# Improved Patient Outcomes through Collaborative Monitoring and Management of Subtle Behavioral and Physiological Health Changes

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## Abstract

*This paper describes a highly mobile collaborative patient-centric, self-monitoring, symptom recognition and self intervention system along with a complementary clinical nursing tool to aid in collaborative patient/clinician chronic cardiac disease management. Our system is composed of a mobile smart phone and wearable sensor suite linked through blue tooth and cell phone technology to a backend data repository, data mining, knowledge discovery, knowledge evolution and knowledge processing system, providing clinical data collection, procedural collection, intervention planning, medical situational assessment and health status feedback for collaborative users. The system uses a combination of physiologic and psychosocial instruments to gather patient specific information. The collaborative system aids patients in learning to recognize disease symptoms and understand the effect on their health of adherence to interventions. Secondly the system provides timely clinical data collection, assessment and interventions so clinicians can improve the overall health and lower the re-admission of their patients.*

## 1. Introduction

Heart failure (HF) is a significant public health problem affecting approximately 5 million Americans [1]. Heart failure, as a chronic and progressive illness, primarily of the elderly, has a negative effect on patients' quality of life with symptoms affecting well being, limiting normal daily living activities, and increasing the risk of multiple hospitalizations [2] at an estimated yearly cost of over 34 billion dollars [3]. Competence in self-care is essential if patients are to respond appropriately to early symptoms and seek timely treatment before symptoms are acute. Self-care of heart failure is difficult for many patients since it involves daily monitoring of symptoms, dietary restrictions, and correctly taking multiple medications [4].

Symptom awareness and monitoring, important for self-care, are confounded by the often insidious yet subtle changes in severity of symptoms, which may impede recognizing their significance. Advanced age and cognition may also affect symptom interpretation. Older patients may discount early symptoms of heart failure decompensation, such as fatigue and dyspnea, by attributing them to aging [5].

Recent heart failure medical management advances include the use of implanted devices to monitor heart rate, fluid status, and heart rhythms and provide a shock to patients experiencing potentially fatal arrhythmias [6]. Such devices also provide potential early cues to decompensation amenable to intervention. Unfortunately, not all persons with heart failure are able to receive such devices for a variety of reasons including cost, eligibility and geographic proximity to a clinic that monitors such devices. Wearable devices easily placed by a patient or clinician are needed to support more frequent access to real-time cardiac physiologic data [7].

Currently, a number of researchers are attempting to develop interventions to improve symptom recognition, interpretation and ultimately improve treatment seeking behaviors [8, 9]. Before heart failure interventions can be developed, more information is needed about the process of symptom recognition in heart failure patients. Currently, no research has correlated physiologic changes in heart failure to patient symptom recognition. Identification and reporting of these correlates may increase the ability to develop interventions that improve symptom recognition and treatment seeking behaviors.

The problem with conventional out-patient post cardiac disease management is the inability to monitor and assess patient health status in real-time within the home setting. Most post hospitalization care protocols require patient visitation by a clinician to assess health and progress. These visitations occur on a widely varying and possibly sporadic basis, typically once per month, leaving little chance of positively affecting patient's outcomes when most needed. Patients in such

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home care settings do not typically comprehend their own disease status or change correctly. Patients have not been trained before leaving the hospital environment on what symptoms are important and how to assess subtle, yet important changes to these symptoms.

Our research developed a highly mobile collaborative patient-centric, self-monitoring, symptom recognition and self intervention system along with complementary clinician patient monitoring and decision support tools aiding in patient chronic cardiac homecare management.

The primary function of the patient collaborative mobile health management tool is to assist patients through simple interactions and feedback in learning how to recognize the relative status of their health condition, to recognize and understand symptom and status changes either positively or negatively and to develop and put into place self interventions to implement in between clinical health care professional encounters.

The second component within our collaborative system, the nursing mobile collaboration tool allows a clinical nurse practitioner to select and interact with a patient(s) to examine, extract patient self reported information and wearable sensor derived information, combine this data with clinician entered real-time measurements, observations and a backend knowledge base to determine the status of a patient relevant to their health history and co-morbidities and to develop an intervention plan tailored to the specific patients needs.

## 2. Background

Currently, little research data exists about the pattern and timing of symptoms in relationship to worsened health outcomes. The common physiologic symptoms of heart failure are nonspecific. Early heart failure symptoms indicating a decline in status include fatigue, dyspnea with activity, cough, edema, and weight gain [10, 11, 12]. However, many symptoms could be attributed by patients to aging, poor sleep, loss of conditioning, overexertion or associated with illnesses such as the common cold or allergies.

Co morbid illness's makes symptom attribution particularly difficult for persons with heart failure. Co morbid illnesses commonly found in this population include hypertension, coronary artery disease, diabetes, chronic lung disease, atrial fibrillation, renal failure, depression, and anemia [13, 14, 15, 16]. Attributing a single symptom to one of the many possible illnesses is difficult for patients, and is often attributed to chronic lung disease [17]. Advanced age further complicates symptom assessment as some diagnoses are commonly dismissed as symptoms of aging.

Finally, the symptom experience is multi-dimensional and unique for each patient. For example, patients with heart failure and those with chronic lung disease describe dyspnea differently [18]. These factors make it extremely difficult for persons with heart failure to recognize, attribute, and differentiate self symptoms.

Implanted devices currently report adequate sensitivity and specificity for monitoring the signs of impending decompensation in heart failure patients [19, 20] and have been successful in identifying early physiologic changes indicative of worsening heart failure. A major issue with these devices is lack of real-time access to data. Knowledge gained can be used by clinicians to improve teaching of symptom recognition and interpretation in persons with heart failure who do not have access to these implanted devices.

Less intrusive mobile physiologic sensing devices are becoming available that provide numerous instruments, such as, blood pressure, electro cardiogram, oxygen saturation, temperature, blood flow, and water retention [21, 22 ].

Another technology supporting improved data access and collaboration is mobile computing [23]. Ellis et al. [24] defined computer supported collaborative work (CSCW) as *"computer-based systems that support groups of people engaged in a common task or goal and that provide an interface to a shared environment."* Collaboration in this context will only work if useful information (e.g. heart physiologic parameters, intervention plans based on interrogation of symptoms and status) can be collected and augmented in ways that allow for collaborative use (e.g. diagnosing a malady, developing or proposing a care plan) by members of a group.

Health care is a highly complex and collaborative domain. Some examples of collaboration in the healthcare domain include examination of electronic medical records [25], mobile and interactive technologies in healthcare [26], and care practices of patient health care teams [27]. Collaboration has not meant mobility in this past work. Only recently has mobile computing received increased attention in health care domains [28, 29]. Even so, most efforts have focused primarily on the knowledgeable care providers in collaboration and not on the patients as members of a health care team [30].

Numerous Collaborative systems applied to learning have also been extensively studied. Research points to the importance of moving away from the traditional models of instruction to concepts using modern constructivist theories [31]. It has been demonstrated that students learn better when they engage in active, collaborative, problem based, inquiry-based, and experiential learning, combined with teaming, learning communities, and use of domain tailored technology [32].

## 3. Potential health impact

To date, informatics has been underutilized in post clinical discharge environments to advance health care objectives. Information technology may aid reduction of mistakes and errors of omission and may drive care standardization, leading to improved patient outcomes.

Based upon these shortcomings, for the clinician, there are four areas that could benefit from mobile collaborative point-of-care computer support: increasing the accuracy and efficiency of patient care delivery, leveraging technology to enhance patient safety, enhancing a clinician's response to patient health changes, and enhancing a clinician's exposure to effective best evidence clinical practice. For the patient there are correlations to the benefits realizable by the clinician. The most important patient benefit, being an improved quality of life through self empowerment, improved knowledge concerning self health condition and comprehension of the health outcomes possible through adherence to self interventions.

The burden of chronic illness on health care systems is increasing. Elderly persons with chronic diseases have enormous difficulty in self-recognizing and categorizing early warning signs of their diseases reoccurrence or change. Recent research pointed out the value of symptom recognition and the correlation of symptom clusters as strong indicators of a patient's deterioration and overall health status [33]. The recognition of subtle symptom changes over time can be a valuable tool to both the patient and clinician in assessing present health, for predicting future trends [34] and for use in selecting and implementing disease and patient specific interventions to effect positive change [35].

If home cared chronically ill patients could possess the tools and training to develop the capability and confidence for self identifying and correctly correlating symptoms of their specific disease manifestation's onset they may reduce the effect or possibly prevent the dire consequences of a chronic condition's reoccurrence and the related hospitalization. Likewise, if a home care visiting clinician were able to more frequently and accurately assess patient symptoms and their progression over time, they could further reduce an elderly patient's need for hospitalization or added clinical care. To aid in patient and clinician symptom recognition training our System (RPHMAS) embeds an assessment-based continuous improvement loop into both clinical and self management tools enabling users to reflect upon the results of their health assessment, develop plans for improvement, test implemented plans and repeat the process potentially improving their overall learning and cognition [36].

In RPHMAS physiologic and psychosocial instruments are used to gather patient specific information. Gathered data include, physiologic measurements, psychological measurements, psychosocial measurements, health history and ontological information, figure 1. This information is collected and fused into our NCODES knowledge base forming new clinical use cases that are continually mined for new knowledge to assess the effectiveness of evidence-based practice over time [37].

The detection of patterns and sequences in time oriented clinical data is an important component and must take into account subtle differences in how each individual patient reacts to the malady and care interventions. Data is extracted and integrated into a knowledge source using an NCODES [38] data extraction tool developed for codification of knowledge acquired from expert practitioners, best practice, reference materials, clinical studies and client historical data sets [39]. During extraction, data is fused using four forms of case equivalence; structural equivalence using metadata mapping between stored cases and new cases, functional equivalence using metadata to mediate marking differences, conceptual equivalence via domain ontology and temporal equivalence.

RPHMAS applications algorithms use these and a variety of other data sets to assess patient status and develop patient centric interventions. For example the RPHMAS patient centric physiological data sets are collected through the wearable sensors, during home well care visits, during clinical well care visits and during unplanned health crisis events. The overall RHMAS knowledge base organizes this information in ways amenable to tool and patient care needs [40, 41].

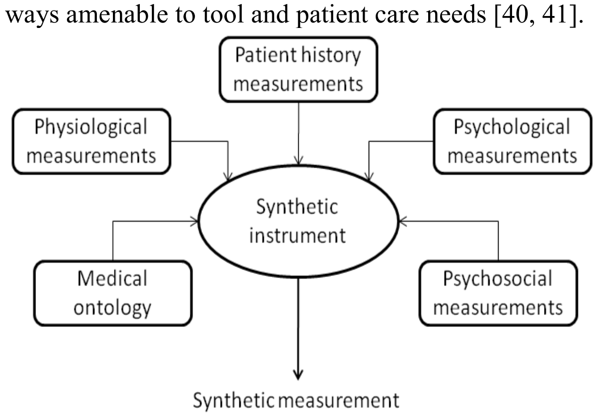


**Figure 1:** Patient centric information model

## 4. RHPMAS system vision

The need to develop a more effective and seamless integration of all forms of related data into health care delivery has been described for over a decade [42, 43], with progress mostly in health care related business processes. RPHMAS system design and user interface design included the clinician and patient from the beginning to improve on acceptance and use. The "questioning strategy" used by experts to guide learning, offers insight into user design issues [44].

In RPHMAS, clinical knowledge is created during interactions between the patient and the clinician, between a patient and automated system or clinician and automated system with all clinical events stored in a knowledge base, Figure 2. Patient centric medical knowledge is made available to clinical practitioners and patients to aid in outcome improvement through two collaborative applications. Personalization of knowledge is constructed as is generalized knowledge through aggregations, reductions, fusion and analysis with other data sets [45, 46, 47].

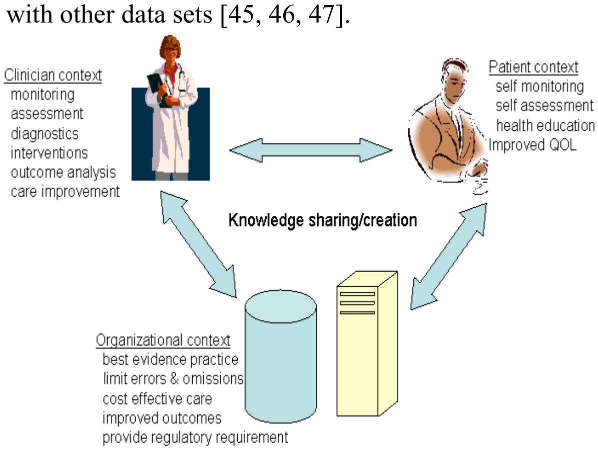


**Figure 2:** Clinical knowledge creation model

RPHMAS is intended to mimic a knowledgeable mentor, guiding users through clinical data collection, situational assessment and decisions using information specific to the individual patient. Through iterative use, successful health management strategies can be learned, practiced and honed. Another desired outcome is the ability to uncover new practice knowledge using data mining methods which have seen very limited use to date in non-hospital based health care settings.

## 5. System design, architecture and use

To improve both patient and clinicians ability to recognize subtle changes in symptoms requires more frequent collection, analysis and presentation of patient physiologic and psychological data to be performed. RPHMAS uses a mobile smart phone and wearable sensor suite linked through blue tooth technology to a backend data repository, data mining and knowledge processing system, Figure 3, to accomplish this. The front end patient and clinician mobile monitoring devices and patient wearable sensors act as the clinical data collection, procedural collection, intervention planning, medical situational assessment and instructional feedback platform. The backend inference engine is based on the integration of case-based and rule-based reasoning subsystems [48]. Clinical knowledge is represented as a set of data rules and associated meta-rules, ranked using evidence-based and usage relationships [49]. An approximate answer to a clinical problem is derived using rules and similarity computations [50, 51,52] computed under four different contexts, depending on the phase of the decision process that the clinician or patients are in [37, 40, 48].

In order to improve the efficiency of case lookup, multi-context clusters of cases are formed using declarative, procedural and semantic context [37, 53]. Searches focus on long multiple events temporal sequences to determine how this patient's present scenario relates to past cases [48]. For trend analysis RPHMAS examines how data items transition over time [49].

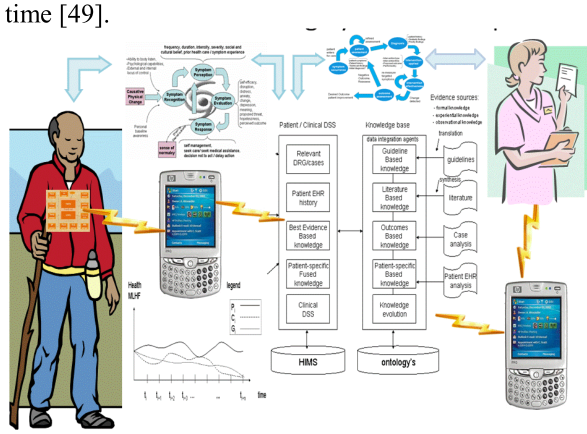

**Figure 3:** RPHMAS system architecture

A clinician can invoke the patient collaboration application to perform a remote virtual home visit, to extract both spatial and temporal physiologic and psychological measurements. A clinician when using the tool performs functions supporting our clinician patient management model, Figure 4, supported within the RPHMAS tool clinician module. The clinician, using RPHMAS, selects patients from those assigned and available on their device screen, selects and performs a variety of physical and psychological health assessments, evaluates patient status using collected and historic information and plans out patient interventions focused on accomplishing desired patient outcomes (e.g. improved quality of life), Figure 5.

The clinical nursing mode application provides for active patient monitoring and extraction of stored and real-time measurements, configurable as an automated process. A second application supports clinician visual assessment of assigned patients. At the highest view, a clinician can request visual annotations (e.g. colored icons, green for all is well, yellow for some issues, orange for serious issues and red for dire issues) to indicate patient aggregated health assessment. Using visual patient representations a clinician can easily select a specific patient and drill down for prior and present assessments using a variety of visual aids. For example, through trend analysis graphs, Figure 6, indicating improvement or degradation, or detailed physiologic graphs showing real-time measurements and historical measurements with expanded details where available due to events such as a clinical

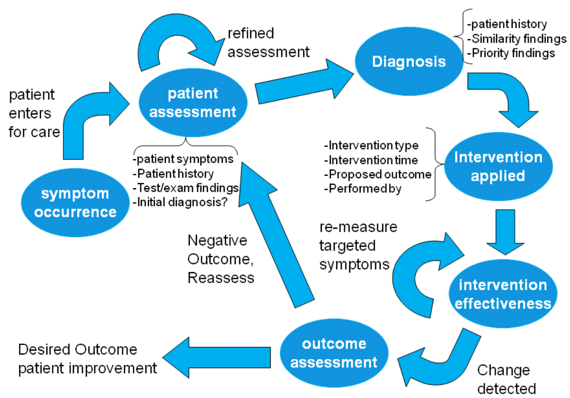


**Figure 4:** Clinician assessment and care model

office visit or hospitalization (e.g. blood workups, etc.). The clinician can further choose intervention analysis and planning tools to examine which form of intervention is best suited for this specific patient [39, 40, 48]. The clinician can also reconfigure the patient wearable sensor suite or cell phone applications to change the periodicity of measurements as well as sensor sensitivity or even add new applications as they become available.

A second collaborative application supports patient self reporting and self analysis of health status. Patients select applications supporting lifestyle, physiologic and psychological assessments. Once completed, patients can transmit data to the backend database or store locally. Self reporting and patient symptom self recognition is based on the symptom self recognition model [9], Figure 7, requiring patients actively be engaged in their health management can further use visual assessment tools to examine progress of their self health management plan. Such feedback supports patient learning. A third self management and

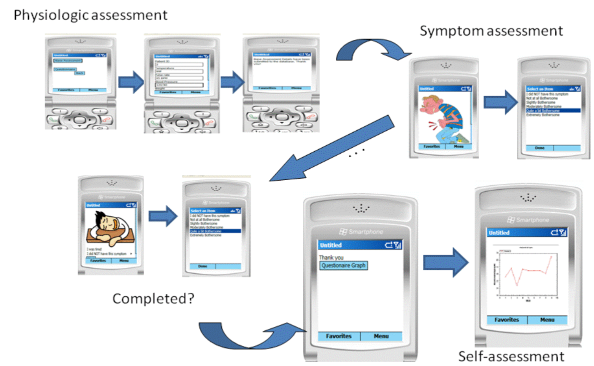


**Figure 5**: Patients usage sequence

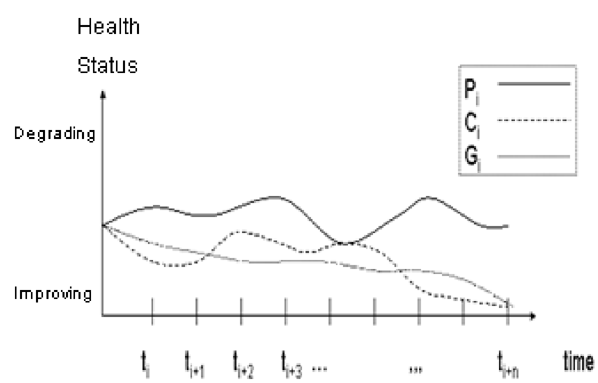


**Figure 6**: Trend analysis graphs

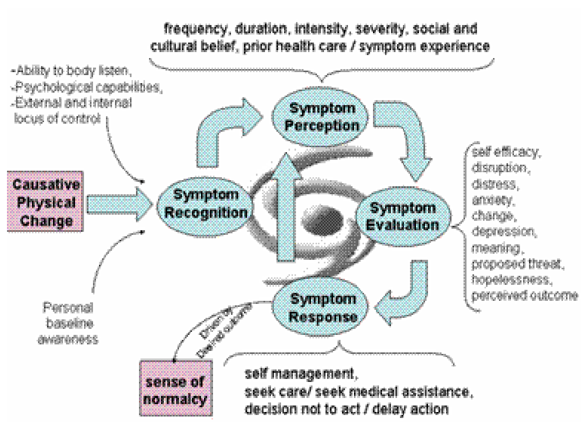


**Figure 7:** Patient symptom recognition model [9]

intervention mobile application, allows a patient to explore a set of self interventions to (e.g. exercise regime, diet alteration, etc.) aid in symptom and overall health management.

Collaborative patient self management has been shown [54, 55, 56] to be an effective tool in helping patients understand, respond to and manage their health condition making them an active participant in their own self care.

# 6. System long term goals

There are four primary research hypotheses that we are addressing as part of the ongoing system implementation testing, verification, validation and exploratory studies. The first is: will using patient self reporting of psychological and physiological symptoms along with correlated physiologic measurements derived from the wearable sensors, result in an increased ability to effectively detect subtle variations in patient heart health both positive and negative indicators. The second hypothesis tested is: will patients and clinicians using this information be better situated to make knowledgeable and correct intervention plans that counter specific symptoms and diagnosis. The third hypothesis being tested is: will the mobility of the applications and fielded platforms aid in patient conformance to care plans and improve patient learning and comprehension concerning symptom recognition and relationship to self care intervention protocols. Lastly, the hypothesis that: will the mobility of applications allow the clinician to be more proactive in patient centric care resulting in improved patient quality of life outcomes and cost effectiveness for health care organizations.

# 7. Initial prototype system testing

Using the prototype patient monitoring and clinician patient management system, a usability study was initially conducted at a clinical conference center, with ten acute care clinicians. All 10 participants were Caucasian with a mean age of 32.2 yrs ± 8 (range = 24-47). Nine participants were female and all were employed in acute care. Length of clinical experience was 8.9 yrs. ± 8 (range 2-25). The user protocol consisted of eight patient-related care tasks. The goals of the study were to evaluate usability, navigation, and clinician satisfaction of the RPHMAS prototype. All clinicians commented positively on the usefulness of the system in practice and discussed potential outcomes such as improved nurse-patent communication, better patient teaching, improved patient symptom and disease change detection, improved patient intervention planning and monitoring, and reduced stress levels. Regarding potential system improvement, they mentioned incorporation of additional safeguards to ensure that assessment data were entered on the correct patient.

## 7.1 Full system testing

System testing will be performed within the context of an exploratory, descriptive study using quantitative design. The setting is a community hospital serving a large, urban community. We have received IRB approval for the study.

### 7.1.1 Procedure

After informed consent is obtained, subjects will be invited to join the study during routine follow up. Demographic, functional status and symptom severity data will be collected during the initial interview and baseline physiologic data will also be collected when wearable sensor are calibrated. Physiologic parameters monitored by the wearable device will be collected automatically into our NCODES database on a daily basis or upon an automated alert. The psychological functional status and symptom severity data will be collected via the collaboration tool weekly or upon demand by the clinician or the patient.

### 7.1.2 Study sample

The proposed sample will include 122 cognitively intact, English speaking persons with heart failure as determined by the Framingham Diagnostic criteria. All subjects will have a wearable mobile sensor device for monitoring of heart failure symptoms. A power analysis indicated that a sample size of 122 patients was sufficient (power = 0.80) to detect small correlations ($r = 0.25$) with an alpha of 0.05, two tailed. A subset of the population does not speak English. Due to this fact, the enrollment period is anticipated to occur over 18 months to enable recruitment of a large enough sample for adequate power for the proposed analyses.

### 7.1.3 Study measures

**Sociodemographic Data Collection Tool:** Demographic factors including gender, age, and presence of a significant other, work status, income and educational level will be collected. Validation of Framingham Criteria will also be done using this tool.
**Functional status:** The Duke Activity Status Index [57, 58] measure consists of 12 items, each weighed based on the known metabolic cost of an activity in metabolic equivalent units. The possible range of this

measure is from 0 (most serious functional impairment) to 58.2 (no functional impairment). The DASI has acceptable reliability and validity in patients with heart disease [59, 60, 61]. Functional status information will be collected minimally, weekly using a cell phone based query system. This data will also be manually collected during clinical or home visitations by a clinician.

**Heart Failure Somatic Awareness Scale:** The Heart Failure Somatic Awareness Scale is an 18-item scale used to measure awareness and perceived severity of typical heart failure symptoms. Scores on the scale range from 0 -5 for each item and 0-90 for the entire scale with higher scores indicating greater symptom severity. The original version had 12 items with theta reliability of 0.71 and discriminant validity [8, 62]. Additional items were added to address dyspnea associated with getting dressed, fatigue, abdominal fullness and nocturia. This scale is used to determine the type, number and severity of heart failure symptoms. Heart failure somatic awareness information will be collected minimally weekly using a cell phone based query system and wirelessly transmitted to our NCODES data base. This data will also be manually collected during clinical or home visitations by a clinician.

**Physiologic data**: including cardiac output, heart rate variability, number of ventricular arrhythmias and fluid status measures will be obtained from wearable sensor devices [21] on a daily basis and automatically uploaded to our NCODES database and manually during routine follow up visits in an outpatient clinic. The measures collected by these wearable devices have a strong predictive ability in determining risk for readmission due to an exacerbation of heart failure in persons with heart failure.

#### 7.1.4 Data analysis

Sensor derived physiologic data and cell phone derived psychosocial data will be automatically entered into our NCODES database. Demographic data will be analyzed using descriptive statistics to categorize the sample population. Correlations between functional status, age, symptom severity and physiologic data will be done using Pearson's correlations and NCODES developed data mining algorithms. Reliability levels on all instruments will be computed.

#### 7.1.5 Results analysis

The results of this study will form an initial understanding of the correlation between physiologic data and symptom severity perceptions in patients with heart failure. This information will be useful for clinicians caring for persons that do and do not have wearable devices for monitoring of early physiologic changes indicative of worsening heart failure. Clinicians can use this information to teach patients about early changes found to correlate well with physiologic changes indicative of worsening heart failure.

The mobile patient and clinician tools developed provide platforms for additional applications development and for mobile learning capabilities and studies. The authors plan to submit future results of the clinical studies and patient / clinician assessment of the learning capabilities of the tools in enhancing elderly heart failure patient self care, outcomes and clinician efficiency of care in future publications.

## 8. Summary

We presented a novel mobile collaborative decision support tool for patient and clinical nurses that utilizes specific patient physiologic and psychosocial information and evidence-based nursing knowledge to offer real-time guidance to the patient and clinician that mimics that of an expert nurse. The system's architecture was presented from two different viewpoints; an informational view and an operational perspective. In the informational description, we utilized multiple sources of information to construct patient specific health assessments based on real-time and historic patient-centric data. In the operational system description, particular emphasis was placed on describing the steps patients and clinicians utilize in performing data collection actions, patient assessments, patient evaluations and intervention planning and execution.

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