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Short Communication

Self-Care Data Sharing to Improve Patient-Provider Communication and Patient Outcomes

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Abstract

Advances in health information technologies have challenges and opportunities for improving patient-provider communication. This secondary analysis aimed to understand patient and provider perception of sharing self-care data for early care decisions. Secondary qualitative analysis of 25 heart failure patients and 10 health care providers data from open ended questions revealed "challenges" as the key theme with several subthemes. Providers challenges included transitional care challenge, lack of self-care and treatment adherence by patients. Patients expressed forgetfulness to take medications as prescribed and unable to differentiate heart failure specific symptoms to seek early care. Providers rated high confidence in using self-care data for decision making (mean 4.4 ± 0.97). Patients rated high confidence in sharing self-care data (mean 4.48 ± 0.87). The feedback from patients and providers helped the team to optimize the mobile system "HeartMapp" under development by adding pill management to improve adherence and a communication feature for shared decision making.

Introduction

Heart failure (HF) is an emerging worldwide threat affecting over 26 million people globally [1,2]. Global aging population of people 65-years and older are projected to increase the burden of HF by three fold [2]. Patients with HF experience an array of symptoms that can range from mild to severe. Despite guideline-directed optimal medical and device therapy, patients often have persistent symptoms with reduced quality of life. The symptom severity of HF are often assessed and classified using the New York Heart Association classification [3]. Even mild symptoms of HF worsened patients' ability to manage daily activities including self-care and adherence to recommended treatment [4].

Advances in health information technologies have created both challenges and opportunities for improved patient-provider communication for effective health management.

Miscommunication or communication breakdowns can lead to lack of adherence to treatment recommendations that could result in negative health outcomes [5]. Enhanced patient-provider communication correlated positively with patient safety and satisfaction, better health outcomes, adherence to recommended treatment, self-management of disease, and health care resource utilization [6,7]. Despite the rapid development of digital health and communication, barriers to utilizing digital communication still exist. Recently, the *Involve Me* intervention was designed to provide patients with the opportunity to communicate symptoms and informational needs prior to consultation via digital assessment [8].

The goal of this secondary analysis was to understand patient and provider perceptions of sharing self-care data with the health care team for early care decisions. Enhanced communication and data sharing with the health care team is proposed to improve symptom management and health-related quality of life and thereby, could reduce readmissions rate.

Materials and Methods

Conceptual Framework

Shared decision making is a key component of patient- centered health care. We propose to explore provider-patient communication and shared care decision using the SHARE approach described by the Agency for Health Care Research and Quality [9]. The SHARE Approach is a five-step process for patient-centered shared care decision-making. (Figure 1)

S **Start** the conversation with your patient

H **Help** your patient explore and compare treatment options

A **Assess** your patient's values and preferences

R **Reach** a decision with your patient

E **Evaluate** your patient's decision

Figure 1: Five Essential Steps for SHARE Approach.

The patient-centered shared care decision making framework offers a structured way to incorporate the process of provider-patient communication considering patient values, preferences, and knowledge of patients to compare treatment options and to reach a mutual shared decision on care for symptom decline to avoid hospitalization. Sharing HF self-care data with health care team via the patient portal via the electronic health record may enhance provider-patient communications for a shared care decision in the management of worsening HF symptoms and thus avoiding hospital admission. The shared care decision making framework has been successfully tested and implemented in preventive care [10], cancer screening [11], and care of patients with diabetes [12].

Design and Sample

Secondary qualitative analysis of the open-ended questions was conducted to understand themes on data sharing. The detail of the feasibility study was published and discussed elsewhere [13]. The feasibility study included 25 patients with HF and 10 health care providers.

Measures

The two open ended general questions.

1) What is one main reason or cause for your worsening HF symptom?

2) Can you identify measures that could help reduce worsening symptoms?

One yes and no question.

1)   Will you be open to sharing daily symptom assessment and weight from a mobile app with your providers? Yes No

If your answer is NO, please give rationale.

Likert Scale Question on Confidence. Rate your response 1-5

For patients: How confident are you in sharing your data with providers?

For providers: How confident are you in using patient data for decision making?

Not at all confident	Somewhat confident	Neutral	Moderate confident	High Confident
1	2	3	4	5

Data Collection and Analysis

All 25 patients and 10 providers completed these questions as part of the primary study during an in-person interview. An exploratory inquiry was performed to investigate the problem of poor self-care management and a strategy to mitigate the problem. During the interview process, special care was taken to minimize the risk of the researcher's influencing the responses by discussing the product that was tested as primary outcome. Open coding of themes was performed to discover significant common or uncommon responses, or relational influences. During coding, overlapping, repetitive, and vague expressions were eliminated. In the end, we used selective coding in the development of the themes listed below. Mean and standard deviation for the self-confidence question and number/percentage for the "yes" or "no" question were calculated.

Themes

Providers	Patients
Challenges • Transitional care challenge • Lack of self-care and treatment adherence	Challenges • Lack of family support • Forgetfulness • Unable to differentiate HF specific symptoms to seek early care
Solution • Home care and telehealth	Solution • Having reminders to seek care when symptoms are associated with HF • Reminders to take medications on time

Confidence in Using Mobile App

Patients rated high confidence in sharing self-care (mean 4.48 ± 0.87). Eighty eight percent (88%) of patients responded as willing to share data if it is easy and available.

"I would share my data if it would help me improve my health condition", said *VS*

"I travel out of country a lot, why should I share my data with my doctor here, how can my

Doctor from here help me when I am in Belize?" Reported by JD

Providers rated high confidence in using self-care data for decision making (mean 4.4 ± 0.97). However, 60% of the providers were willing to use patients' data for care decision.

"I would prefer having patient data available to my office/clinic nurses and home care nurses to triage and refer patients for early care" reported Dr. DV.

Discussion

The feasibility study tested the HeartMapp system, a mobile application that was designed to prompt the patients to complete daily assessment of self-care activities (i.e., daily weight and HF symptoms check) that are tracked and timestamped within the HeartMapp system. HF symptom severity is classified within HeartMapp system using artificial intelligence and machine learning algorithm as colored zones (green zone-stable-no symptoms; yellow-mild symptom decline, orange-moderate symptoms, and red zone- worse symptoms). The algorithm is based on the New York Heart Association classification [14]. The original HeartMapp system included four fully developed components and one under [13] that included: assessment (i.e., weight, vital signs, and HF symptoms, cognition, and mood), exercise (i.e., deep breathing exercise and 6-minute walk test), CHF info (i.e.,12 modules of HF education), stats (i.e., graphical display of patients entry), and vital sign (i.e., links to other devices such as Fitbit under development). (Figure 2) for comparison of prior and current Heart Mapp.

Primary HeartMapp.   Current Enhanced HeartMapp
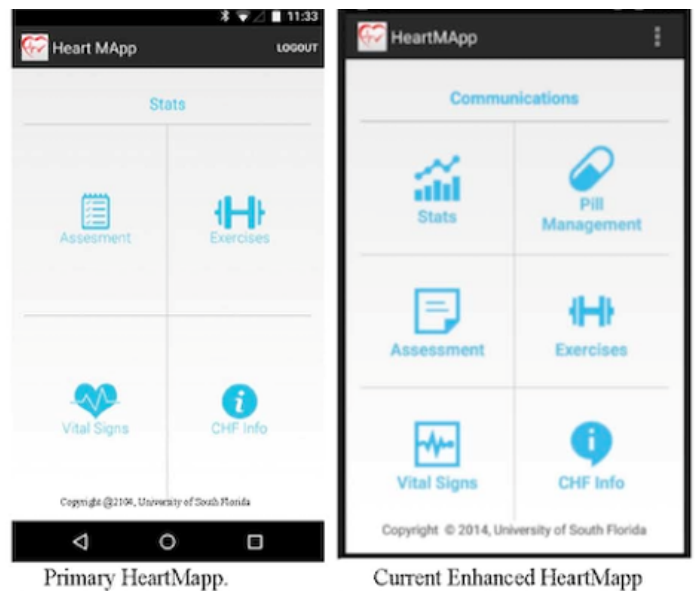
Figure 2: Side by side Comparison of Preliminary and Enhanced HeartMapp.

The feedback from patients and providers helped the team to optimize the HeartMapp system by adding pill management to improve adherence to medication and a communication feature to share HF self-care data with health care team for shared decision making. The HeartMapp system is designed to provide feedback to patients on their symptom severity (Green zone- stable, no symptoms, continue to take your medications as prescribed; yellow zone-mild symptom decline, call provider and if prescribed to take an extra dose of water pill-take it before calling to be seen earlier; orange zone-moderate symptoms, call provider to be seen at the clinic immediately; and red zone- worse symptoms, call 911 need immediate attention).

The pill management component allows patients to add their medication list and set alert timing. The HeartMapp will alert patients on their scheduled time to take the medication as scheduled and enter action. This allows health care teams to

monitor adherence to prescribed medications. The HeartMapp shares patients (only those patients who gives access to the providers) self-care data including weight and HF symptoms with the providers. The HeartMapp will alert providers' office of patients who are not in the "green zone" for triage and early access to care.

The graphical display of patients' symptom data is hypothesized to foster provider-patient communication for making shared care decisions in case of symptom decline, thus reducing HF readmission rates. Engagement with the HeartMapp system will be measured as number of shared decision-making with providers to address HF symptom decline when present (e.g., no symptom decline—no shared-decision making, or symptom decline with shared decision making), thus reducing HF readmission. The result of this secondary analysis facilitated the team to revise the HeartMapp with additional components to foster patient-provider communication and medication management.

Future Vision

Currently, we propose to explore the frequency and proximal outcome of engagement with the HeartMapp system among veterans. We will measure the number of times participants responded to self-care prompts from the HeartMapp system to determine the percentage of engagement. The proximal outcome of engagement with HeartMapp is shared decision-making with providers to address symptom decline in reducing HF readmission. (e.g., symptom decline ¾shared decision for management; no symptom decline- nothing) based on SHARE approach components (Figure 1). Also, we propose to explore the impact of the HeartMapp system on health services utilization and costs. The findings on reduced readmission and cost-effectiveness will provide critical evidence regarding the utility of HeartMapp. If findings are as expected, and widespread implementation is ultimately achieved, the long-term societal impact of this study will be substantial for the 6.2 million Americans.

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