Title: Heart Failure Patients’ Perceptions and Use of Technology to Manage Disease Symptoms

Authors: Amanda K. Hall, MHSE, MS, Virginia Dodd, PhD, MPH, Amy Harris, MPH, Kara McArthur, Clifford Dacso, MD, MPH, MBA, and Lara M. Colton, MD

Affiliations for author Amanda K. Hall: Center for Digital Health and Wellness, Department of Health Education and Behavior, College of Health and Human Performance, University of Florida, Gainesville, Florida

Affiliation for author Virginia Dodd: Department of Community Dentistry and Behavioral Science, University of Florida, Gainesville, Florida

Affiliation for author Lara M. Colton: Weill Cornell Medical College, The Methodist Hospital System, Houston, Texas

Affiliation for author Clifford Dacso: Molecular & Cell Biology and Medicine, Baylor College of Medicine

Affiliation for authors Kara McArthur and Amy Harris: Abramson Center for the Future of Health, The Methodist Hospital Research Institute, Houston, Texas

Author Correspondence: Amanda K. Hall, 1021 NE 20 Ave, Gainesville, FL 32609, mandikhall@gmail.com or cell phone: 352-514-3976
Abstract

Background: Technology use for symptom management is beneficial for both patients and physicians. Widespread acceptance of technology use in healthcare fuels continued development of technology with ever-increasing sophistication. While acceptance of technology use in healthcare by medical professionals is evident, less is known about the perceptions, preferences, and use of technology by patients. Introduction: This study explores patients’ perceptions and current use of technology for managing heart failure symptoms (MHFS). Materials and Methods: A qualitative analysis of in-depth individual interviews using a constant comparative approach for emerging themes was conducted. Fifteen participants (mean age 64.43) with heart failure were recruited from hospitals, cardiology clinics, and community groups. Results: All study participants reported use of a home monitoring device, such as an ambulatory blood pressure device or bathroom scale. The majority of participants reported not accessing online resources for additional MHFS information. However, several participants stated their belief that technology would be useful for MHFS. Participants reported increased access to care, earlier indication of a worsening condition, increased knowledge, and greater convenience as potential benefits of technology use while MHFS. For most participants financial cost, access issues, satisfaction with current self-care routine, mistrust of technology, and reliance on routine management by their current healthcare provider precluded their use of technology for MHFS. Discussion: Knowledge about heart failure patients’ perceptions of technology use for self-care and better understanding of issues associated with technology access can aid in the development of effective health behavior interventions for individuals MHFS and may result in increased compliance, better outcomes, and lower healthcare costs.

Introduction
Heart Failure

Congestive heart failure, commonly referred to as heart failure (HF), is a chronic disease leading to disability and death.\(^1\) HF is a major public health problem affecting 5.8 million Americans, resulting in approximately 300,000 deaths and 670,000 newly diagnosed cases each year.\(^2,3\) After age 65, the population incidence of HF nears ten per 1000.\(^4\) As a result HF is among the main causes of hospitalization for people \(\geq 65\) years old, half of whom will be re-hospitalized within 6 months.\(^5\) As such, the American Heart Association (2010)\(^6\) estimated the 2009 costs of US HF related-incidents at $39.2 billion.

Managing heart failure symptoms (MHFS) is complex and often requires changes in patients’ diets, daily activities, and medications to optimize symptom control and prevent acute decompensation.\(^1\) Proficient patient self-management skills are important to MHFS on a daily basis.\(^7\) Diet, vital signs (e.g., weight and blood pressure), and medications need to be monitored regularly to prevent exacerbations, hospitalizations, and ultimately reduce healthcare costs.\(^8\) Many HF patients have poor knowledge of their disease process, lack skills to manage their condition, have insufficient access to healthcare providers, lack social support, and experience little motivation to comply with prescribed self-care regimens.\(^9,10\) Furthermore, daily weighing is a cornerstone of outpatient HF self-management. Yet, not more than 40% of HF patients weigh daily, despite near-universal implementation of daily weighing by hospitals and outpatient facilities as recommended by clinical guidelines for education and planning.\(^11,12,10,13\)

Technology

Emerging technologies provide opportunities to decrease both the high demands and burdens associated with self-care, as well as the MHFS-associated healthcare costs. The literature offers multiple studies citing the benefits of telemonitoring technology when used to
remotely monitor vital signs of HF patients. Current interventions using technology such as telemonitoring devices to remotely monitor patients’ vital signs are associated with reduced rates of rehospitalization and mortality, as well as MHFS-associated healthcare costs.\textsuperscript{14,15,16} Findings from a systematic review and meta-analysis by Clark et al. (2007)\textsuperscript{14} support favorable clinical outcomes when remotely monitoring HF patients. In fact, meta-analysis results point to reductions in both hospitalization and mortality rates by 21\% and 20\% respectively.\textsuperscript{14}

While the literature offers much research supporting the benefits of telemonitoring, other randomized controlled trials report no significant differences between telemonitoring intervention and comparison groups on outcome measures such as number of emergency room visits and hospitalizations.\textsuperscript{17,18} These results may stem from the complexity of MHFS, including learning to use new technology, which can be challenging for elderly patients (Joyce & Loe, 2010; Marziali, 2009; Sanders et al., 2012). As stated by Suter, Suter, and Johnston (2011),\textsuperscript{19} “Technology, like all tools, is only as effective as the skill level of its users” (p. 5). Therefore, HF patients are sometimes faced with learning to use technology along with understanding how to manage their newly diagnosed heart failure symptoms.

Rahimpour, Lovell, Celler, and McCormick (2008)\textsuperscript{20} conducted a qualitative study exploring patients’ perceptions regarding use of telemonitoring technology. Their findings reveal major patient concerns including anxiety, low self-efficacy, provider support, and user friendliness of the technology. Moreover, study conclusions point to high self-efficacy and low anxiety levels as strongly influencing patients’ acceptance of telemonitoring technology.\textsuperscript{20}

HF telemonitoring technology devices are likely to assume a larger role in MHFS. Improvements in the technology are enabling the provision of more specific information to healthcare professionals, information that is useful for early detection of HF
exacerbations. While technology advances are encouraging, findings from a review by Schmidt et al. (2010) indicate potential problems not in the acceptance of remote home monitoring interventions (90% acceptance rate), but in the actual willingness of HF patients to participate in the interventions. These findings indicate a technology acceptance rate of 90% in contrast to the intervention acceptance rate of 50%. Sustainability of telemonitoring interventions is also of concern since Chaudhry et al. (2010) report adherence rates to a telemonitoring intervention as attenuating from 90% in week 1 to almost 55% by week 26.

Without a clear understanding of the factors influencing both acceptance and use of technology by patients for MHFS, continued technological improvements are unlikely to affect healthcare outcomes. Although literature exploring the use of telemonitoring technology in managing chronic diseases is expanding, studies specifically addressing HF patients’ perceptions and actual current use of technology for self-care purposes are lacking. Health information technology (e.g., home monitoring devices) will not benefit patients until they are willing to accept, use, and perceive the technology as beneficial to their health, particularly when compared to usual or standard care methods (Or & Karsh, 2009). The purpose of this study is two-fold (1) to explore patients’ perceptions and use of technology for MHFS and (2) to assess HF patients’ current use of technology for health.

**Materials and Methods**

Much research indicates patient uncertainty regarding health information technology use as a barrier to regular and sustained use of telemonitoring equipment (Jimison et al., 2008). As a result, health technology researchers continue efforts aimed at developing “user-friendly,” less intimidating technological devices for home use. One such device is the Blue Scale (Blue Box, Inc.). The Blue Scale device tracks multiple vital sign readings important for HF patient home
monitoring while the patient grasps handles which are large and attached to a reinforced base for adequate support and fall prevention. For the purposes of this study, the Blue Scale device was employed to explore patients’ perceptions and current use of technology for monitoring heart failure symptoms.

**Participants and Measures**

Initially, 21 eligible adults were identified and recruited for participation through hospitals, cardiology clinics, and community groups in the greater Houston metropolitan area. All 21 participants consented to participate in the study. For varied reasons, one participant voluntarily withdrew from the study and five were ineligible and not included in the final analysis. The study sample consisted of 15 adults (age range, 45-82 years, M = 64.43. SD = 10.28) (see Table 1 for demographics). Study participants were compensated with a $25 gift card.

Fourteen participants reported receiving a formal medical diagnosis of congestive heart failure (New York Heart Association functional class I or above) from a physician. One participant self-reported a diagnosis of congestive heart failure; medical confirmation was not available. The sample was 66% male and 33% female. The racial composition was 60% White and 26.7% Black; 13.3% of participants were of Hispanic/Latino origin. The study was reviewed locally and received Institutional Review Board approval.

To assess self-care knowledge and practice, participants were given the European Heart Failure Self-Care Behavior 12-item Scale (EHFScBS), Usability Scale, and the Olso three-item Social Support Scale. Two questions on the EHFScBS refer to units of measure not commonly used in the U.S. To avoid misunderstanding, these items were converted to reflect common units relevant to study participants (e.g., kilograms to pounds and liters to cups). Also
collected was information related to past 30-day device use, vital sign self-recording behavior (e.g., wrote down blood pressure or weight in past 30 days), and experience with the Blue Scale device for HF patients. Table 1 provides additional information.

**Interviews**

Fifteen individual semi-structured interviews lasting from 10 to 30 minutes were conducted by a member of the research team in locations conducive to private conversation. Each interview was audio taped. Prior to the interview participants were asked to step on and off the Blue Scale device. Participants then completed a demographic questionnaire and each of the quantitative measures. The interview was initiated following completion of the survey instruments. Interview questions ranged from “what do you do to manage your heart failure” to “do you use technology to improve or monitor your health.” For discussion and reference purposes participants received printed Blue Scale screen shots of a fictitious patient’s vital signs. Because a constant comparative approach was employed, data were collected and analyzed concurrently. Use of this approach allows for integration of emergent themes and ideas into subsequent interviews.\(^\text{32}\)

**Analysis**

Audiotapes were transcribed verbatim by a trained medical transcriptionist. Following transcription the verbatim transcripts were compared to the audio recording to ensure accuracy. The verbatim transcripts were organized and coded for initial themes. To establish reliability, three independent researchers individually coded each transcript, and then met to discuss identified codes. Differences were discussed and the final coding scheme emerged. All qualitative data was analyzed using NVivo10 software (QSR International, Inc.). Quantitative data was analyzed using SPSS version 19 (IBM SPSS Statistics).
Results

Study participants varied in knowledge related to self-care of HF (EHFScBS range, 16-50, on a 1-5 Likert scale). However, mean self-care scores (M = 29.21, SD = 9.62) confirm participants’ basic understanding of proper MHFS. One participant’s responses to two questions on the EHFScBS were difficult to decipher, so for one response the two circled numbers, one and four on the five-point Likert scale, were averaged and for the missed response, the average of the scale was imputed. All participants reported use of a device in their homes sometime in the past 30 days to measure a vital sign (e.g., blood pressure or weight) and most reported recording the data either in a daily log, on a piece of paper, or stored in a home ambulatory device. This sample reported a high level of social support. The descriptive data analysis complements and provides further insight into the qualitative findings. Table 2 offers more information on these findings.

Managing Heart Failure Symptoms

When asked about self-care for MHFS, participants most frequently mentioned medications, followed by diet and social support, either from friends, family, doctors, or nurses. Participants also emphasized the importance of maintaining a daily routine, including either staying on a consistent plan or increasing compliance with recommended self-care behavior so as to avoid HF complications that could result in an emergency visit to the hospital or unplanned visit to the doctor. When asked to describe the effects of HF on their daily activities, participants’ cited shortness of breath, decreased daily activity, and an increased need to relax or rest; symptoms which caused participants to feel as though they really had to “push” themselves to move through their normal daily activities. While participants varied in their perceptions of how HF affected them physically, some defined the effects of HF in terms of emotions such as fear of
pain or death. In fact, a number of participants listed fear as compromising not only their willingness and ability to seek additional health information, but also their willingness to take an active approach to MHFS.

**Technology Use and MHFS**

When asked about MHFS and technology use, reliance on physicians emerged as a common theme. Most participants reported seeking advice and information on HF self-care from their doctor. One participant stated,

“*I mean, your doctor’s your first choice in light of information. But the chance you didn’t get it, I would use WebMD.*”

While participants reported asking their doctor for advice on MHFS, compliance with the recommendations for MHFS, such as recording of daily vital signs, often depended on whether the participants expected their doctor to ask for their recorded blood pressure and/or weight readings during office visits. However, participants acknowledged the importance of recording their vital signs between office visits, and expressed their preference for technology that would record their vital signs because “they are important for the doctor to know and check.”

All participants responded positively towards the general concept of using technology to aid in improving or managing their health in general and for MHFS. While some participants tempered this positivity with a discussion of being overwhelmed by technology and concerned about keeping up with technological advancements, others liked the ability to obtain objective data.

“It’s objective data that you get from the machine; what I am telling you it’s very subjective...”

“Yeah this way you couldn’t cheat on your weight and stuff, you know.”
Also present were technology-related themes such as increased access to healthcare services that would facilitate more communication with doctors and sharing of real time health information, which would provide early indicators for worsening conditions, convenience, increased knowledge, and decreased healthcare costs.

“I feel like it’s something that the doctor could have without you having to call in and tell him. Um, kind of instant information, which is good. In the long run, it’d probably will end up helping save your life.”

“Just because the technology gets...can get the information to your doctor faster than you could. And, um, I mean, how good is that to be able to instantly find out what’s going on in your body, you know, so you can do something about it instead of waiting three or four days to get to the doctor and maybe something happening.”

However, apart from a high prevalence of over-the-counter device use and positive attitudes towards technology, most study participants did not use other types of technology. Approximately one third of participants mentioned use of a computer and the Internet. Common online activities included emailing, finding information on medications and/or health information, and searching for doctors and locations for medical tests. Participants described accessing health information by means of Internet sources such as, WebMD (most common), Google search, disease-specific websites (i.e., Crohn’s and Colitis Foundation of America), and ‘ask a doctor’ sites. Participants reported verifying information found online with their physicians. Overall, participants describe their physicians as their predominant and most reliable source for health information.

“I mean you read so many things out there on the web is wrong information, so I’d rather take if from someone or an organization, a registered legitimate organization.”

Overall, social media use for gaining health information was not widely accepted among participants. However, a few participants reported using Facebook for social reasons. In general, participants much preferred telephone conversations to social media use.
“I don’t want to email you or talk with you over Facebook where 9,000 other people can know what is going on, but that is just me.”

Health applications (apps) were positively perceived, but not often downloaded or used. Barriers to technology use included privacy concerns, mistrust of online information, low computer-use self-efficacy, low e-health literacy, and the associated financial costs.

**Medical Devices and Telemonitoring**

Participants were asked to define telemonitoring, telehealth, and telemedicine. Most participants defined “telemonitoring,” but lacked knowledge of telehealth and telemedicine. Responses varied from no understanding to the following,

“*it means that you can submit things through the phone, submit data through the phone*”

“*telemonitoring means that, you know, you wear something, there’s a device and somehow you connect it and communicate with somebody else.*”

Interestingly, among these participants use of over-the-counter monitoring devices was overwhelmingly common (see Table 2). Blood pressure devices were most frequently and regularly used; some participants expressed preference for portable blood pressure devices capable of storing blood pressure readings for a short period of time. Participants were also familiar with the following devices: defibrillator, glucometer, Life Vest, Prothrombin Time/International Normalized Ratio (PT/INR) device, pulse oximeter, scale, Continuous Positive Airway Pressure (CPAP) machine, and hematology machine (complete blood count).

While most participants reported monitoring their blood pressure regularly, few monitored their weight daily. This was consistent with findings from question one on the EHFScBS, “I weigh myself every day” where very few participant responses included “I completely agree.” Further discussion with many participants revealed a lack of knowledge regarding the association between daily weighing, fluid build-up or fluid gain, and prevention of
HF exacerbation. Participants were aware of the importance of daily weighing, but offered reasons for not weighing such as forgetfulness, travel, broken or lack of a scale at home, time, not wanting to know their weight daily, or depending on other indicators such as edema for MHFS.

Discussion

This study explored HF patients’ perceptions and use of current technology and the association of this use with their experiences and acceptance of technology use for MHFS. All participants in this study reported using at least one over-the-counter technology-related device, while some mentioned using more than one. However, even though many participants were managing more than one chronic condition, the most often reported and consistently used technological device was a blood pressure monitor.

While blood pressure is an important measure and indicator of health status, participants were less compliant with daily weighing. Because the healthcare industry is recognized for promoting regular blood pressure monitoring as essential to maintaining good health, it is likely older adults fail to perceive the importance of daily weight monitoring to health maintenance. The topic of daily weighing sparked emotional responses from participants who associated daily weighing with being overweight or “not fit,” instead of an additional “vital sign” or indicator used to augment their blood pressure readings for monitoring volume status.

This finding represents an opportunity for healthcare professionals and device manufacturers to work with HF patients to design devices for measuring weight that do not provoke negative weight-related emotional responses. Devices that report weight solely in terms of deviation from the patient’s baseline weight, or allow users to choose whether to view their numerical weight or transmit it blindly to their caregivers may be more acceptable.
Frequent use of technology by these HF participants included over-the-counter devices, followed by use of the Internet. Study participants mentioned various barriers to access and limitations to use of Internet health information, and in the end, most depended on their physicians for health information or to validate information found online. Therefore, it is critical that clinicians recommend appropriate and credible websites to patients who tend to gather health related information online. The American Heart Association website includes a list of online patient resources.

While participants lacked complete understanding of the term “telemonitoring,” in general, they are positive about the use of technology for MHFS. Therefore, acceptance and use of telemonitoring technology was favorable among study participants, particularly if it is physician initiated. However, patient acceptance and use of telemonitoring technology depends somewhat on their experiences with general technology. As a result, prior to prescribing telemonitoring technology for patient use, healthcare providers are encouraged to explore issues related to patients’ access, preferences, use, and experiences with technology. Consideration of these issues will help in prescribing appropriate technology for patient use, resulting in improved adherence to MHFS. Based on information retrieved from the literature and findings from this study a list of suggested assessment items are provided in Table 3.

Finally, among these participants, social media use was not popular. Therefore, recommendations for social media use are guarded. Patients who are comfortable with social media should be advised to limit their interactions to professional sites such as the American Heart Association, and to avoid Facebook and sites offering comments and advice lacking references and credibility.
Furthermore, findings suggest that the reluctance of HF patients to use technology in order to take a more active approach to MHFS may stem from fears of disability or death associated with their abilities to appropriately process complex, technology generated information about their condition. Future studies should examine ways to decrease HF patients’ technology-related fears. For example, healthcare providers and medical device manufacturers, working with HF patients, could design user-centered devices that allow patients to customize features. Customizing would allow for increased compliance with daily monitoring since fears associated with HF should decrease.

Conclusion

This study explored patients’ perceptions and use of technology for MHFS. Additionally, HF patients’ current use of technology for MHFS was assessed. The high incidence and healthcare costs associated with HF in the US coupled with the proliferation of new technologies to MHFS present an opportunity for healthcare professionals to leverage technology to increase self-care compliance and improve health outcomes for HF patients. However, new technology, no matter how innovative, will not change outcomes if patients are not willing or able to use the devices correctly and consistently. Therefore, determining user needs and experiences with medical devices is essential. More empirical research is needed to verify findings from this qualitative study. Findings from this study provide formative research for healthcare professionals in the development of health behavior interventions to more appropriately match HF patients with technology that will facilitate needs related to MHFS and optimize healthcare resources for increased quality of care.

Study Limitations
Current study findings contribute to understanding heart failure patients’ perceptions and use of technology to manage disease symptoms. Findings from this patient sample augment the literature in the areas of technology interventions. Despite the rich data emerging from the qualitative study, limitations exist. We employed a self-selected convenience sample of older adults recruited at hospitals, cardiology clinics, and community groups in the greater Houston metropolitan area; participant stage of heart failure was unknown. Findings from this study may not be generalizable to other groups, but probably provide an accurate representation of older adults’ perceptions and acceptance of technology use for health interventions. The accuracy of these self-reported data is unknown, and use of individual interviews to collect data may have caused some participants to offer responses perceived as socially desirable to the interviewer.

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References


Reprint requests should be directed to:

Amanda K. Hall, 1021 NE 20 Ave, Gainesville, FL 32609, mandikhall@gmail.com or cell phone: 352-514-3976