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A Mobile Care Coordination System for the Management of Complex Chronic Disease

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Abstract. There is global concern about healthcare cost, quality, and access as the prevalence of complex and chronic diseases, such as heart disease, continues to grow. Care for patients with complex chronic disease involves diverse practitioners and multiple transitions between medical centers, physician practices, clinics, community resources, and patient homes. There are few systems that provide the flexibility to manage these varied and complex interactions. Participatory and user-centered design methodology was applied to the first stage of building a mobile platform for care coordination for complex, chronic heart disease. Key informant interviews with patients, caregivers, clinicians, and care coordinators were conducted. Thematic analysis led to identification of priority user functions including shared care plan, medication management, symptom management, nutrition, physical activity, appointments, personal monitoring devices, and integration of data and workflow. Meaningful stakeholder engagement contributes to a person-centered system that enhances health and efficiency.

Keywords. Care coordination, care management, chronic disease, person-centered, mobile application

1. Introduction

Cardiovascular disease accounts for approximately 31% of global deaths, and the global burden continues to rise [1]. Cardiovascular disease often presents with comorbidities such as depression, hypertension, and diabetes, which further complicate the delivery of care. Care for patients managing complex chronic disease involves diverse practitioners, multiple specialists, and numerous transitions between medical centers, physician practices, clinics, rehab centers, community resources, and homes. High quality care coordination allows members of the healthcare team to provide care more efficiently, reduce patient and caregiver burden, and improve health outcomes [2,3]. Globally, for individuals with chronic or prolonged conditions, care is complicated, fragmented and poorly coordinated [4].

Active engagement of individuals with their healthcare teams and participation in care coordination has been shown to be beneficial [5,6] and may improve the quality of care and reduce avoidable emergency department visits, hospital admissions and re-admissions, and other unnecessary healthcare costs [7]. Currently, systems such as electronic health records (EHRs) offer solutions for healthcare teams (including clinicians, staff, and health workers) within individual institutions. For individuals (and family and caregivers), there are numerous mobile health applications or portals

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focused on lifestyle change or limited administrative tasks such as appointment requests. Neither of these systems supports deep engagement. Recently, care coordination technologies have emerged to try and fill this gap. A landscape assessment of 25 commercial systems in 2014 found that none adequately addressed patient engagement, collaboration, and sharing needs [8]. We used principles of stakeholder engagement and user-centered design to develop a mobile application for person-centered care coordination for cardiovascular disease.

2. Methods

Key informants were purposively recruited to reflect diversity in experience managing complex chronic disease from the perspectives of patient, caregiver, clinician, care coordinator, and administrator. An interview guide was created that covered topics of current experiences and challenges with care coordination and priorities for a care coordination system. Interviews were conducted one or two interviewers together, and lasted an hour. Detailed notes were taken. Notes were independently coded for major themes and needs by the two interviewers. Two representative scenarios were developed to guide specification of requirements. This project was deemed not human subjects research (UC Davis IRB# 782917-1).

3. Results

14 interviews were completed: 4 patients, 2 family caregivers, 3 nurse care coordinators, 2 advanced practice nurses, a cardiac rehabilitation specialist, a cardiologist, and a primary care physician. The scenarios below are followed by priority user needs (Table 1).

Scenario A: Long-term management of complex chronic disease
Ms. A is a 72 year-old woman who has been living with type II diabetes for 12 years. She developed cardiovascular disease and was recently informed that she has heart failure. She has noticed greater difficulty in walking with hip and leg pain. Ms. A takes eight prescription medications: Metoprolol (beta-blocker), Lisinopril (ace inhibitor), Coumadin (anti-coagulant), Lasix (diuretic), Lipitor (statin), and Losartan (angiotensin receptor blocker), as well as Metformin for diabetes and Atavan for anxiety. All are taken daily but on different schedules, e.g. before going to bed, 1 hour before taking food, or with food. Ms. A sometimes doesn't take Lasix if she plans to go out for the afternoon because it causes frequent urination. Several medications cause Ms. A to be dizzy and fatigued. She describes them as making her feel "loopy" and prevents her from driving. She's not sure they are working so she sometimes decides to take a break from them. Ms. A needs to limit intake of vitamin K-rich foods, e.g. kale/collards/grapefruit, pomegranate, as vitamin K can make Coumadin less effective as a blood thinner. She is also on a low-sodium and diabetic diet and restricted fluid intake. Ms. A's healthcare team includes a primary care doctor, cardiologist, diabetes educator, dietician, and pharmacist who are located in four different facilities. She lives alone in a two-story home. Her son lives in the same town and although he works full-time and has a family, he frequently helps with her healthcare and daily living needs. Her daughter lives in another state and checks in regularly with both of them. Ms. A's greatest concerns are remaining independent and having the energy to visit with friends and family.

Scenario B: Care coordination following a transition from hospital to home

Mr. B is a 53 year-old man who has recently been diagnosed with heart failure after being admitted to the hospital following an ER visit for shortness of breath. Mr. B has had heart problems before but has never heard of heart failure and doesn't understand what causes it or what it means. He has been prescribed Coreg (carvedilol, a beta blocker) that slows heart rate and helps to manage hypertension, digoxin, a medicine to strengthen and regulate heartbeat, Lasix (diuretic), hydrochlorothiazide (blood pressure medication), and levothyroxine (thyroid medication). Medications are taken on different schedules throughout the day and week. While still in the hospital, he met with a dietician, who explained to him the importance of a low-sodium diet and gave him a packet that included nutrition information for heart failure patients, including specific instructions on how much salt he should be eating (<1500 mg per day). He has also been referred to a cardiac rehab center but has not yet made an appointment. He has follow-up appointments once a month with a cardiologist for the first three months, which will taper off to once every three months. However, since he has been experiencing several problems with his medications, he is seeing the cardiologist every 2 weeks. His cardiologist is working to adjust his blood pressure medication, since his blood pressure is highly unstable. He measures his blood pressure, weight, and pulse every day, and shares this information with his doctor when asked. He has been assigned a care coordinator, who calls him every three weeks to make sure he is ok. When he has a question, he calls the on-call cardiologist, since he does not have a way to get in touch with his care coordinator. He is feeling overwhelmed and depressed with all of the new lifestyle changes and medications. Due to his illness he is taking medical leave from work. He lives alone, around 50 miles away from his cardiologist's office. He has a son in college whom he usually sees during holidays.

Table 1: Summary of priorities and corresponding user functions

Priority/Challenge	User Functions
Shared Care Plan	
Goal setting	Document personal goals; document clinical goals.
Measures and outcomes	Collect person-reported outcomes (PROs), e.g. symptom scores, and clinical measures, e.g. HbA1c, lipids, blood pressure, ejection fraction, weight, anxiety and depression scores. Dashboard for tracking measures and progress toward outcomes.
Self-management plan	Commitments, resources, and personal strategies for identified goals where individual management is appropriate.
Roles and contacts	Complete list of healthcare team members, family/caregivers, preferred contact information, e.g. email, phone, PHR. Describe what to do for immediate and urgent care needs. Provide means to publish care plan to others.
Medication Management	
Medication instructions	Complete list of all medications with indications, dose, frequency, timing, and directions.
Medication schedule	Daily medication schedule and reminders with dose, time, and directions for administration.
Purpose of medication	Medication information readily available.
Medication tracking	Tracking of medication adherence including reporting reason for not taking medication. Decision-making tools for appropriate self-titration, or when to contact a provider. For providers: periodic summary of medication adherence, problems and side-effects experienced, and reasons for missed medications.
Prescription refill	Schedule refills at least two weeks before last dose of current supply, and before last refill on prescription.

Medication reconciliation and decision support	Interface with providers, care coordinators, pharmacists for management of drug-drug interactions, prescription changes, side effects.
Symptom Management	
Assessment	Symptom and mood assessment tools that are used with clinicians or care coordinator review and guidance on appropriate interventions. Tracking of data longitudinally.
Support	Motivational aids. Individually tailored suggestions from personal data. Evidence-based recommendations where possible.
Nutrition	
Nutrition education	Library of sample menus and educational resources on nutrition for patient's condition(s)
Tracking food items	Food tracking capability, including micronutrients; Integration of other food trackers.
Support	Motivational aids. Individually-tailored suggestions from personal data. Evidence-based recommendations where possible.
Physical Activity	
Physical activity education	Exercise plan and recommendations; Library of sample exercises specific to condition
Tracking activity	Exercise tracking capability, including ability to report reasons for not exercising or problems experienced Integration of pedometer data or other wearable devices
Support	Individually-tailored suggestions from personal data. Evidence-based recommendations where possible.
Appointments	
Follow up appointments and services	Identify and schedule routine follow-up visits and services needed, timeframes, and referrals, e.g. primary care visits, specialist visits, labs, foot and eye exams
Referrals and scheduling	Store referrals if needed. Set tickler reminders to schedule visits or follow up on referrals.
Reminders	Set appointment reminders
Transportation	Contact and schedule transportation service, caregiver, or other mode of transport.
Personal monitoring devices	
Biometric data	Ability to collect data from personal monitoring devices, e.g., weight scale, blood pressure, heart rate, glucose monitor.
Data analysis	User-friendly analysis tools to understand data. Create actionable data visualizations and integrate or transfer relevant summary data or trend reports to EHRs/PHRs.
Integration	
Preparation for healthcare visits	Provider-friendly presentation of key indicators from functions above, in summary tracking/trending report. Documentation of person's notes, questions and concerns related to functions above included with provider report.
Health documents	Ability for person to store, organize, and retrieve pertinent medical and pharmaceutical records and images, device data, person – generated data.
Workflow	Integrate data from all functions and provide capability to analyze, visualize findings, make decisions, and communicate with healthcare team, family members and other caregivers. Organize activities across these groups.

Discussion

A shared care plan can align patients and providers by setting shared goals and developing a care plan around these goals. The application will have the capacity to input a comprehensive care plan and will include a dashboard to track person-relevant measures and outcomes. Specific attention in the shared care plan should be paid to activities that affect both health and quality of life such as medication and symptom management, nutrition, and physical activity. Integration of the data from personal monitoring devices and the ability to push a subset of analyzed and summary data to the EHR will be prioritized. Integration also requires the ability for patients to access their own healthcare records and documents, and to keep these records in a place where they are usable and easily accessible for patients, caregivers, and clinicians. Interoperability between systems will also substantially improve care coordination capacity and allow for the meaningful use of patient data [9,10]. In line with participatory methods, next steps include co-design sessions with key informants. Testing of the resulting prototype will help to assess the extent to which functions meet needs, identify areas for improvement, and discover potential solutions to problems. We will also explore potential limitations to adoption of the technology: technology literacy, health literacy, privacy concerns and patient trust, no or intermittent connectivity, no access to a care coordinator or provider assisting with the creation of shared goals or a long-term care plan or multiple coordinators representing health system or payer. Meaningful stakeholder engagement will help to create a compelling and person-centered system that can improve health, decrease costs, and enhance patient accountability and autonomy.

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