Nahm et al., 2012; Noblin et al., 2012; Price-Haywood et al., 2017; Seon-Yoon & Eun-Shim, 2015). The authors were contacted regarding permission to use the eHEALS and permission was granted. The participants will be asked to select their response (strongly disagree, disagree, neither agree nor disagree, agree or strongly agree) to the eight eHealth literacy questions including: I know **what** health resources are available on the Internet: I know **where** to find helpful health resources on the Internet; I know **how** to find helpful health resources on the Internet; I know **how to use** the Internet to answer my questions about health; I know how to use **the health information** I find on the Internet to help me; I have the skills I need to **evaluate** the health resources I find on the Internet; I can tell **high quality** health resources from **low quality** health resources on the Internet; and I feel **confident** in using information from the Internet to make health decisions (Norman & Skinner, 2006a). The scores from the eight individual questions are totaled with a possible range of 8-40. Higher scores reflect higher perceived eHealth Literacy. This variable is important toward the perceived usefulness of the HIT. Permission to use the eHEALS instrument was provided by the primary author (Norman & Skinner, 2006a).

Self-management. The gold standard for measuring self-management in the adult with heart failure is the Self-Care of Heart Failure Index (SCHFI) based on the Situation-Specific Theory of Heart Failure Self-Care (Riegel et al., 2016). The latest version (7.2) was tested using confirmatory factor analysis and three scales were noted including self-care maintenance, symptom perception and self-care management with significant correlations and a global reliability index of 0.70 or greater for all scales (Riegel et al., 2019). The SCHFI assesses the perception of the person with heart failure regarding self-care maintenance (10 items), symptom perception (9 items) and self-care management (8 items) on a Likert-type scale. The scales are scored separately and then summed and standardized to provide an index score ranging from 0-100 with index scores higher than 70 indicative of adequate self-care management (Riegel et al., 2019). Permission to use the SCHFI was obtained with a signed agreement with the primary author (Riegel et al., 2019).

Data Collection Procedures

Using a site license for Qualtrics® Survey Research Suite, a questionnaire will be created incorporating the informed consent, the six questions representing socio-demographic data, one question representing the SA-NYHA Classification, six questions regarding portal use, the six item HIT Self-efficacy scale, the eight item eHealth Literacy instrument, and the 29 items from the SCHFI (version 7.2) to total fifty six items in the survey. The survey will be able to be completed in a reasonable timeframe without undue survey burden. The Duquesne University consent letter template will be used to create the consent form and will be modified to reflect an 8th grade reading level according to the Flesch-Kincaid grade level assessment (Solnyshkina et al., 2017). The survey will be piloted by volunteers of the CHMG patient panel selected by the Concord Hospital Human Investigations Committee.

The first screen of the survey will be the informed consent letter verifying that they are an adult over the age of 18 years, a current patient of a CHMG cardiology practice, have a diagnosis of heart failure, are registered to use their facility patient portal and that consent is given. If a response is not given, an alert will be triggered to force a response. If the survey participant selects an affirmative response to the consent, the second question is presented. If a denial of consent is given, the participant will be taken to the end of the survey and appreciation of thanks by use of skip logic. The survey will be created using the anonymize response option. Personal information will not be recorded, and panel associations will be removed. The survey link will be open until a target sample of 77 participants has been obtained and then will be uploaded into an excel spreadsheet and then into IBM SPSS Statistics 25 (IBM Corp., 2017) for analysis. The data will be maintained on the PI's personal, password-protected computer.

Data Analysis

Prior to analysis, the data will be screened to assess the accuracy of the data file and to note any missing data. The data will be reviewed using descriptive statistical analysis with frequency distribution noting range, mean, standard deviation, skew and kurtosis. The data will be reviewed for extreme values and missing data. Decisions will be made regarding the data to maintain the integrity of the data set and limit the introduction of bias.

The data analysis technique for the proposed study is a multiple regression to determine how much of the variation in the outcome/dependent variable of interest (self-care management as measured by the SCHFI) can be explained by the independent/explanatory variables (portal use, eHL, and HIT SE) (Field, 2017). The analysis will allow the researcher to evaluate the contribution of each independent variable (r^2) and the proportion of the variation in the outcome variable predicted by the set of the independent variables (R^2) (Field, 2017). The first assumption that must be met to determine if this is the correct data analysis technique include that the outcome variable is measured at a continuous level. As noted in the description of the SCHFI instrument, the scales are scored separately and then all scale totals are summed and standardized to obtain an overall index of self-care on a scale from 0-100 (Riegel et al., 2019). The index score will be treated as the outcome/dependent variable for analysis.

The second assumption that must be met is that there are two or more independent/ explanatory variables that are measured at the continuous or nominal level (Field, 2017). All of the instruments noted including the eHL, HIT SE, and patient portal use instrument will be measured with a Likert-type scale and treated as continuous or nominal data for the multiple regression. In addition, the demographic data will be measured in a nominal or categorical level for data analysis (Gravetter, 2015). The overall goal of analysis will be to determine overall fit of the model or the variance explained and the relative contribution of each independent variable to the total variance (Field, 2017).

The first step in the analytic process will be to screen the data using a seven step data screening check list to: assess the accuracy of the data file; address missing data and outliers; assess normality regarding skew and kurtosis; assess homoscedasticity; homogeneity of variance and variance-covariance; assess multicollinearity; and conduct data transformations as necessary (Tabachnick & Fidell, 1996). Descriptive statistical analysis will be conducted first to assess histograms, and Q-Q plots for means, medians, standard deviations, skew and kurtosis. The box plots will be reviewed to detect extreme points or outliers and the Cook’s Distance, Mahalanobis Distance and Leverage values will be calculated to aid in the decision on how to address these extreme points to avoid altered results. Then the bivariate correlation procedure will be conducted to determine if there is a correlation between the variables. The next step is to conduct the linear regression procedure which will generate output for independence of observations (the Durbin-Watson statistic), linearity and homoscedasticity (scatterplot of the studentized residuals against the predicted values and the values obtained), multicollinearity (Tolerance and VIF), outliers, normality and obtain a main multiple regression result (Field, 2017). The specific aims of this proposal include:

Aim 1: Describe patient portal use among persons with heart failure to include frequency of use and use of features such as the secure portal messaging system to email their provider or make appointments for routine or follow up care. This will be analyzed by descriptive statistics with frequency distribution noting range, mean, standard deviation, skew and kurtosis. **Aim 2**: Explore potential differences in patient portal use among patients with heart failure based on gender, age, race, educational background, yearly household income, years since diagnosed and Self-Assigned New York Heart Association (SA-NYHA) Classification. This will be analyzed by creating three categories of users including a non-user, light user and active user and comparing them to the categories of the demographic data. **Aim 3:** Examine associations between patient portal use and HIT self-efficacy, eHealth Literacy, and self-management using the Self-Care of Heart Failure Index (SCHFI) in the heart failure population. This will be analyzed by multiple regression analysis of SCHFI (the index score from 0-100) by the type of patient portal user, HIT self-efficacy score and eHealth Literacy score with a significant *p* value of 0.05 for a two tailed test.

Study Limitations

The population in Merrimack County of New Hampshire is 89% white or Caucasian (CDC, 2015). The generalizability to other populations with more racial diversity may be limited. In addition, the median income is $60,000 with 11% living in poverty which may impact access to the technology including computers, smartphones and the internet necessary to access the patient portal. Lastly, while 92% have a high school education or higher, there is a fair percentage of patients who may have limitations in understanding the survey instruments and drop out before survey completion.

Barriers, Challenges and Potential Strategies

There are several potential problems that must be addressed including recruitment problems, and sampling, recall and response bias (Polit & Beck, 2004). Reluctance to answer the survey in an electronic fashion related to a perceived threat to the security of their personal health information which may impact recruitment. A potential strategy includes providing participant education on the anonymity and removal of any panel associations with the Qualtrics program. Overall sampling bias can occur which can lead to the demographics of the sample not reflecting the population. To address this, the socio-demographic responses will be compared to the CDC data for Merrimack County to identify differences impacting generalizability. As this study relies on self-reported data, recall bias can distort the measurement. To address this, the participants will be encouraged in the survey instructions to reflect on their answers and try to answer as accurately as possible. Lastly, response bias can be noted as some individuals may respond based on perceived social desirability and congruence with social norms. To address this, the participant will be encouraged to respond frankly with the intent to improve overall patient centered care by identifying initiatives toward quality improvement. The participants will also be reminded of the anonymity of the responses.

Protection of Research Participants

Duquesne University Institutional Review Board (IRB) policies and procedures will be followed to protect the participants’ rights to confidentiality and privacy. The principal investigator will maintain current collaborative institutional training initiative (CITI) certification throughout the study. An IRB protocol summary form, consent form based on a consent template and recruitment flyers will be submitted to the faculty advisor, nursing reviewer and IRB chair for review and revised as necessary. A CHMG Human Investigations Committee initial protocol submission summary application will also be completed and submitted for study approval. After approval, the consent form will be incorporated into the electronic survey. The participants will be informed that if they agree to participate in the survey, that they can refuse to answer any question and/or if they change their mind that they can conclude the survey at any time. They will be informed that the responses will be anonymous. They will be informed that the information that is provided will not be identifiable but will be treated confidentially and that all written information will be stored securely on a personal laptop that is password protected. Potential benefits include the communication of summary findings to the organization which may enhance understanding of their perceptions and lead to the identification of ways to improve the functionality of the patient portal and improve care for the adult with heart failure.

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Patient Portal Use by Adults with Heart Failure: An Integrative Review

Abstract

Heart Failure is a chronic condition affecting many with an emphasis on self-management to improve outcomes and decrease the cost of care. A potential strategy to improve the self-management of heart failure includes the use of a patient portal. The purpose of this integrative review is to synthesize what is known about patient portal use by adults with heart failure to identify contributing factors for use and areas for future research. Within the three zones of the Health Information Technology Acceptance Model, predominant themes contributing to patient portal use were identified. Within the health zone, the predominant themes were physical and mental health, quality of life and social interaction. Within the information zone, the predominant themes included knowledge about heart failure and self-care, information sharing and communication. Within the technology zone, the predominant themes include the barriers and facilitators of patient portal use and overall usability. Overall, the patient perceptions of the patient portal can lead to the acceptance and use of the technology that can enhance self- management. Healthcare providers should partner with adults with heart failure to maximize the features of the patient portal to support self-management.

Key Words: Patient Portal; Heart Failure; Literature Review; Health Information Technology Acceptance Model

Introduction

Problem Identification and Significance

Heart Failure (HF), a chronic condition affecting nearly 6 million adults, has a 50% five year survival rate and an economic burden of nearly $31 billion annually (Heidenreich et al., 2011; Mozaffarian et al., 2016). Like many chronic conditions, an emphasis on effective self-management is necessary to improve clinical outcomes, reduce the cost of care and enhance the person's perception of quality of life. A potential strategy to enhance self-management of HF involves the meaningful use of health information technology such as the patient portal (PP) also called a tethered personal health record (PHR) which is an extension of a provider's electronic health record.

The web-based PP includes personal health information as well as links to patient education regarding disease processes, laboratory and diagnostic results. It also provides administrative functions such as medication refill requests and a mechanism for sending and receiving secure messages to and from the provider. However, the usefulness of the PP is more than simply a repository of information. Using a PP as a dynamic platform for enhancing knowledge and patient-provider communication can support self-management (Ong, 2016). A systematic review by Mold; et al. (2018) found that chronic disease self-management was improved for persons with type 2 diabetes mellitus (Mold et al., 2018). This finding suggests that the use of a PP may improve outcomes such as self-management for other chronic conditions such as HF, but PP use among adults with HF has not been comprehensively explored in the literature. Thus, we do not have a good understanding of the use of a PP by adults with HF. This understanding may translate to improved outcomes, a reduced cost of care, and improved quality of life for adults with HF.

Despite major advances in care, HF is still a costly chronic illness with poor clinical outcomes and impacts on quality of life (Benjamin et al., 2017). An urgent need exists for low cost solutions. While other forms of health information technology that a person might purchase themselves would be a consideration, a PP that is provided and maintained by the healthcare organization is a low-cost alternative for the patient. A PP can provide the resources, support knowledge acquisition and active participation necessary for self-management. Required to demonstrate the meaningful use of health information technology as described by the Health Information Technology for Economic and Clinical Health Act of 2009, healthcare organizations can meet this stipulation by providing PP access to their patients. An opportunity exists for nurses and other healthcare providers to support the use of health information technology such as the PP to enhance the knowledge and self-care required of the adult with heart failure.

Purpose and Specific Aims

The purpose of this integrative review is to synthesize what is known about patient portal use by adults with heart failure. The specific aims are to appraise the research (quantitative and qualitative) that has been conducted to describe contributing factors for patient portal use by persons with heart failure that may support self-management and to identify areas for future research.

Theoretical Framework

To provide a lens with which the existing research could be studied, the Health Information Technology Acceptance Model (HITAM) was used to guide the analysis of this integrative review. This model incorporates constructs from the Health Belief Model (health belief and status), the Theory of Planned Behavior (efficacy beliefs that lead to the development of attitudes and intention toward behavior change) and the Technology Acceptance Model (technology reliability and perceived usefulness) (Kim & Park, 2012). These well-known theories have been distilled into three zones of influence within the HITAM: health status, quality of the information and the usability of the technology (Figure 1). The HITAM, with these three zones of influence, provided a sound theoretical foundation for structuring the exploration and analysis of the research in this integrative review.

As applied to the topic of PP use and HF, in the health zone, the diagnosis of a chronic disease such as HF and a perceived threat to health status leads to information seeking behavior (Kim & Park, 2012). The information zone addresses whether or not the information on the PP is perceived to be reliable and useful and impacts communication with the healthcare provider and shared decision-making. The technology zone addresses the patients' perceived reliability of the technology and PP usability. The perceptions within the three domains mediate the development of a positive attitude which leads to the intent to use health information technology for self-management. The use of this conceptual framework will facilitate the understanding of the contributing factors toward use of a PP in the adult with HF. An understanding of the contributing factors of PP use is important to support the use of health information technology in self-management of this prevalent and costly chronic disease.

Methods

The Whittemore and Knalf methodology for conducting an integrative review includes several stages of the process including the problem identification, search for literature, data evaluation, data analysis and presentation of synthesized findings (Whittemore & Knafl, 2005). It is important to comprehensively determine what is known about PP use for the population of HF patients if we are to uncover whether PP use for the positively impacts self-management. Because the Whittemore and Knalf methodology allows for the combination of diverse research methodologies within a literature review, it was useful in providing an inclusive process for examining the literature to answer the research question: what is known about patient portal use by the adult with heart failure?

Literature Search

A health services librarian was consulted to identify relevant search terms and priority databases critical to the literature search stage. Three premier databases were queried including the Cumulative Index to Nursing and Allied Health (CINAHL) Complete, PubMed, and SCOPUS. Key words, mesh headings and the use of field codes such as title, abstract and text words were identified. The search was not limited by a specific time frame. However, the earliest literature on HF and PP use was published in 2004. The majority of the literature was published within the past 10 years, reflective of the federal legislation supporting the use of health information technology.

To discover as much literature as possible to answer the research question, search terms were intentionally left relatively broad. For the first variable of interest, heart failure, inclusion criteria was limited to this specific disease process due to the chronic nature of HF that necessitates substantial effective self-management. Alternative terms used in the search were *congestive heart failure, heart decompensation, or myocardial failure.*

The second variable of interest was use of patient-centered electronic health records. While many terms were used to describe an electronic, web-based platform to support health care, the focus of this review was specifically on patient-centered platforms supportive of self-management. Thus, electronic platforms that were healthcare provider-focused or for provider documentation were not of interest and literature search terms included *personal health record,* *patient portal, personal medical record, patient generated clinical data, patient-generated data, and self-recorded health data* in addition to the umbrella term of *electronic health records*.

The initial search led to the identification of 170 articles from the Cumulative Index to Nursing and Allied health Literature (CINAHL), 234 from PubMed and 519 from Scopus (Figure 2). In addition, we reviewed the reference lists of key articles and several systematic reviews identified by searching journals known to publish research on health information technology. The table of contents and search feature for the online *Journal of Medical Internet Research (JMIR), Journal of American Medical Informatics Association (JAMIA)*, and *CIN: Computers, Informatics, Nursing* were also searched using the inclusion criteria of patient portal and heart failure. Articles were excluded if the use of health information technology was healthcare provider centric or the population was not that of an adult with heart failure. This hand search resulted in an additional 87 studies. In total, 1007 references were imported into the online software program *Covidence* (Melbourne, Australia) for screening, as noted in the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) flow diagram (Moher et al., 2009). (Figure 2). Duplicates (n=282) were identified and removed. The title and abstracts of the remaining 725 references were screened with attention to the research question and eligibility criteria; 478 additional studies were then removed. In most cases, the research examined the provider use of an electronic health record or reflected data mining, i.e. utilizing stored patient data to uncover relationships in the population of interest. Occasionally, other forms of HIT were reported but not identified as the use of a PP or tethered personal health record. Less frequently, a tethered personal health record was a variable of interest but in a different patient population.

The full text of 247 studies were reviewed for inclusion, and 165 did not reflect the tethered personal health record or PP; 41 were not specific to the HF population. Fourteen studies were opinion based editorial publications, 11 were undetected duplicates, and 4 were research proposals rather than reports of completed studies. Thus, 12 studies were included for the third stage of data evaluation. Although the PRISMA figure is intended for use in systematic reviews, a PRISMA diagram is included in this integrative review to increase rigor and transparency in how articles were selected for inclusion in the review.

Eight of the twelve were quantitative designs including three randomized controlled trials (RCT),(Brennan et al., 2010; Earnest et al., 2004; Ross et al., 2004) two cohort studies,(Wu et al., 2005; Zan et al., 2015) one secondary data analysis from a cohort study,(Holden et al., 2017) one usability study,(Wakefield et al., 2017) and one cross sectional study (Schprechman et al., 2013). Three of the studies used qualitative designs (Ferguson et al., 2010; Mickelson et al., 2015; Rohani Ghahari et al., 2018). The last study was described as both a study and a quality improvement project; this project was considered a research translation and is congruent with the purpose of our integrative review(Dang et al., 2018).

Data Evaluation

The third stage of the integrative review process is data evaluation and quality appraisal. The twelve studies were reviewed to identify the purpose, study design, sample characteristics, outcome measures, findings, themes and quality (Table 1). Nine of the twelve studies were appraised for methodological rigor using the Critical Appraisal Checklists from the *Joanna Briggs Institute (JBI)* (Institute, 2014). Each study was appraised individually with items on the checklist rated as meeting the criterion (yes) or not (no or unclear). High quality was determined as meeting 70% of the criteria, medium quality at 50-69%, and low quality at <50%. Six of the studies were determined to be of high quality (Mickelson et al., 2015; Rohani Ghahari et al., 2018; Ross et al., 2004; Schprechman et al., 2013; Wu et al., 2005; Zan et al., 2015). Three of the studies were appraised to be of medium quality (Brennan et al., 2010; Earnest et al., 2004; Ferguson et al., 2010).

A specific JBI checklist was not available to appraise the secondary data analysis, usability study or the quality improvement project. The authors of the secondary data analysis had access to the data from a National Institute of Health (NIH) funded cohort study and were affiliated with the organization conducting the study (Holden et al., 2017). While a main disadvantage to the use of secondary data is a lack of control in data collection, and advantage lies in the data source of the original cohort study, appraised to be of high quality. The high-quality usability study by Wakefield et al was assessed by four patients and five clinicians for PP usability including usefulness, usability, and safety (Wakefield et al., 2017). A kappa statistic was not noted for agreement, but low inter-observer variability and strong reproducibility with two or more observers was reported (Hulley, 2007). The last study was described as a quality improvement project by the author (Dang et al., 2018). As such, the Quality Improvement Minimum Quality Criteria Set (QI-MQCS) was utilized to appraise the project (Hempel et al., 2015). All of the criteria were met, making this QI project of high quality. Thus, nine articles were determined to be of high quality and three of medium quality.

Data Analysis

The fourth stage in the integrative review process is that of data analysis. After constructing the matrix table for data extraction, themes were identified and noted (Table 2). The most common themes identified were overall health status; quality of life; social interactions; HF knowledge and self-care; information sharing and communication; and barriers/facilitators impacting PP usability. During the process of thematic identification, congruence with the concepts in the HITAM models was realized. Therefore, the HITAM model was used as a theoretical framework guiding the analysis and synthesis of what is known about PP use by adults with HF. The model categorizes the influential factors into three domains called the health, information and technology zones (Kim & Park, 2012).

Results

Description of Sample

All studies were conducted in the United States save one conducted in Canada (Wu et al., 2005). The predominant methods for data collection in the quantitative studies were self-report questionnaires, electronic medical record chart review and PP review for the number of logins, hit days, and areas of use. The qualitative studies used focus group and interviews for data collection. The sample size of the quantitative studies ranged from 20-282 participants while the qualitative studies ranged from 9-24. All of the samples were predominantly male, White, married, and with some college education. The mean age of the participants ranged from 48.7 to 72.1 years.

The earliest two studies by the research teams of Earnest and Ross (Earnest et al., 2004; Ross et al., 2004) were noted in the references of many publications and are considered to be seminal studies in the field of PP research in the heart failure population. Seventy-five percent of the studies were conducted within the previous decade with 50% (n=6) of the studies published within the previous five years. This timeframe is likely reflective of the healthcare reform policy initiatives of the past decade.

Overall, while research has been conducted to evaluate the experience of using a PP for other chronic conditions, minimal research has been conducted to evaluate the specific experience of using a PP by a person with HF, as evidenced by only twelve articles meeting the broad eligibility criteria in this review. Examination and synthesis of this limited body of research is important for gaining knowledge to leverage the use of a PP toward enhanced self-management in this population.

Synthesis of Findings

The final stage in the integrative review is the presentation stage and synthesis of findings. Reflecting on the research question; what is known about PP use by the adult with heart failure, we synthesized the existing research literature to uncover factors that may encourage PP use and support self-management. A synthesis of the overall themes or factors contributing to PP use by the adult with HF was appraised by using the three zones of the HITAM model—health, information and technology—as a theoretical guiding foundation. Within the health zone, the predominant themes were physical and mental health, quality of life and social interaction. Within the information zone, the main themes were HF knowledge and self-care, information sharing and communication. Lastly, the major themes in the technology zone were the barriers and facilitators of PP use and overall usability.

Health Zone

In the health zone of the model, behavioral beliefs, health beliefs and concerns, and health status are mediated by the perceived threat to health, (Kim & Park, 2012) and the themes of *physical and mental health, quality of life* and *social interaction* emerged within this zone. Nine of the twelve studies identified the impact of health as a contributing factor for PP use by the adult with heart failure (Brennan et al., 2010; Dang et al., 2018; Earnest et al., 2004; Ferguson et al., 2010; Rohani Ghahari et al., 2018; Ross et al., 2004; Schprechman et al., 2013; Wu et al., 2005; Zan et al., 2015). Two studies (Earnest et al., 2004; Ross et al., 2004) identified the impact of physical health on patient portal use with the Kansas City Cardiomyopathy Questionnaire (KCCQ) and one team with the Medical Outcomes Short Form 12 (SF-12) (Brennan et al., 2010). By contrast, only three studies identified the impact of mental health and mental status using the patient health questionnaire (PHQ-8) for depression and the modified mini mental status exam. Higher modified mini mental status exam scores were noted for PP users (Brennan et al., 2010) and those reporting email use (Schprechman et al., 2013) while lower scores on the PHQ-8 indicative of mild or no symptoms of depression were found in the majority of PP users (Zan et al., 2015).

Quality of life (QoL) was a major concept in five of the studies with most researchers using the KCCQ section on QoL, the Minnesota Living with Heart Failure Questionnaire (MLHFQ) or the Multidimensional Index for Life Quality Questionnaire for Cardiovascular Disease (MILQ) (Brennan et al., 2010; Dang et al., 2018; Earnest et al., 2004; Ross et al., 2004; Zan et al., 2015). A significant improvement in QoL existed in PP users compared to non-users in the quality improvement project (Dang et al., 2018). However, no other study noted statistically significant effects on QoL as a result of PP use.

Social interaction was also a major concept for five of the studies (Earnest et al., 2004; Ferguson et al., 2010; Rohani Ghahari et al., 2018; Ross et al., 2004; Wu et al., 2005). The teams of Earnest et al. and Ross et al. utilized the KCCQ instrument to assess social interaction and identified socioeconomic disparity in PP use such as education, race, income and access to technology (Earnest et al., 2004; Ross et al., 2004). Non-users were less likely to have a college education; be White or non-Hispanic; have an income greater than $45,000 per year; and have access to a home computer and the internet (Earnest et al., 2004; Ross et al., 2004). Social isolation and concern about resuming normal social activities were identified in two additional studies (Ferguson et al., 2010; Rohani Ghahari et al., 2018). Positive aspects of social interaction were noted by Wu et al as using the PP to send messages seeking reassurance or exchanging pleasantries with healthcare providers and staff (Wu et al., 2005).

There were other themes related to the health zone, including self-efficacy, health literacy and utilization of healthcare resources. Self-efficacy (SE) was examined in three studies, (Dang et al., 2018; Earnest et al., 2004; Ross et al., 2004) but no significant differences in scores were noted on the component of the KCCQ instrument measuring self-efficacy, when comparing PP users and non-users (Earnest et al., 2004; Ross et al., 2004). In the quality improvement project, no significant differences in self-efficacy scores were noted as measured by the Self-Efficacy for Managing Chronic Disease Scale between PP users and non-users (Dang et al., 2018). Thus, self-efficacy did not appear to play a role in patient portal use in this small sub-sample.

Health Literacy (HL) was assessed with the Newest Vital Sign (NVS) instrument, and one study noted that 75% of the participants had adequate HL, which is an important finding indicating that the majority of adults with HF in this study had the ability to obtain and understand information about their health (Rohani Ghahari et al., 2018). The Medical Term Recognition Test (METER), a tool for HL used by one team, showed that higher METER scores predicted e-mail use but not internet use in a PP (Schprechman et al., 2013). In this study, the majority of participants reported that health information was not obtained electronically with the use of the internet, but rather in verbal and written communication with their healthcare provider and staff.

Finally, healthcare resource utilization as an indirect measure of health status was a variable of interest in three studies (Brennan et al., 2010; Ross et al., 2004; Wu et al., 2005). One team found no significant differences in health service use between those in the technology enhanced practice as compared to usual care (Brennan et al., 2010). However, the two other teams noted a significant difference in healthcare resource utilization; those in the PP group had more emergency department visits in one study, (Ross et al., 2004) and more planned hospitalizations were noted in the other study (Wu et al., 2005). The specific type of healthcare utilization is important because an increase in planned hospitalization can reflect an increased attention to self-management while the increase in emergency department utilization may indicate an opportunity to improve self-management of HF.

Information Zone

In the information zone of the model, normative beliefs and the reliability of the health information lead to a perceived usefulness and ease of use of the PP; the themes of *HF knowledge, self-care, information sharing* and *communication with the healthcare team* emerged in this zone (Kim & Park, 2012). Many researchers considered the relationship between patient portal use and each of these theme areas. Knowledge about the disease process including risk factors, trajectory of illness, laboratory and diagnostic testing to monitor for complications, and both pharmacological and non-pharmacological interventions are important for self-management of this chronic condition as explored by the majority of the researchers (Dang et al., 2018; Earnest et al., 2004; Mickelson et al., 2015; Rohani Ghahari et al., 2018; Schprechman et al., 2013; Wu et al., 2005). One researcher noted many observations between self-management and knowledge gaps that could be addressed with educational links imbedded into the PP (Mickelson et al., 2015). A preference for on demand education via the PP was also identified (Rohani Ghahari et al., 2018). HF knowledge was a significant variable of interest in the quality improvement project (Dang et al., 2018). However, there were no significant differences in HF knowledge between PP users and non-users. This finding suggests that HF patients received education in traditional formats as well as through the effective use of technology. The educational content available on the PP was explored via a qualitative component in one of the earliest studies, and themes of learning about their condition, decision making and participation in care were identified among PP users (Earnest et al., 2004).

Self-management was identified as a variable of interest in five studies (Brennan et al., 2010; Holden et al., 2017; Mickelson et al., 2015; Wu et al., 2005; Zan et al., 2015). Brennan et al. (2010) assessed self-management with the Self-Care Heart Failure Index (SCHFI) and found that those exposed to the PP technology demonstrated better self-management of chronic heart disease. Holden et al. (2017) conducted a secondary data analysis and identified six clusters or personas with significant differences in self-management, PP use, internet availability, and co-morbid conditions where highest portal use was associated with being a married white woman with internet access and high health literacy (Holden et al., 2017). The promise of improved self-management lies in the belief that it will translate to improved clinical outcomes, improved quality and lower costs of care.

Patient adherence/participation/engagement/empowerment was a key variable in four studies (Earnest et al., 2004; Rohani Ghahari et al., 2018; Ross et al., 2004; Zan et al., 2015). Ghahari used Altarum Consumer Engagement (ACE) Scale while Ross used the General Adherence Scale from the Medical Outcomes Study. Ghahari found that the participants had low to medium ACE scores demonstrating overall low patient engagement for both PP users and non-users while Ross found that those who used the PP had significantly better adherence than those who did not (Ross et al., 2004). In addition, the qualitative study and a cohort study identified decision support, imperative to patient engagement, as a key variable in increased PP use (Ferguson et al., 2010; Wakefield et al., 2017). Lastly, enhanced communication with the healthcare team was noted by PP users in the 5 of the 12 studies (Earnest et al., 2004; Ferguson et al., 2010; Rohani Ghahari et al., 2018; Ross et al., 2004; Wakefield et al., 2017). For example, the communication of patient information as well as question and answer exchanges were found to be core themes in the Heart Failure Internet Communication Tool (HFICT) designed as an early PP prototype (Wu et al., 2005). The relationship between the provider and the adult with HF is dependent on patient engagement, communication and decision support to promote self-management of a chronic condition.

Technology Zone

Finally, the technology zone of the model is comprised of perceptions of the PP technology including anxiety or enjoyment with using the portal and objective usability, and emerging themes within this zone include *barriers and facilitators of PP use* and *overall usability* (Kim & Park, 2012). Consistent with the concept of the digital divide, barriers exist regarding the use of the PP by those with limited computer or internet use; these barriers can translate to increased anxiety and decreased enjoyment with using the computer, internet or PP (Ong, 2016). Overall usability was addressed by five of the studies (Mickelson et al., 2015; Rohani Ghahari et al., 2018; Ross et al., 2004; Schprechman et al., 2013; Zan et al., 2015). Limited usability of the technology is a potential barrier that may constrain the perceived benefits to patient engagement and improved outcomes such as effective self-management. When usefulness and satisfaction with the PP was measured in the quality improvement project, the participants reported high satisfaction but voiced concerns that more hands-on instruction was necessary (Dang et al., 2018). The Heart Failure Connectivity Questionnaire measured computer and internet use, and researchers found that the majority of the participants reported access but not use of the PP for HF self-care purposes (Schprechman et al., 2013). In this regard, an opportunity exists to explore differences between access or registration for the portal and meaningful use of it.

Discussion

The Whittemore and Knalf methodology (Whittemore & Knafl, 2005) guided this inclusive integrative review process which aimed to synthesize what is known about PP use by adults with HF. The findings were synthesized into three themes or zones of contributing factors for PP use according to the HITAM model. Findings from major themes within the health zone suggest that physical health has been examined most frequently with regard to patient portals. Overall physical and mental health was reported as better by those using the technology enhanced care of the PP and declining health negatively affects PP use (Brennan et al., 2010; Dang et al., 2018; Earnest et al., 2004; Ferguson et al., 2010; Rohani Ghahari et al., 2018; Ross et al., 2004; Schprechman et al., 2013; Wu et al., 2005; Zan et al., 2015). However, limited evidence is available regarding the effect of mental health on usage, highlighting an opportunity to further explore the impact of mental health in relationship to PP use. In contrast to our results, others have noted that an increase in co-morbid conditions and frequency of hypo- or hyperglycemic episodes increased PP use among patients with type 2 diabetes mellitus (Mold et al., 2018). Efforts to register and support adults with heart failure should be directed to persons with New York Heart Association Stage I-III rather than Stage IV which denotes severe limitation (Holland et al., 2010). Additionally, although enhanced QoL was statistically significant for PP users compared to non-users in one project from our review, (Dang et al., 2018) no other studies found a significant change in QoL among PP users. By contrast, another researcher found that an increased QoL was associated with decreased PP use among patients with other cardiovascular conditions such as acute coronary syndrome, angina, and dysrhythmias

(Wiggers et al., 2014). Thus, further research into the impact of QoL is warranted to expand upon these findings. Findings from our review noted that socioeconomic disparity impacted PP use (Earnest et al., 2004; Ross et al., 2004). Similar to our results, others have noted that age, gender, ethnicity and education impact PP use in other chronic conditions (Mold et al., 2018). Identifying disparities that limit PP use can help with initiatives addressing inequities and improve self-management via the PP. Moreover, positive social interactions were noted among PP users; thus, providing links to HF support groups through the PP may be an effective way to support these interactions.

The concepts of self-efficacy, health literacy, and healthcare utilization were also noted within the health zone. Findings suggest that there were no differences in self-efficacy between PP users and non-users (Dang et al., 2018; Earnest et al., 2004; Ross et al., 2004). Findings also suggest that poor health literacy may prevent PP use, e.g., a high health literacy score predicted computer and internet use in one study (Rohani Ghahari et al., 2018) and email use in another (Schprechman et al., 2013). While *general* self-efficacy and health literacy was examined, a more specific focus on *Health Information Technology* self-efficacy and *electronic* health literacy may be warranted (Kim & Park, 2012; Norman & Skinner, 2006). The adult with HF may or may not have the health information technology self-efficacy or the electronic health literacy required for meaningful use. Additionally, although PP users were more likely to have planned hospitalizations, this outcome may be the result of enhanced communication with the HC provider, (Wu et al., 2005) which would certainly be a positive outcome associated with PP use.

The major themes from the information zone were HF knowledge; self-care and self-management; and patient engagement related to information sharing/communication. HF knowledge was a central target among half of the included articles, but findings were equivocal regarding the impact of PP use. A critical component of HF management, self-management was a focus of nearly half of the reviewed studies with some positive associations between the use of technology and enhanced self-management among patients with HF. Importantly, HF patients also reported being interested in the use of a PP to improve self-management (Rohani Ghahari et al., 2018). This stated interest is valuable information for informatics nurses and individuals on interdisciplinary teams challenged with supporting meaningful use metrics. The use of a PP has been found to be associated with improved knowledge of diabetes symptoms and treatment regimens as well as an increase in self-management and communication with their provider, (Mold et al., 2018) which is congruent with our findings. Our findings are mixed regarding the impact of PP use on patient engagement/empowerment/adherence (Earnest et al., 2004; Rohani Ghahari et al., 2018; Ross et al., 2004; Zan et al., 2015). This result contrasts with the finding that PP use was associated with a greater sense of empowerment in the type 2 diabetes population (Mold et al., 2018).

The major themes from the technology zone include barriers/facilitators to use of the technology and overall usability. Of concern is the usability of the technology itself. Qualitative and usability studies showed that usability and acceptance can impact adherence to PP use. Not unexpectedly, limited computer or internet use was associated with concerns about PP use, and although satisfaction was high additional direct instruction on its use was desired (Dang et al., 2018). Failure to address this expressed need will further limit the use of the PP and reduce an opportunity to enhance self-management. Moreover, because accessing the portal did not necessarily translate to using it for the purpose of self-management, (Schprechman et al., 2013) added patient training specific to the portal features that can be used to manage one’s chronic HF is also essential. There should be a renewed emphasis on educating the adult with HF about the use of a PP and offering continued support in this new behavior. This need for patient education about how to use the PP is important for nurses who care for adults with HF and desire to help patients support their self-management. The HITAM model does suggest that the perceived usefulness and ease of use of the technology coupled with patient perceptions of health threats can lead to a positive attitude toward portal use. Our findings are consistent with those for the type 2 diabetes population as accessibility and usability impacted meaningful use of the PP (Mold et al., 2018).

Despite our broad research question and eligibility criteria, the literature search for this review yielded only 12 studies, which is likely reflective of the Health Information Technology for Economic and Clinical Health (HITECH) Act, enacted just 11 years ago. Prior to 2009, the use of health information technology was provider centric as the healthcare team adjusted to the transition from paper to electronic documentation. HITECH provided a stimulus for the provision of electronic access for consumers as a way to improve patient engagement. With the enactment of the HITECH Act, eligible facilities and providers began to offer a tethered personal health record or PP to adults with HF to attest to the meaningful use guidelines in the legislation. Meaningful use of the tethered personal health record or PP was theorized to improve patient engagement and clinical outcomes (Ong, 2016). Since there is an overall small body of evidence about PP use among patients with HF, more research is needed to determine if this is the case.

Limitations

While the research overall was of medium to high quality, there were limited statistically significant findings associated with PP use by the adult with HF. Additionally, since it has only been 11 years since meaningful use of the PP was encouraged, there are some terminology challenges that impacted the literature search for the variables of interest. Personal health record, PP, and patient generated data reflect a patient centered construct. Yet, confusion still exists with the terminology for electronic records, such as an electronic medical record or electronic health record which is primarily used by clinicians and the tethered personal health record or a PP used by patients. This challenge was minimized by collaborating with a health services librarian to identify key words integral to the search. However, these terminology challenges could have impacted the search results and consequently data evaluation, analysis and synthesis. A second limitation is that this integrative review was conducted by a single reviewer. A second reviewer for consensus of eligibility might have enhanced the rigor of the review process.

Implications for Practice and Research

Historically, healthcare for the HF population is very costly. Nurses and other healthcare providers should seize the opportunity to enhance the self-care of this chronic condition by providing a PP with links to HF specific information to support knowledge acquisition. Patients must be shown how to access and use this specific information. Enhanced knowledge can support shared decision making in the management of HF. The PP can also facilitate communication between the person with HF and the members of the healthcare team providing an opportunity to enhance the patient/provider relationship.

Future research should explore implementation studies to support use of the PP by this population by involving the end user in design modifications specific to their needs. Moreover, exploration of the personal attitudes, beliefs and values in using the PP for self-care of this chronic condition is necessary to further promote the use of the PP. Lastly, additional studies to explore relationships between PP use and outcomes reflective of enhanced self-management are necessary to establish the evidence base for the effectiveness of this tool.

Conclusion

Many contributing factors for PP use by patients with HF have been described in this appraisal of the research. Healthcare providers and information technology staff should now partner with adults with HF to maximize the features of this technology to support self-management of this chronic condition. This partnership should address PP usability to enhance the functionality as well as provide more education and training in PP use. In this partnership, true benefits to the use of health information technology can be realized.

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Figure 2.1

Health Information Technology Acceptance Model (Kim & Park, 2012)

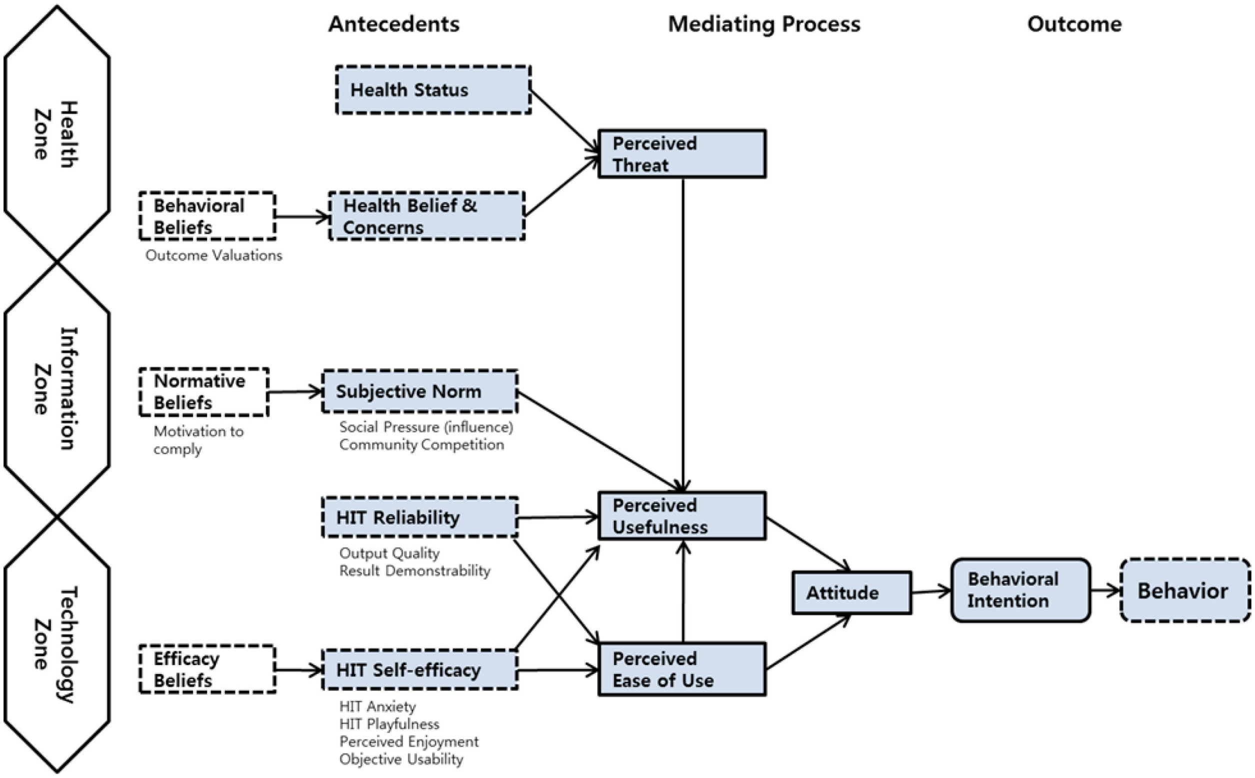

Figure 2.2

PRISMA flow diagram Used with permission.

Table 2.1

Summary of Studies

Author(s), Year, Title	**Purpose**	**Study Design**	**Sample Size, N**	**Variables Used**	**Findings**	**Themes**	**Quality Assessment**
Brennan et al 2010 "Technology enhanced practice (TEP) for patients with chronic cardiac disease home implementation and evaluation"	To assess if TEP improves self-management of chronic heart disease, clinical status, quality of life, unplanned use of services and satisfaction with nursing care	Randomized Controlled Trial (RCT): Usual care (UC) and TEP	N=282 with cardiac disease N=146 in TEP and 136 in UC	Short Form 12 Physical and Mental Clinical Status Self-Care Heart Failure Index (SCHFI) Multi-dimensional Index for Life Quality (MILQ)	Physical health, mental health, Quality of Life (QOL), self-management better for those in TEP compared to UC [a] No differences in service use or satisfaction with nursing care	Outcome variables Clinical status, self-management QOL, Satisfaction with nursing care and un-planned service use	Medium 8/13 62%
Dang et al 2017 "Evaluating an Electronic Health Record Intervention for Management of Heart Failure Among Veterans"	To assess the feasibility of using the Veterans Administration My Health eVet and secure messaging as an educational and monitoring platform for patients with Heart Failure (HF).	Quality Improvement Project	N=120 HF patients	Minnesota Living With Heart Failure Questionna (MLHF) Self-Effica For Managing Chronic Disease Scale Dutch HF Knowledge Scale My HealtheVet Use Patient Satisfaction Questionna	QOL improved For Portal users Compared to Non-users[a] No differences In self-efficacy Or HF knowledge	QOL Self-efficacy (SE), HF Knowledge Ease of portal use satisfaction	High 16/16 100%

Author(s), Year, Title	**Purpose**	**Study Design**	**Sample Size, N**	**Variables Used**	**Findings**	**Themes**	**Quality Assessment**
Earnest et al 2004 "Use of a patient accessible Electronic Medical Record (EMR) in a practice for CHF: Patient and physician experiences"	To evaluate the experiences of patients and physicians in a clinical trial of an online electronic medical record (SPPARO, System Providing Patients Access to Records Online)	RCT Quantitative and Qualitative	N=107 CHF patients 54 in intervention group and 53 in control group and N=7 physicians	Kansas City Cardiomyopathy Questionnaire (KCCQ) for physical symptoms, Self-Efficacy (SE), Social interaction, QoL Qualitative: Grounded Theory for thematic content analysis	Patient empowerment scale differences between patient and physicians with physicians more likely to believe that patients would worry more, find reports confusing, or find notes offensive[a]	Learning more about their condition, coordinating care, medical decision-making, reinforcing memory, increasing participation in medical care, streamlining the flow of information, confirming normal results and the accuracy of their record, difficulties in understanding clinical notes, and concerns.	Medium 9/13 69%

Author(s), Year, Title	**Purpose**	**Study Design**	**Sample Size, n**	**Variables Used**	**Findings**	**Themes**	**Quality Assessment**
Ferguson et al 2010 “Towards a personal health management assistant”	To design & prototype a personal health management assistant to develop a new more patient-centric vision of personal health records	Qualitative Study-Focus Group	N=9 HF patients	Thematic Analysis for three broad conclusions	Support for patient-generated observations is crucial, applications that support decision making & taking action are necessary, applications need to support effective sharing of information	Significant time and effort is spent gathering and collecting personal health information for management Social isolation for HF patients	Medium Quality 6/10 60%
Ghahari et al 2018 “Using cardiac implantable electronic device (CIED) data to facilitate health decision making: A design study”	Explore patient experience, identify preferences and understand support with and for CIEDs and CIED remote monitoring	Qualitative Focus Group	N=24 persons living with HF and their informal caregiver/ spouse	Independent Coding and Thematic analysis using NVIVO coding Newest Vital Sign For Health Literacy (NVS) Atarum Consumer Engagement (ACE)	Three categories: 1. experiences with cardiac Implantable Electronic Devices 2. Preferences for alerts and data presentation 3. education support 25% use a Computer and the Internet with Poor-very Poor Health Literacy (HL), 75% with Adequate HL	Health Literacy (Patient Engageme Perceived needs For reports communication, and on demand education the Personal Health Record (P	High 8/10 80%

Author(s), Year, Title	**Purpose**	**Study Design**	**Sample Size, n**	**Variables Used**	**Findings**	**Themes**	**Quality Assessment**
Holden et al 2017 "Know thy eHealth user: Development of biopsychosocial personas from a study of older adults with heart failure"	To develop biopsychosocial personas of older patients with heart failure using quantitative analysis of survey data.	Secondary data analysis from Vanderbilt Inpatient Cohort Study	N=30 older adults with HF	Content Analysis on semi-structured interviews	Cluster analysis yielded six distinct clusters ranging in size from 2-8 patients, 16 of 37 variables were signifycantly different between clusters at the selected[a]	Six personas: Self-Management Patient Portal (PP) Use Internet Availability Demographics Comorbid conditions	High
Mickelson et al 2015 "Medication-related cognitive artifacts used by older adults with heart failure"	To examine how older adult patients with heart failure use cognitive artifacts (including a PHR) for medication management.	Qualitative	N=30	Iterative content analysis	15 types of Cognitive Artifacts Including e-PHR	Usability Acceptance Medication management Knowledge gaps	High 8/10 80%

Author(s), Year, Title	Purpose	Study Design	Sample Size, n	Variables Used	Findings	Themes	Quality Assessment
Ross et al 2004 "Providing a Web-based Online Medical Record with Electronic Communication Capabilities to Patients with Congestive Heart Failure: Randomized Trial"	To assess how a patient-accessible online medical record affects patient care and clinic operations.	RCT surveyed at baseline, 6 and 12 months	N=107 HF patients 54 intervention and 53 control group	KCCQ-primary variable was Self-Efficacy America Academy of Medicine Question-naire (Modified) General Adherence Scale	Users differed from non-users by education, race, income, type of insurance, previous use of the internet, and access to a home computer[a] No differences for self-efficacy or general adherence. The intervention group had more emergency department (ED) visits[a]	Barriers and Facilitators Self-Efficacy Patient-provider communication Adherence ED visits Health Status Patient Satisfaction with Health Care team communication	High 10/13 77%

Author(s), Year, Title	**Purpose**	**Study Design**	**Sample Size, n**	**Variables Used**	**Findings**	**Themes**	**Quality Assessment**
Schprechman et al 2013 “Health literacy and global cognitive function predict e-mail but not internet use in heart failure patients”	To assess whether health literacy, heart failure knowledge, and cognitive function was related to internet and e-mail use in older adults with heart failure (HF).	Cross sectional	N=119 older adults with HF	HF Connectivi Questionna For compu Internet us Medical Term Recognitio Test (METER) HL Dutch HF Knowledg Scale Modified Mini Mental State (3MS Exam	Those with higher health literacy were more likely to report e-mail use[a] METER scores did not predict internet use Those with higher 3MS scores were more likely to report e-mail use[a] Scores were similar on the Dutch Heart Failure Know-ledge Survey in partici-pants who reported internet use and those who did not.	Internet use, e-mail use, PHR/PP use HL Cognitive Impair-ment	High 7/8 88%

Author(s), Year, Title	**Purpose**	**Study Design**	**Sample Size, n**	**Variables Used**	**Findings**	**Themes**	**Quality Assessment**
Wakefield et al 2017 “Design and evaluation of a web-based symptom monitoring tool for heart failure”	To design a Web-based tool to be compatible with the HC system patient portal to facilitate symptom monitoring and symptom recognition in patients with chronic heart failure and conduct a usability evaluation of the Web site.	Usability Study	N=4 Adults with HF	Heuristic evaluation Usability testing using Morae usability data Collection software Descriptive statistics for System Usability Scale (SUS)	Participants generally had a positive view of the Web site and indicated it would support recording their health status and communicating with their doctors. Participants expressed a need to incurporate decision support within the site and wanted to add other data (ex. Blood Pressure) and have the ability to adjust font size.	HF Decision Support Communication with the HC team PHR Usability	High

Author(s), Year, Title	**Purpose**	**Study Design**	**Sample Size, n**	**Variables Used**	**Findings**	**Themes**	**Quality Assessment**
Wu et al 2005 "Pilot study of an internet patient-physician communication tool for heart failure disease management"	To determine whether patients would use the Heart Failure Internet Communication Tool (HFICT) over a sustained period of time, and to evaluate the safety and maintainability of such a tool.	Prospective observational cohort study	n=62 with a new diagnosis of HF	Qualitative content Analysis of patient messages Descriptive stats for Users and non-users	Planned Hospital Increased in Users[a]	Use and non-use Communication Themes: Patient info, Symptoms, Questions, self-care, social responses HC Utilization	High 9/11 82%
Zan et al 2015 "Patient engagement with a mobile web-based telemonitoring system for heart failure self-management: A pilot study"	To evaluate the feasibility of using the iGetBetter system for disease self-management in patients with heart failure.	Cohort Study	N=20 adult heart failure patients	Patient Reported Outcomes Measurement Information Systems (PROMIS) HF-QoL Patient Health Questionnaire (PHQ-8) for depression	Most reported feeling more: connected to their health care team, confident in performing care plan activities, and better prepared to start discussion about their health with their doctor. Most had weekly engagement with the program. Hospital utilization did not differ between the groups.	Usability Satisfaction Effects on care Engagement with the Intervention Hospital resource Utilization QOL	High 9/11 82%

Table 2.2

Thematic Analysis

Health Zone	Brennan et al 2010	Dang et al 2018	Earnest et al 2004	Ferguson et al 2010	Ghahari et al 2017	Holden et al 2017	Mickelson et al 2015	Ross et al 2004	Schprechman et al 2013	Wakefield et al 2017	Wu et al 2006	Zan et al 2015
SE		X	X					X				
HC Resource Utilization	X							X			X	
Physical Status	X		X					X				
Mental Status	X								X			X
Quality of Life	X	X	X					X			X	X
Health Literacy					X				X			
Social Interaction			X	X	X			X			X	
Information Zone	Brennan et al 2010	Dang et al 2018	Earnest et al 2004	Ferguson et al 2010	Ghahari et al 2017	Holden et al 2017	Mickelson et al 2015	Ross et al 2004	Schprechman et al 2013	Wakefield et al 2017	Wu et al 2006	Zan et al 2015
HF Knowledge		X	X		X		X		X		X	
HF Self-Care/ SM	X					X	X				X	X
HF Decision Support			X	X						X		
Adherence/ Engagement/ Empowerment			X		X			X				X

Information Sharing			X	X	X						X	X
Communication with Health Care Team			X	X	X			X		X		
Technology Zone	Brennan et al 2010	Dang et al 2018	Earnest et al 2004	Ferguson et al 2010	Ghahari et al 2017	Holden et al 2017	Mickelson et al 2015	Ross et al 2004	Schprechman et al 2013	Wakefield et al 2017	Wu et al 2006	Zan et al 2015
PHR/ PP Usability		X			X	X	X			X	X	
Concerns with PHR/ PP			X	X								
Barrier Facilitators to PP/ PHR Use: Internet Experience					X	X		X	X			X
Barrier Facilitators to PHR/ PP Use: Computer Use					X		X	X	X			X
Patient Satisfaction	X	X						X				

Patient Portal Use, Health Information Technology Self-Efficacy, Electronic Health Literacy, and Self-Management among Patients with Heart Failure:

A Cross Sectional Study

Abstract

In a study of heart failure patients registered for their patient portal, participants had moderate to high health information technology self-efficacy and electronic health literacy. Yet only 35% were active portal users, and self-management of heart failure was sub-optimal.

Keywords: Patient Portal, Heart Failure Self-Management, Electronic Health Literacy, Health Information Technology Self-Efficacy

Patient Portal Use, Health Information Technology Self-Efficacy, Electronic Health Literacy, and Self-Management among Patients with Heart Failure:

A Cross Sectional Study

By the year 2030, the prevalence of heart failure is projected to increase by 46% affecting more than 8 million people with an anticipated cost increase by 127% to nearly $70 billion annually (Benjamin et al., 2017). Like many chronic conditions, self-management is an essential component of the plan of care for maintaining a healthy lifestyle. The challenges in self-management for those suffering with this chronic disease can have an enormous impact on the patient's health and quality of life due to persistent fatigue, dyspnea, and depression.

Yet, many persons have sub-optimal self-management skills which can result in emergency department visits and hospitalizations. Rates of hospitalizations are increasing for those with heart failure, and an estimated 83% were hospitalized at least once after diagnosis with over 40% hospitalized at least four times (Benjamin et al., 2017). Innovative strategies are needed to improve self-management skills and enhance health outcomes for those with heart failure.

One such strategy to enhance self-management of heart failure involves the use of health information technology (HIT), such as the patient portal, to manage personal health information. A patient portal is a personal health record, tethered to a patient's electronic medical record. Using patient portals, patients can view their protected health information such as lab results and medication lists, health related education, and use other functions to support their self-care, such as medication refills (Health IT.gov., 2017). A patient portal can provide quality information to patients and support the shared decision making between the patient and the formal caregiver, the healthcare provider (Ghahari et al., 2018).

Two main antecedents are reported in self-management including self-efficacy and health literacy (Van de Velde et al., 2019). Self-efficacy is the person's belief in their ability to succeed (Bandura, 1977) while health literacy is the degree to which individuals seek and use information to make health decisions (Nutbeam, 2008). Studies have explored the association of general self-efficacy with patient portal use by persons with heart failure noting that an increase in general self-efficacy supports use (Earnest et al., 2004, Ross et al., 2004, Dang et al., 2018). General self-efficacy differs from health information technology (HIT) self- efficacy, which encompasses the belief that one can succeed in the use of HIT (Kim and Park, 2012). There have been no studies exploring the association of HIT self-efficacy with patient portal use by a person with heart failure. Likewise, the association of general health literacy and patient portal use by the person with heart failure has been explored noting that greater health literacy also supports portal use (Ghahari et al., 2018; Schprechman et al., 2013). General health literacy differs from electronic health literacy, which is added ability to use technology to search, read and understand health information (Norman & Skinner, 2006). There has been a lack of research to explore the relationship between electronic health (eHealth) literacy and patient portal use by a person with heart failure. A deeper understanding of the relationship between the extent of patient portal use, self-efficacy and health literacy in the self-management of heart failure is needed, specifically as portal use relates to health information technology, self-efficacy and electronic health literacy.

Historically, patient portal use by individuals with a chronic condition, such as heart failure, had been defined by whether patients had registered for their portal or not (Ammenwerth et al., 2012). More recently, the definition of patient portal use has been expanded to explore the frequency of the patient's use as well as the use of specific portal features (Nahm, Son, et al., 2020; Nahm, Zhu, et al., 2020; Nahm et al., 2019). This is an important distinction as *registration* for the patient portal is not the same concept as actual patient *use* reported to support patient engagement necessary for self-care management (Health IT.gov., 2019). The current study examined actual portal use rather than portal registration only.

A gap in knowledge exists in understanding the relationship between patient portal use, HIT self-efficacy, electronic health literacy and self-management in the person with heart failure. This research is important to persons with heart failure and for informal and formal caregivers to support self-management, improve patient outcomes and address costly healthcare utilization.

Purpose

The purpose of this cross-sectional study is to answer the question: “What is the relationship between the use of a patient portal, health information technology (HIT) self-efficacy, electronic health literacy, and the self-management of heart failure?” There were three specific aims including:

1) Describe patient portal use among persons with heart failure to include frequency and use of specific features, such as the portal messaging system to email their healthcare provider or make appointments for routine or follow up care.

2) Explore potential differences in patient portal use among persons with heart failure based on gender, age, race, educational background, yearly household income, years since diagnosed and the Self-Assigned New York Heart Association (SA-NYHA) Classification.

3) Examine associations between patient portal use, HIT Self-Efficacy, and electronic health literacy in the self-management of heart failure.

We also present reflections on and lessons learned from our attempts to recruit participants and collect data during the COVID-19 global pandemic.

Related Literature

An integrative review of the literature to synthesize what is known about patient portal use by persons with heart failure revealed predominant themes contributing to use (Kallmerten et al., 2021). The Health Information Technology Acceptance Model guided the literature analysis, and the review noted themes within the health, information and technology zones (Kim & Park, 2012). Within the health zone, the predominant themes identified as contributing factors to patient portal use included physical and mental health, quality of life and social interaction. For example, preserved physical health translated to an increase in patient portal use. There were no differences in patient portal use reflective of perceived self-efficacy, and higher reported health literacy was noted for computer and internet use but not patient portal use. Within the information zone, knowledge about heart failure and self-care, information sharing, and communication themes were identified. Some positive associations were noted between patient portal use and self-management. Within the technology zone, barriers and facilitators of patient portal use and overall usability were predominant. If the patient portal was perceived to be useful, actual registration and use was reported (Kallmerten et al., 2021). These findings were consistent with the research conducted by Kim and Park (2012) who reported that perceived threats to health, usefulness, and ease of use affected patients' attitudes and intent to use a portal.

A recent study to explore predictors of patient portal use by persons with multiple chronic conditions reported that a diagnosis of heart failure was a significant predictor of patient portal use (Powell & Deroche, 2020). Another team reporting on healthcare services use noted that while patient portal use by persons with heart failure did not translate to fewer readmission rates, emergency visits or reduced hospitalization length of stay, there was a significant reduction in the number of hospital visits (Bao et al., 2020). Overall, the patient perceptions of the patient portal by the person with heart failure can lead to the acceptance and use of the technology which may impact self-management. Further understanding of the factors that support patient portal use by the person with heart failure may inform interventions using the patient portal to support self-management and improve patient outcomes.

Theoretical Framework

Variable selection for this study was guided by the theoretical framework Health Information Technology Acceptance Model (HITAM), which distills the facilitating and barrier factors of acceptance of HIT into the three zones of influence mentioned above (Kim & Park, 2012). In the health zone, the presence of a chronic condition such as heart failure as well as the perception of *general* self-efficacy impacts the perceived threat to health. In the information zone, the quality of the information as well as health literacy, or the ability to use the information, impacts one's perception of usefulness. In the technology zone, the usability or functionality of the patient portal in addition to the *HIT self-efficacy* impacts the perceived ease of use. These perceptions lead to a positive attitude and the intent to use the technology to change behaviors important in self-management (Kim & Park, 2012). A recent cross-sectional study by Kallmerten et al (2021b, *in press*) replicated the findings of the HITAM study noting that the perception of susceptibility to and seriousness of chronic disease contribute to the overall perceived threat to health and *indirectly* correlate to behavioral intention. By contrast, the perception of usefulness and ease of use were found to have a strong *direct* correlation to the intent to use a patient portal (Kallmerten et al, 2021b, *in press*).

Method

Design, Setting and Sample

A cross sectional design with an electronic survey was used to study the variables of interest. Three healthcare organizations in the Northeastern United States participated in recruitment, including a tertiary referral center (422 staffed beds), a large community medical group (221 beds) and a small community medical group (96 beds). A convenience sample was obtained via response to an encrypted recruitment email containing the anonymous survey link. The recruitment email was sent by an honest broker of the organization to patients who met the inclusion criteria of an adult with a diagnosis of heart failure who had registered for their patient portal for the large and small community medical groups. The tertiary referral center added an additional inclusion criterion for participation; patients needed to have selected and "opt-in" feature through the patient portal, indicating their interest in participating in research studies.

Survey Instruments

The electronic survey, created with the *Qualtrics®* online survey platform, included the informed consent and a total of 59 items- seven demographic data items, the single Self-Assigned New York Heart Association Classification (SA-NYHA) item, six items on patient portal use, six items on HIT self-efficacy, 10 items on electronic health literacy, and 29 items measuring self-care of heart failure. A description of each of the measurement tools within the survey follows.

Demographic Characteristics

Six items asked for self-identification of gender, age, race, educational background, yearly household income and years since first diagnosed with heart failure. Importantly, previous research has identified barriers to patient portal use reflective of social determinants of health

(Mold et.al., 2018). The survey functionality included a *requested* rather than a *forced* response, and in the instance of income included a choice of *prefer not to answer*. This functionality allowed the participant to provide no response without receiving a prompt to answer the question in order to proceed with the survey.

Self-Assigned New York Heart Association (SA-NYHA) Classification

The New York Heart Association (NYHA) Classification is the gold standard for predicting outcomes in heart failure, and this classification is determined by one's healthcare provider (Bennett et al., 2002). Holland et al (2010) created a questionnaire asking patients to respond to the descriptors of the standard instrument and then compared the NYHA classification assigned by their medical providers to the self-assigned instrument. The Self-Assigned New York Heart Association (SA-NYHA) Classification was comparable to the clinician assigned classification and was also predictive of future outcomes (Holland et al., 2010). Thus, the instrument has predictive validity when used by patients (Holland et al., 2010).

Patient Portal Use

The six questions regarding portal use were from the publicly available Health Information National Trends Survey (HINTS5, Cycle 2) (Blake & Moser, 2019). Questions include frequency of access in the previous year as well as specific feature use. Specific feature use questions include whether the patient had viewed, downloaded and transmitted personal health information as well as the use of communication features, such as sending secure messages with and without medical information. If the patient had accessed the patient portal within the previous twelve months, they were presented with the question about the use of features of the patient portal. If they had not accessed the patient portal within the previous 12 months, they received a question to note their reasons for non-use.

Health Information Technology Self-Efficacy

The six items for HIT self-efficacy were from the HITAM Questionnaire and asked for the patients' perceptions of their capacity to use online health information (Kim & Park, 2012). The Likert-type scale options of strongly disagree, disagree, neither agree nor disagree, agree or strongly agree were selected for statements such as, *I am good at using technology*, *I am confident in using technology,* and *I think I can utilize online health information.* Each strongly disagree was scored with one point through six points for each strongly agree selection. The six items are scored by summing to create a composite score with a range of 6-30, and higher scores reflect higher HIT self-efficacy (Kim & Park, 2012). The HIT self-efficacy tool has a reported Cronbach alpha statistic of 0.89 indicating good reliability. The variable was found to correlate significantly for HIT reliability, perceived ease of use and usefulness, attitude and the behavioral intention to use a patient portal (Kim & Park, 2012). Reliability testing conducted with the sample in the current study noted a Cronbach alpha statistic of 0.92, indicating good reliability.

Electronic Health Literacy

The ten items of the Electronic Health Literacy Scale (eHEALS) assessed electronic health literacy (Norman & Skinner, 2006). Two questions regarding the perceived importance and usefulness of the internet are included but not scored as part of the eHEALS composite score. The remaining eight items are on a Likert-type scale and used to assess patients' perceptions to questions such as *I know what health resources are available*, *I know where to find them, how to use them and I have the skills to evaluate them*. Each strongly disagree was scored with one point through six points for each strongly agree selection. The scores for the eight items, with a range from 8-40, are summed for an overall composite score; higher scores reflect higher electronic health literacy (Norman & Skinner, 2006). Reliability testing in the current study noted a Cronbach alpha of 0.92 indicating good reliability.

Self-Management of Heart Failure

The Self-Care of Heart Failure Index (SCHFI v.7.2) is the gold standard for assessing self-care maintenance, self-care monitoring and self-care management among patients with heart failure (Riegel et al., 2019). The instrument is comprised of a total of 29 items that address behaviors of self-care maintenance, self-care monitoring and self-care management according to a Likert-type scale of never, sometimes and always. Each behavioral index is scored separately with a raw score derived by summing the participants' response, and then the score is transformed to an index score; higher scores reflect more optimal self-care. Each index score is obtained by subtracting the lowest possible score from the raw score, dividing by the highest possible score and multiplying by 100 (Riegel et al., 2019). Higher index scores reflect higher self-care behaviors necessary for chronic disease management; scores over 70 indicate an adequate level of heart failure self-care (Riegel et al., 2019). Each scale was evaluated for reliability with this sample and Cronbach alpha statistics of 0.68 for the self-care maintenance scale, 0.88 for the self-care monitoring scale, and 0.76 for the self-care management scale.

Data Collection Procedures

Following Institutional Review Board (IRB) approval and completion of HIPAA Compliance Documents for Duquesne University, approval for this study was received from the large and small community medical groups through their Human Investigations Committee. The tertiary referral center required submission for IRB approval as well as a de-identified data use agreement. Finally, an IRB Authorization Agreement was submitted noting the relationship between all involved institutions.

Through collaboration with key stakeholders at each facility, an honest broker identified potential patients to recruit using the aforementioned inclusion criteria. The limited functionality of the patient portal messaging capabilities at the smaller community medical practices led to the decision by the Chief Medical Information Officer (CMIO) to send the recruitment invitation via a mass encrypted email because the functionality of the patient portal did not include an eMessage function. The larger healthcare organization utilized a different vendor for the patient portal and determined it was feasible to send the recruitment email through the patient portal as a secure message. The CMIO for the tertiary care facility expressed concerns about multiple eMessages sent through the portal, which was the result of increased use of technology during the COVID-19 pandemic. To limit the perceived increase in eMessages to patients, the CMIO decided the invitation to participate would be sent only to those registered for their portal who had also selected an option about an interest in research participation. Once the recruitment eMessage had been received by the person with heart failure, the anonymous link within the eMessage could be accessed for survey completion using the platform Qualtrics®. A final question was included at the end of the Qualtrics® survey asking if the participant would like to provide an email address to receive a $10 gift certificate as compensation for survey completion. The survey responses were not linked in any way and were stored in two separate locations.

Method of Analysis

Using descriptive statistical analysis, all demographic characteristics were explored noting frequencies, distribution, and percentages. Patient portal use was explored noting frequencies, distributions, and percentages for all categorical data while the mean, standard deviation, and range were determined for perceived usefulness (Aim 1). Contingency tables and chi-square tests of independence were conducted between the portal use categories of non-user, light user and active user and the demographic characteristics of gender, age, race, education, incomes, site where they receive their care, years since first diagnosed with heart failure, and the SA-NYHA (Aim 2). Finally, a Kruskal-Wallis H test and Jonckheere-Terpstra (JT) analysis were conducted to determine if there were differences between the dependent variable of patient portal use and the independent variables of HIT Self-Efficacy, Electronic Health Literacy and the three scales of the SCHFI: self-care maintenance, self-care monitoring and self-care management (Aim 3). Preliminary screening of the data revealed that there were 28 total responses. However, eight responses were removed prior to analysis due to incomplete surveys.

Results

Description of the Sample

Of the 20 complete survey responses, 10 participants identified as male (50%) and 10 identified as female (50%). All participants were older than age 50 with 90% between the ages of 60-79 years. All participants identified as white (100%). Only 4 of the participants (20%) did not have any college education with 5 participants (25%) reporting a graduate degree. Ninety-five percent of the participants had been diagnosed with heart failure in the previous ten years and most classified themselves as having either Class I or Class II Heart Failure with the SA-NYHA Classification (See Table 1).

Description of Patient Portal Use

To address the first specific aim, the participants reported the number of times that they accessed the portal in the previous year, their use of the patient portal features, type of information on their patient portal, their use of the portal to send medical information, and perceived patient portal usefulness. See Table 2. Over half of the sample reported accessing their portal five times or fewer in the previous 12 months. Except for use of the feature to send a secure message to their provider, most participants did not use the medication refill, form completion, request for correction, or the download or upload of protected health information documents features. When asked if their online medical records included certain types of medical information, most (65-70%) replied that they were aware that their patient portal contained information about their health/medical problem and allergy lists as well as office visit summaries and clinical notes. Most were not aware that their immunization/vaccine status was available. The majority did not send medical information retrieved through the portal to formal or informal caregivers. Finally, while 75% affirmed that their online medical record was very/somewhat useful in monitoring their health, 20% report that they do not use their online medical record in this manner.

Three participants (15%) reported that they had not accessed their patient portal at all in the previous year and were presented with a series of questions from which to choose possible reasons for not accessing their online medical record. While two of the three stated they would prefer to speak to their healthcare provider directly, two out of three also indicated that they did not have an online record (Table 2).

Exploration of Differences in Patient Portal Use

To address the second specific aim and compare demographic characteristics with reported patient portal use, three categories of portal user were created. Those who selected 0 to the question of number of times that the patient portal was accessed in the previous 12 months were categorized as a *non-user*. In addition, the responses of those who reported access 1-2 times in the previous year were reviewed, and all 5 denied use of any patient portal features; these 5 were also classified as a *non-user*. Thus, for non-users, n=8. Those who indicated that they accessed the patient portal at least 3 times, but no more than 9 times were categorized as a *light* *user* (n=5). Finally, those who reported that they had accessed their patient portal at least 10 times in the previous year were categorized as an *active user* (n=7).

There was a statistically significant association between category of patient portal user and the facility where they received their care, $x^2(4) = 18.19, p = .001$. Upon further exploration, all active users were from the tertiary referral center; participants from the small and large community medical groups were all non-users and light users.

There was also a statistically significant association between the category of patient portal user and their SA-NYHA Classification recoded to Class I/II and Class III/IV, $x^2(2) = 6.59, p = .037$. While the chi square test of independence is an omnibus test, an analysis of the variable of SA-NYHA noted that for those in the combined Class I/II category (n=15), 53% were categorized as non-users, 27% as light users and 20% as active users. By comparison, for those in the combined Class III/IV category (n=5), all were either light (20%) or active users (80%). This suggests that, for this sample, as the perceived ability for physical activity is hampered represented by the higher self-classification scores, patient portal use increases. There were no statistically significant findings for any other demographic characteristics.

Descriptive Statistics for HIT SE, eHL and the Self-Care Heart Failure Index (Table 3)

HIT Self-Efficacy

With a mean score in the top third of the possible range, the sample in this current study reported an overall moderately high perceived self-efficacy for using HIT (Table 3). When examining the HIT Self-Efficacy scores for each category of patient portal user, those in the category of non-user had the lowest mean score of 21.5 (*SD*=4.69, range=17-30), while the light user had a mean score of 24.8 (*SD*=3.83, range=20-30), and the active user had a mean score of 24.29 (*SD*=3.546, range=19-29).

eHealth Literacy

As noted in Table 3, this sample also reported moderately high electronic health literacy with a mean eHEALS composite score in the highest third of the possible range of scores. In addition to the eHEALS composite score, two extra questions addressed the perceived usefulness and importance of the internet in helping with decision making regarding their health. Overall, this sample reported scores higher than the mid-point, indicating greater perceived usefulness and importance of the internet. However, two participants selected the choice that the internet was *not useful at all* and two participants selected *not important at all* to the question about how important the ability is to access health resources on the internet.

Self-Care Heart Failure Index (SCHFI)

As previously noted, the Self-Care Heart Failure Index is comprised of three separate scales for self-care maintenance, self-care monitoring and self-care management in addition to three supplemental questions regarding timeliness to symptom recognition and relationship to HF and treatment effectiveness (Riegel et al., 2019). With index scores over 70 for the first two scales, this sample reported overall adequacy for heart failure self-care maintenance and monitoring (Riegel et al., 2019). See Table 3.

By contrast, the overall index score for Self-Care Management was below 70 indicating an opportunity for improvement. This scale asks the question: *When you had symptoms, how likely are you to use one of the following: reduce sodium intake for the day, reduce fluids, take a medicine, call the provider for guidance, ask a family member or friend for advice, try to figure out why you have symptoms and limit your activity until you feel better?* Only fifty percent said that they were very likely to reduce their sodium for the day and only 25% said that they were very likely to reduce their fluid intake. 65% reported that they would limit their activity until they felt better. Among the three categories of patient portal use, the non-users had the highest self-care management index score with a mean of 62.5 (*SD*=19.69, range 29-86), while the light users had the lowest score with a mean of 57.2 (*SD*=24.05, range= 21-79), and the active user had a self-care management index score mean of 61.1 (*SD*=26.18, range=21-100).

SCHFI Supplemental Questions. Two supplemental questions were posed after the self-care monitoring section and asked the participant to reflect on the last time that they had symptoms. The first question asked: *how quickly did you recognize that you had symptoms?* The second question asked: *how quickly did you know that the symptom was due to heart failure?* The Likert-type question had five responses ranging from *I have not had symptoms* to *I responded very quickly.* As noted in Table 3, overall, the participants responded quickly with symptom recognition but reported a response delay in realizing that their symptoms were due to their heart failure. Following the self-management section, a question was posed asking the participant *to think of a treatment you used the last time you had symptoms* and *whether it made them feel better*. For this final question regarding symptom treatment effectiveness, 11 (55%) were very sure that the treatment made them feel better while 7 (35%) were somewhat sure or not sure. The remaining 10% reported that they did not do anything when they had symptoms.

Differences between Patient Portal User Groups and HIT SE, eHL and SCHFI

Using the Kruskal-Wallis H test and Jonckheere-Terpstra analysis, there were no differences noted for any pairwise comparisons between patient portal use (non-user, light user, active user) and HIT self-efficacy, electronic health literacy, or the three scales of the SCHFI: self-care maintenance, self-care monitoring and self-care management. The largest *H* statistic showed the greatest difference between the categorization of patient portal user and HIT self-efficacy, but the relationship was not statistically significant. The strength of this statistical parameter suggests that there may be a trend toward statistical significance worthy of future study (Table 4).

Discussion

The purpose of this study was to examine the relationship between patient portal use, HIT self-efficacy, eHealth literacy and the self-management of heart failure. Due to the small sample size, the results are exploratory in nature. While the earliest studies described patient portal use in terms of registration for the portal (yes/no) (Ammenwerth et. al., 2012), we explored the concept of portal user according to the frequency of their access and provided information on their reported use of features. We also assessed characteristics of the patient portal user in terms of their demographic profiles, perceived SA-NYHA Classification, HIT self-efficacy, and eHealth literacy. There were three salient overall findings identified in this study. First, the characteristics of the user suggest that the participants in this study have sufficient HIT self-efficacy and eHealth literacy necessary for patient portal use. Second, the characteristics of patient portal use suggest that patient portal registration does not translate to actual use and, despite 15/20 participants reporting that their online medical record was somewhat useful or very useful, nearly all the patient portal features were not used by most of the sample. Third, self-reported self-management of heart failure, particularly during symptom flare-ups, was sub-optimal. While the small sample size limits generalizability, this study may contribute to understanding of patient portal use by the person with heart failure. The feasibility of this study during a pandemic will also be discussed.

Characteristics of the User

Overall, the participants in this study have adequate HIT self-efficacy, eHealth literacy, self-care maintenance and self-care monitoring. Our analysis found that the non-user reported lower HIT self-efficacy, which is an important antecedent to the perceived usefulness and ease of use of the patient portal (Kim & Park, 2012). This sample also reported moderately high eHealth Literacy which is an important contributing factor impacting perceived patient portal self-efficacy, usefulness, ease of use and positive attitude toward use (Son et al, 2021).

There were statistically significant differences between the categories of patient portal use and the site where they received care. The association between patient portal use and the site of care should be considered cautiously as the additional inclusion criterion by the large tertiary referral center to recruit only those who had opted-in to participating in research suggests sample bias. All but one of the participants from the large tertiary center reported active patient portal use with the other participant reporting light use. It is unclear as to whether this reflects the functionality and usability of the patient portal utilized by this facility or the opt-in process.

The association of patient portal use with the SA-NYHA is consistent with the findings by Kim and Park (2012) that health status contributes to a perceived threat to health and can impact the intent to use a patient portal. An integrative review of the literature exploring patient portal use by the adult with heart failure noted that declining health often negatively impacts use of the patient portal (Kallmerten et al, 2021a). However, in this sample, the SA-NYHA Classification for III/IV showed a higher percentage of active users (80%) and light users (20%), while those in Class I/II were divided nearly evenly with 53% non-users and 47% light/active users. These results should also be considered cautiously because of the potential sample bias from the large tertiary center with the most active users coming from this facility.

Characterization of Patient Portal Use

Actual patient portal use is more accurately reflected by portal registration plus the frequency of access and the use of features (Nahm et al, 2020). While our sample size was very small, our findings suggest that underutilization of the patient portal is still a concern, e.g., 40% of the sample did not access their portal with any regularity. In addition, despite registration in their patient portal, two-thirds reported that they *do not have* an online medical record, suggesting that awareness is a concern.

An important metric captured by the facility as part of the meaningful use reimbursement is that of the percentage of persons who use the view-download-transmit feature (Ong & Kelly, 2015). This sample reports low feature use with only 30% who have downloaded personal health information, and 70% have not submitted patient generated data to their provider to enhance their care. In addition, a majority chose the response of *no* or *don't know* to the question about whether their patient portal included their immunization or vaccine history. Immunization status is especially important for the person with heart failure, especially during a pandemic. These data suggest there is an opportunity to improve the use of features with education and marketing initiatives, e.g., patient testimonials sharing experiences downloading or uploading patient-generated data and viewing their immunizations might support self-management.

Self-Management of Heart Failure

The overall mean index score less than 70 on the Self-Care Management Scale indicates sub-optimal self-care management by persons with heart failure (Riegel et al, 2019). As noted, higher self-care management index scores were noted for those in the non-user category when compared to the light and active portal users although the differences were minimal. This finding is consistent with previous research showing no significant effect of the use of technology enhanced practice on self-management (Brennan et al, 2010). An opportunity exists to leverage the use of HIT, such as a patient portal, to address the two dimensions of the scale: recommended behaviors and problem-solving behaviors. Specifically, when symptoms were noted, only 50% reported that they further reduced their salt, and only 25% reported a reduction in fluid intake. Similar to other chronic diseases such as diabetes, reinforcement for education on symptom control is necessary (Down, 2020).

Impact of the COVID-19 Pandemic on Research

A discussion regarding the findings of this study absent the context of the times is incomplete. When a report was received in February of 2020 from the original facility noting patients who met the inclusion criteria was well below the a priori target sample size of 77, an IRB amendment was filed to recruit from other facilities. Meetings were held with key stakeholders, and additional IRB applications were submitted in late February and early March of 2020 to expand recruitment.

On March 11, 2020, the World Health Organization (2020) characterized the outbreak of COVID-19 infections as a global pandemic with implications for the health, economy, and social fabric of our nation. Within days, the Department of Health and Human Services (2020) provided guidance on prioritizing research initiatives, and all new research not directly addressing the pandemic was suspended immediately. While nearly every facility in the state was agreeable to discussing collaboration in late February and early March, by month’s end, all organizations except one withdrew the offer.

During the crisis, researchers were faced with a dilemma of trying to complete the research while remaining cognizant of scarce resources. The feasibility of research was called into question with suggestions to pivot to electronic methods of recruitment, data collection, collaboration and dissemination (Byrd et al., 2020; Fleming et al., 2020; Hashem et al., 2020). Many researchers were required to review the current status of their study and consider options to pause the research, persist through the pandemic or pivot the focus of the research (O'Brien et al., 2020). Because the current study was in the data collection stage with electronic data collection consistent with social distancing guidelines, the decision was made to persist. This decision was not without challenges. Data collection continued slowly via the virtual recruitment and electronic survey at the original sites, but still the COVID-19 pandemic posed an enormous challenge for recruiting participants.

Once restrictions on new research were lifted in summer 2020, collaborations facilitated IRB approval at the tertiary referral center. An initial report of over 1000 persons meeting the inclusion criteria was obtained. Persistence led to an opportunity to recruit while adhering to social distancing guidelines, albeit with a new timeline for study completion. In light of the pandemic, this option was very welcome as it was noted by many that non-COVID research would become another casualty of the pandemic (Singh et al., 2020).

While the decision was made to persist with the study, a decision made by the CMIO at the tertiary referral center in December of 2020 severely limited data collection. Due to the pandemic, an increasing volume of eMessages were sent to their patients for announcements of telehealth visits, changes in guidelines for clinical care encounters, and other patient-provider communication. While the IRB approved sending the recruitment eMessage to those persons with heart failure who were registered for their patient portal, the CMIO stipulated that a new policy required that only those who had indicated that they were interested in participating in research would receive the link. Thus, the number of persons who met the inclusion criteria was reduced from over 1000 to a mere 25 potential participants who had opted-in to the offer to participate in research. This extreme reduction of potential participants limited the ability to recruit the target sample size, necessitated stopping the study, and required a pivot in data analysis.

According to Hulley et al (2013), the important elements of a good research plan are that it be feasible, interesting, novel, ethical, and relevant (FINER). Although the current study addressed a thought-provoking question to increase our understanding of factors that may support self-management of heart failure, especially relevant considering our circumstances in the pandemic, participant recruitment was not feasible. In the end, the target sample of 77 participants could not be achieved, which impacted the power to answer our research question and detect any differences in self-management related to reported patient portal use, HIT self-efficacy, and eHealth literacy.

Implications for Practice and Research

This study contributes to improving practice by expanding our understanding of patient portal use by persons with heart failure. We know that the patient portal is still underutilized and that efforts to increase awareness and use need attention. We know that there exists an opportunity to encourage patient generated data to improve patient-provider communication and enhance care. There is also an opportunity to increase immunization/vaccination awareness which is especially timely in times of a pandemic. Self- management of heart failure in this sample was below the guidelines noted by the SCHFI instrument, and the findings can be used to reinforce with patients the need to restrict sodium and fluids during symptom exacerbation.

Finally, implications for continued research include the opportunity to explore ways to improve patient portal usage and its impact on self-management. Research is needed to determine interventions to leverage the use of the patient portal features. In addition, research exploring the motivational drivers important to the person with heart failure to use their patient portal is needed. Replication of this study post pandemic with an adequate size sample is necessary to further improve our understanding of relationships between patient portal use, HIT self-efficacy and eHealth literacy in the self-management of heart failure. Lastly, studies are needed on how best to support researchers' decisions to pause, persist or pivot during a pandemic or other crisis.

Limitations

The limited ability to recruit enough participants for survey completion means that this sample may not represent the target population, and this insufficient sample size limits analysis. Additionally, the self-report nature of the survey responses and request for behaviors conducted over the previous 12 months may have resulted in social desirability and recall bias respectively. The low response rate suggests the potential for nonresponse bias. The opt-in to research requirement for one facility may have resulted in a sampling bias.

Conclusion

This study provided a beginning understanding of patient portal use by persons with heart failure including the differences in patient portal use when considering individual demographic factors, HIT self- efficacy, electronic health literacy, and perceptions of self-care. Although lower HIT self-efficacy and electronic health literacy can negatively impact the use of the patient portal (Kim & Park, 2012, Son et al 2021), this sample reported moderate to high HIT self-efficacy and electronic health literacy but limited portal use. Therefore, these antecedents did not appear to impact patient portal use in this small sample. While initiatives to increase the percentage of patients who are registered have been noted, (Ong & Kelly, 2015) these efforts have not translated to an appreciable increase in actual patient portal use among these participants. Finally, this study underscored the sub-optimal self-management noted among persons with heart failure, especially when symptoms of exacerbation are present.

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Table 3.1

Demographic Characteristics (N=20)

Demographic Data	***n* (%)**
Gender	
Male	10 (50)
Female	10 (50)
Age	
18-49	0 (0)
50-59	1 (5)
60-69	10 (50)
70-79	8 (40)
80 or older	1 (5)
Race	
White	20 (100)
Other	0 (0)
Education	
< High School	0 (0)
HS or GED	4 (20)
Some College	4 (20)
Associate Degree	4 (20)
Bachelor's Degree	3 (15)
Master's Degree	3 (15)
Doctorate	2 (10)
Income	
$24,999 or less	3(15)
$25-49,999	5 (25)
$50-99,999	5 (25)
>$100,000	0 (0)
Prefer not to answer	7 (35)
Years Since First Diagnosed with HF	
0-5	11 (55)
6-10	8 (40)
11-15	1 (5)
>16	0 (0)
SA-NYHA Classification	1 (5)
I	14 (70)
II	3(15)
III	2 (10)
IV	

Table 3.2

Patient Portal Use (from Health Information National Trends Survey: HINTS5) (N=20)

Patient Portal Use			***n* (%)**
Times accessed online medical record in previous 12 months			
0			3 (15)
1-2			5 (25)
3-5			3 (15)
6-9			2 (10)
10 or more			7 (35)
How useful is your online medical record for monitoring your health…?			
Very Useful			6(30)
Somewhat Useful			9 (45)
Not Very Useful			1 (5)
I do not use my online medical record to monitor my health			4 (20)
Reasons for No Access (n=3)	**Yes**	**No**	**Don't Know**
Prefer to Speak to HCP directly	2 (66)	1 (33)	
No website Access	1 (33)	2 (66)	
No need to use	2 (66)	1 (33)	
Privacy/Security Concerns	1 (33)	2 (66)	
Don't have an online record	2 (66)	1 (33)	
Other Reason	3 (100)	0 (0)	
Reported online medical record features used			
Med Refills	8 (40)	12 (60)	
Form Completion	6 (30)	14 (70)	
Request Correction	5 (25)	15 (75)	
Secure Messaging	12 (60)	8 (40)	
Download PHI	6 (30)	14 (70)	
Uploaded PHI	6 (30)	14 (70)	
Decision Making	8 (40)	12 (60)	
Electronically sent medical information to…			
Sent to another HCP	8 (40)	12 (60)	
Sent to a family member/person involved with care	4 (20)	16 (80)	
Sent to a service or app	0 (0)	20 (100)	
Type of Information			
Health/Medical Problem List	14 (70)	0 (0)	6 (30)
Allergy List	13 (65)	2 (10)	5 (25)
Office Visit Summary	14 (70)	1 (5)	5 (25)
Clinical Notes	13 (65)	1 (5)	6 (30)
Immunization/Vaccine Information	8 (40)	2 (10)	10 (50)

Table 3.3

Descriptive Statistics for Key Study Variables (N=20)

Variable	M	SD	Range
HIT Self-Efficacy Composite Score	23.3	4.2	6-30
eHealth Literacy Composite Score	31.1	5.4	8-40
eHealth Literacy Supplemental Questions			
• Usefulness of the Internet	3.8	1.0	1-5
• Importance of the Internet	3.9	1.1	1-5
Self-Care Heart Failure Index (SCHFI)			
• Self-Care Maintenance Index Score	78	14.4	0-100
• Self-Care Monitoring Index Score	74.3	21.2	0-100
• Self-Care Management Index Score	60.7	22.0	0-100
SCHFI Supplemental Questions			
• Timeliness in Symptom Recognition	4.2	0.9	1-5
• Timeliness to know it was due to HF	3.7	1.1	1-5
• Symptom Treatment Effectiveness	3.2	1.1	1-4

Table 3.4

Differences between Patient Portal User Groups and HIT SE, eHL, and SCHFI

Variable	**HIT SE**	**eHL**	**SC Maintenance**	**SC Monitoring**	**SC Management**
Kruskal-Wallis					
• H Statistic	3.254	.817	.403	.098	.307
• p value	.197	.665	.817	.952	.858
• Effect	.728	.183	.090	.022	.069
Jonckheere-Terpstra					
• Standardized Test Statistic	1.434	-.425	-.458	.176	-.281
• p value	.152	.671	.647	.861	.779
• Effect	.320	-.095	-.102	.039	-.063

Note. Patient Portal User Groups= Non-User, Light User, or Active User
HIT SE-= health information technology self-efficacy
eHL= electronic health literacy
SCHFI= Self-Care Heart Failure Index