Discordant Chronic Comorbidities: CHI SRC Paper

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ABSTRACT

Discordant Chronic Comorbidities (DCCs), or the presence of two or more chronic illnesses with opposing treatment instructions in a patient, can make it difficult for patients and healthcare providers to prioritize and manage the treatment of each individual disease. Some difficulties that arise from having DCCs include medication conflicts, social and familial dependencies, **[w7:recommended not to be infront of the list]seeing multiple health care providers** , etc. This research seeks to understand the hardships that patients with DCCs face in managing their health. Furthermore, this research aims to create an intervention that will effectively support these patients to manage their health. This study focused on 16 patients with DCCs, all of whom had Type 2 Diabetes **[w7:1 from South Indiana, 1 from Illinois, and 14 from Bloomington, IN -make clearer]and were from in and around Bloomington, IN** . During the interview, the patients answered a structured questionnaire and were engaged in a photo elicitation task where they described objects and aspects of their lives that either support or stifle their health management. A qualitative analysis of the content from the patients' interviews revealed themes that guided the creation of wireframes of a potential application. In this paper we describe the problems and solutions that patients **[w7:change faced]face** when managing and prioritizing the treatment of DCCs, as well as the wireframes created as potential solutions to make the management of their treatment easier.

Categories and Subject Descriptors

H.4 [**Information Systems Applications**]: Miscellaneous; D.2.8 [**Software Engineering**]: Metrics—*complexity measures, performance measures*

General Terms

Theory

Keywords

comorbidities, discordant chronic comorbidities, medication management, mobile applications, wireframes

1. INTRODUCTION

Chronic conditions, or conditions lasting five or more months, are becoming increasingly common in patients. These conditions typically require patients to play an active role in managing their own conditions due to the length of time patients are living with a condition. Due to the difficult nature of many conditions, this often leads to poor management of the disease, which in turn can often lead to patients developing other chronic diseases. The development of discordant chronic comorbidities, or multiple chronic conditions with unique and often opposing treatment instructions**[w7:Advised to add comma here],** has become increasingly common, and creates difficulties for providers and patients when it comes to managing conditions. Despite the increased numbers of patients with discordant chronic comorbidities, there is a lack of studies on these patients as well as a lack of tools to aid individuals with comorbidities in managing their conditions. In this study we aim to develop a tool to help individuals with discordant chronic comorbidities better manage their overall health and well being.

The challenge in studying patients with comorbidities often arises from their compounding health issues, which often leaves these patients sicker and spending more time in**[w7:advised to remove the word "hospital"]** clinical environments. This presents a unique challenge in understanding the barriers to successful self-management of their diseases as well as discovering what tools would potentially be useful in improving their self-management skills. As there are few papers on patients or tools for patients with chronic comorbidities, we looked for papers focusing on patients with multimorbidities, as well as papers about self-management, medication management, and apps to help manage diseases. These papers allowed us to identify the need for studies focusing on patients with chronic comorbidities, as well as the need to look at designing technology to effectively support patients with chronic comorbidities in managing their diseases. We also identified the need to develop technology that aids with other aspects of self-management in addition to medication management, as most mobile applications on the market focus exclusively on medication management while ignoring other aspects of chronic disease treatment management.

By studying patients with discordant chronic comorbidities, and specifically focusing on patients with Type 2 Diabetes and other chronic conditions, we were able to develop a tool to help patients better manage their chronic conditions. One reason this research focuses on Type 2 Diabetes as the index disease to study discordant chronic comorbidities is that the World Health Organization argues that, at least 170 million individuals suffer from diabetes [16]. Furthermore, the Centre for Disease Control (CDC) reports that, in United States alone, about 21 million people have diabetes [1]. Studies by Thorpe et al. [25] have revealed that the number of people living with diabetes and other chronic comorbid conditions is high and drastically increasing. These patients often need frequent general practice consultations, complex and structured care as well as coordination between different health care providers to ensure better quality of care.We also discovered the primary barriers these patients face when it comes to managing their treatment, and the solutions they have developed to address the needs of their conditions. In this paper, we make three primary contributions, the first of which is the study and collection of data from patients with discordant chronic comorbidities. Our second contribution is identifying the barriers faced by patients with chronic comorbidities in successfully managing their conditions. Our third contribution is represented by the tool we have developed to help patients manage their conditions.

2. RELATED WORK

As chronic conditions become increasingly prevalent among patients, a plethora of studies have been done examining the impact of chronic conditions, how patients manage a chronic condition, and focusing on technology developed for patients with a single chronic condition. However, few studies [w4:recommended to reword 'have been done']have focused on patients with [w7:removed multimorbidities, best to stick with comorbidities] comorbidities, which are two or more chronic conditions, and almost no studies have looked at patients with discordant comorbidities, which are chronic conditions with opposing treatment instructions. Due to the inadequate amount of research on discordant comorbidities, we pulled information focusing on a variety of similar topics including multimorbidities, self-management, medication management and adherence, and mobile applications. [w4:recommended to explain relevance of related work]By studying these areas, the researchers were able to identify ideas and processes used in the treatment of single chronic conditions, which can serve as the basis for developing technology designed to suit the more complex need of patients with discordant chronic comorbidities .

2.1 Multimorbidities

Multimorbidities, the presence of two or more chronic illnesses in an individual, can create difficulties in managing and treating these illnesses. Bayliss et al. [2] found 15 primary challenges faced by individuals with multimorbidities which were the compound effect of multiple conditions, physical limitations, the compound effect of medications, the challenge of coordinating multiple medications, the burden of taking multiple medications, side effects of medications, lack of knowledge about their conditions, financial constraints, low self-efficacy, the burden of the dominant effect of one condition, the emotional impact of having chronic conditions, inadequate communication with health care providers, the need for social support, logistical issues, and the need to better understand their conditions. [w7:fix so not run on]This combination of challenges makes the management of multiple conditions more difficult, but also leads to patients with multimorbidities being more willing to learn self-management strategies and more willing to see non-physician medical professionals such as nurses, chiropractors, nutritionists, physicians assistants, or others to supplement their care [19]. Multimorbidities can make other aspects of managing care[w7:this part was in the wrong place], such as managing medications, more difficult than if a patient only had one chronic condition. Doyle et al. [5] found that in order to encourage patients with multimorbidities to use a long-term medication management application, the app had to have the ability to create medication lists, educate users about their different medications, manage changing medications, and support individuals in scheduling and taking medications as prescribed.

Multimorbidity is increasingly prevalent in patients with diabetes, with several studies looking at the frequency of patients with diabetes and other multimorbidities. Teljeur et al. [24] found that 90% of patients with diabetes had at least one additional chronic condition, and more than one-fourth had more than 4 additional chronic conditions. Studies have also found that the number of chronic conditions an individual has increases with their age [8], and that these patients with multiple other chronic conditions in addition to diabetes typically placed a lower priority on their diabetes, as other conditions were more intensive, resulting in[w7:"these" was unnecesary] patients often being unsuccessful in managing their diabetes [12]. This leads to patients with diabetes receiving lower quality medical care for discordant conditions, due in part to the limited amount of time during visits with health care providers to address all concerns they may have. However, in situations where patients are able to maintain e-mail or phone correspondence with providers in between regular appointments, patients with and without multimorbidities experienced the same standard of care as these alternative communication channels with health care providers were able to fill in the care gaps and circumvent time constraints during appointments [22].

2.2 Self-Management

Self-management is the process of empowering patients with the knowledge, skills, and tools to facilitate self-care, and to encourage them to be an active participant in the treatment of their conditions. For patients with chronic conditions, self-management is a necessary aspect of their care to ensure that they are taken care of, even when not frequently seeing a doctor. Self-management relies on the needs, goals, and life experiences of patients with chronic conditions to improve clinical outcomes, health statistics, and their quality of life [6]. Self-management often involves the collaborative health care model, where patients work with their health care providers to manage and treat their diseases. It also often focuses on holistic outcomes, including a [w4:add an apostrophe]patient's physiology, symptoms, physical and emotional functions, their personal health perceptions, and their quality of life [13]. Self-management can be broken into three main components - medical management of the condition(s), creating and maintaining new behaviors or

routines, and dealing with the emotional impact of having a chronic condition. In order to successfully manage each of these components, patients need to learn skills such as problem solving, decision making, how to find and utilize resources, how to form partnerships with their health care providers, and how to take action to improve their health [14].

Several studies have explored the benefits of self-management, specifically for patients with one or more chronic conditions. When studying diabetes patients in an intensive treatment and education program, Polonsky et al. [23] found that **[w7:add comma],** compared with individuals in a standard diabetes treatment program, those in the intensive treatment and education program experienced a greater drop in their A1c, monitored their blood-glucose levels more frequently, paid more attention to the carbohydrate and fat-contents of food, and overall had better glycemic control. Patients in intensive self-management educational programs typically had increased levels of exercise and fewer uses of health services such as extra doctors visits or hospital stays, which contributes to lowered health care costs and higher quality of life for patients [15]. In addition, patients with self-management skills are more likely to know how to research and find information, which leads to a better understanding of their disease and treatment options, which can be especially helpful for patients who are unable to treat their conditions using the standard treatment options [17].

There are several barriers to successful self-management which are preventing patients from successfully managing their conditions. Bodenheimer et al. [3] found that the lack of trained personnel, the lack of funds for self-management education, and the current medical model, which leaves patients dependent on physicians, prevents many individuals from learning to self-manage their conditions. Financial worries, lack of awareness to self-management education programs, lack of physician or family support, and pain also prevent many patients from being able to successfully self-manage their conditions [11].

2.3 Medication Management and Adherence

For many patients with multimorbidities, managing multiple medications is a crucial part of successful self-management of their disease. When it comes to managing medications, the biggest concerns of patients are the ability to obtain reliable information on medications, maintaining autonomy when it comes to medication and treatment decisions, concerns about polypharmacy, discrepancies between traditional and alternative medical therapies and treatments, and the challenge of coordinating medications lists and health records between multiple health care providers [9].

For patients with Diabetes, medication adherence is an important aspect of treatment. Nkansah et al. [18] found that diabetes patients who managed their medications with the assistance of a pharmacist had improved glycemic control, were more likely to maintain their desired weights, and were more likely to reach their blood pressure goals. Electronic monitoring systems, such as those used to monitor insulin use in diabetics, have been shown to improve medication adherence as they can help patients easily monitor blood sugar levels and identify when they need to take more insulin, as well as aid health care providers in identifying patients who need more support [4]. In studying various methods to find the best medication management system, Granger et al. [7] found that the integration of in-person contacts with electronic monitoring systems, technology based medication reminders, and pharmaceutical database monitoring improved medication adherence and resulted in a positive impact on overall patient outcomes.

2.4 Mobile Applications and Technology

Recent studies have looked extensively at mobile applications as a tool to aid with the management of chronic diseases. Apps are useful for many individuals to aid them with tracking medications and numbers such as glucose scores, but Owen et al. [20] found that apps were more helpful for individuals who were changing their routines or experienced high fluctuations in glucose scores than for stable individuals as the ability to correlate glucose scores to daily activities was useful in understanding their scores and developing healthy habits. This often leads users to use only the features of the app that they find useful, especially if they have other monitoring methods that they don't want to change, which leads patients to interpret data in a non-clinical manner as they don't store all their data in the same place [10]. In studying ways to encourage consistent interpretation of data, Pernencar et al. [21] found that wearable sensors with connected mobile apps captured clearer statistics which encouraged the user to take an active role in managing their health by providing them the tools to consistently interpret and evaluate different aspects of their health.

3. OVERVIEW OF QUALITATIVE FINDINGS

After a thorough qualitative analysis of the DCC's patients' interviews, several major themes emerged. These themes represented barriers that patients face **[w7:change to]in** successfully managing their discordant chronic comorbidities, and strategies that patients use to overcome the problems that they face.

One major concern faced by DCCs patients is the lack of communication among the medical providers **[w7:change whom]who** they see and the resulting problems such as contradicting medications, diets, etc. DCCs patients feel that their medical providers prescribe them medications and treatments without considering other medication and treatments prescribed by the other providers. In the words of a patient *"Okay, so I'm talking to my kidney doctor, and he sees... he goes, 'Why are you taking B-vitamin? And cinnamon?' And I go, 'Well, my diabetic... He suggested that I take this.' 'Oh, you don't need that,' you know? He's going based on what his labs say, you know? 'You don't need that. That's not going to help.' And then you go, 'Oh... okay!'"* DCCsP13. Many of the patients interviewed mentioned lack of communication among medical providers as a concern in one way or another. As the same patient pointed out *"You know? But your diabetic doctor's not going to prescribe insulin based on your kidney schedule..."* -DCCsP13. One strategy used by some patients is carrying a list of the medications they take every time they go to the doctor, that way the provider is aware and can prescribe a new medication, if needed, that does not conflict with the ones the patient is currently taking. As a patient shares, *"I always keep a list of medications, a list of all my doctors, a list of how*

long I've been in the hospital, etcetera... And I provide that to every medical professional that I go to -DCCsP13. However, other patient do not take such initiative. Patients who do not take such an active role in communicating with their medical providers are more most likely to take conflicting medications, which is bad for their health.

Another major issue that emerged is polypharmacy. DCC's patients often end up on too many medications as a result of having multiple conditions that need treatment. One patient explains, *So all of my medications are basically production. What I have in my hand there, I have a couple of fluoxetine, whichi is an SSRI, an anti-depressant, there's quetiapine, which I take both at night to sleep, and as a mood stabilizer, there's some clonazepan, which is benzodiazepine, which I take for anxiety, that one I do take pure... And there are 2 vitamins there, there is a vitamin D capsule which low levels of vitamin D can contribute to depression, so I take that. And then, an iron supplement, because I have had anemia, and anemia contribute to depression"* -DCCsP9. The routine of taking so many medications can become a daunting burden. A strategy used by patients to manage so many medications is using pill planners and schedules. A patient who wishes to have a more specific pill planner than the one already owned said, *"A much more specific pill box. Like 'take these on Monday, Tuesday, Wednesday, Thursday, Friday, Saturday, Sunday.' I would have–and maybe this exists, I don't know–the Monday column would have a box for wakeup and a box for morning, before lunch, lunch, after lunch, before dinner, dinner, after dinner, sleep. And every day would have however many boxes that was for those specific times"* -DCCsP7. Having a well structured schedule for medications helps DCCs taking the right medication at the right time, which reduces the risks of misusing medication, or overdosing.

Another problem that emerged from the analysis is prioritizing illnesses and treatments. Patients with multiple chronic conditions often have to follow specific diets, exercise routines, regimes medications, and other treatment protocols. However, in many cases patients find themselves unable to follow a diabetes diet and a dialyses diet, for instance. In the words of a patient, *"But on a renal diet, you have to look at the vegetables and say, 'Oh. I cannot have raw spinach. You know, I have to limit raw spinach.' But, you know, diabetic doctors: 'Oh! Eat a big spinach!'"* -DCCsP13. In many cases like this, patients are faced with a decision to make, a decision that results on favoring one condition while disfavoring others. A strategy that patients often use to help them make such decisions is finding reliable information. They seek advises from peers, medical sources, etc. DCC's patients frequently also have medical support from case managers or health coaches who help them decide how to prioritize their treatments. For example, *"My health coach handles swimming and exercising, and anything to do with my health. My case manager is there so for example my son wants to move out, well what's available to him or if I couldn't get to the gr ocery store I needed to get there my case manager take me. Or she could take me to the doctor."* -DCCsP3. DCCs patients have access to reliable information, they just have to know where and how to find it.

An additional barrier that many patients with discordant chronic comorbidities faced was coping with their vulnerabilities and dealing with the mental implications of having multiple chronic conditions and the impact they have on an individual's life. For many patients each condition has its own set of difficulties to contend with, and varying mental and physical limitations which a patient must learn to overcome. Many patients discuss the need to come to terms with an altered life view, and the importance of realizing the impact that chronic conditions will have on one's life. Patient 7 discussed the importance of *"Learning how to recontextualize your life, things you enjoy and you have been doing for a while was immensely important to me. I didn't realize that's what I was doing at the time, but finding a different set of parameters for something that I have been doing."* -DCCsP7. Once patients come to terms with their new lives, it it important that they find ways to reach a sense of normalcy within their new realities in order to be able to successfully manage their chronic conditions.

One thing patients often do to help them adjust and thrive in their new life styles is establishing and maintaining various support networks. For most patients, there support networks have multiple components and can include friends and family, social networks, other patients with similar conditions, online support groups, and the support of their medical network. Friends and family help to provide a patient with emotional support in understanding their conditions, physical support in maintaining their independence and ability to complete daily tasks, and support in adhering to a medication or treatment regimen. Social networks have the ability to provide patients with a distraction from their conditions, and a way to focus on something else such as crafting or video games. For some this network can intersect with their network of other patients who they turn to for treatment advice and support in understanding the difficulties of living with chronic illnesses, such as Participant 11, who when discussing their knitting group said, *"So, a lot of the people I knit with, the vast majority of them are women. About half of them also do have other forms of anxiety or depression. So, I can kind of commiserate with them. We can talk about, you know, things that have been frustrating for us in the last week. Sometimes, I talk to them about some frustrations I've been having with schoolwork or just work, and they can kind of empathize with that. Sometimes, they rant and I listen."* -DCCsP11. Groups that intersect multiple types of support often allow patients to find support in others who can understand the challenges of their specific conditions, as well as help them to realize that they are not alone in facing the challenges associated with their conditions. It is also important for patients to develop a medical support network, which is often comprised of medical professionals other than their physicians, such as therapists, health coaches, pharmacists, and other who can help patients develop skills to manage the treatment of their chronic conditions. Developing this network is a crucial part of a patient being able to successfully manage and prioritize the treatment of their chronic conditions, as this network can help to provide advice, serve as a resource and source of reliable information, and help a patient to determine strategies that they can use to better manage their conditions. A strong medical support network, in combination with other networks of friends and family, social networks, and other patients can help to provide a patient with the emotional,

physical, and informational support that they need to successfully manage their discordant chronic comorbidities.

Another strategy that many patients use to help them adjust to their new lives is learning how to adhere to the non clinical aspects of their treatment, such as diet, exercise, or monitoring their conditions. Many chronic conditions require patients to change their diet and exercise in order to improve their overall health, such as Type 2 Diabetes. This can be a difficult transition for many patients, as it may require them to learn new skills such as limiting the amount of a type of food they eat or tracking the number of carbohydrates they eat in a day. Once patients area able to find the diet and type of exercise that they enjoy and that fits in their daily lives, they often begin to see health benefits such as weight loss, lower blood pressure, or a reduction in symptoms. While the rewards are high, it is often difficult for patients to make this transition and learn how to eat healthier and exercise. While doing this, patients also often have to become accustomed to monitoring their symptoms in order to help manage and understand their disease. For Type 2 Diabetics this often takes the form of monitoring one's blood sugar, which typically involves a patient sticking themselves in order to record their glucose levels. It can be difficult for some patients to get into the routine of watching what they eat, exercising, and monitoring their glucose levels. Patient 9 discussed how *"...the sooner [patients] realize that it's a full time job and you are gonna have to dedicate so much time to controlling it. The faster you realize that, the faster you can do it and the faster you can take control of your health."* -DCCsP9. Once a patient is able to get into this routine, they are often able to better manage their conditions and better handle any medical situations that may arise. Incorporating non-clinical aspects of treatment such as diet and exercise are an important part of a patient adjusting to their new lives, and can help patients learn to manage and prioritize the treatment of their discordant chronic conditions.

An additional barrier that many patients face in successfully managing and prioritizing the treatment of their discordant chronic comorbidities is the financial difficulties that are associated to treating multiple chronic conditions. While clinical costs from seeing multiple health care providers or taking multiple medications are often at least partially covered by a patients insurance, many fear that if their insurance coverage is changed that they may no longer be able to afford all of the medications in the amount that they need. This can lead some worried patients to not take medication as prescribed, such as Participant 9, who cited concern that she may lose her insurance coverage as a reason for *"...trying to stockpile all of my supplies. I use infusion sets and cartridges longer than I should. I try to use less insulin, I refill my insulin as soon as possible."* -DCCsP9. This can often lead to complications, which can often lead to increased hospitalization and costs. In addition, patients also often have to worry about the costs of non-clinical aspects of their treatment, such as the cost of a gym membership, the higher prices of healthy food, or transportation to medical appointments. Concerns over the financial aspects of their treatment can often deter a patient from trying new treatments, and can prevent them from successfully managing their conditions. While patients were not able to provide any potential solutions for this challenge, it is important to recognize it and keep it in mind as a significant challenge patients with discordant chronic comorbidities must overcome.

4. WIREFRAMES

To develop an intervention that will effectively support DCC's patients manage their health, researchers performed a cognitive walkthrough. Researchers concluded that the best option would be to develop a mobile application. This mobile application will be built around four major solutions and strategies that emerged from the patients' data qualitative analysis. Such solutions and strategies include medication management, communication with support network as well as medical providers, access to reliable information, and options to ease financial concerns related to medications.

One way that the app will support medication management is with the "pillbox", and "medications" options. When the user opens the pillbox option, on the top they will see the time at which the next round of medications are due and what medications must be taken. The user then has the option to hit "taken" or "delay". Below, the user will see the time and pills for the next four rounds of medications. Inside the pillbox, the user can also add a new medication, which can be done either by taking a picture of the pill bottle or manually. The user can also go the the medications option. Inside the medications option the user will find a list of all the medications being taken (active), and the ones taken in the past but not taking anymore (inactive). The active medications will appear on the top of the list and the inactive medications will appear on the bottom of the list faded out. Within the medications, the user can add a new medication, go to the pill box, or click on one medication to open information about it. Information about the medication includes time and dosage it needs to be taken, doctor who prescribe it, date of refill if needed, questions to ask the doctor about the medication, and prices comparisons for the medication.

Communication with support network as well as health care providers will be supported by the app through the "share info" option. Through this option, users can choose what type of information they want to share–medication list, side effects, measurements, questions for doctors, list of doctors, appointments, etc. Users can also have two options to share the information–text message and email. Users can also download a hard copy of the information and print it in case they want to show it to the doctor or a someone from their support network in paper. Because most DCC's patients see multiple health care providers due to having multiple conditions, and sometimes these providers do not communicate, it is important for the patient to have the ability to easily share their medical information with their health care providers. "share info" makes it easy for users to share their medical records with providers.

Users will also have the capability to use the application as a diary and record side effects, various health measurements, upcoming appointments, and more. By allowing users to keep this information in one place they will be able to easily and efficiently share it with their health networks, and access it wherever they may be which will encourage them to record their symptoms and side effects, as well as share those with

their doctors so that they can take an active role in managing their conditions.

Within the application users will be able to search and find easy to understand, reliable information about their conditions and treatments. Within the Information section of the app, users will have the ability to search and learn about conditions, see questions that they may want to ask their doctor, and learn about other possibilities for treatment that they may want to discuss with their doctors. This section of the application will allow patients to learn more about their conditions and have a better understanding of them, which is an important step in the process of learning to self-manage their conditions. When patients are able to access reliable information, they are better prepared to meet with their doctors and advocate for themselves.

The app will also provide users the opportunity to set goals, which will enable them to focus on other aspects of their health and well being, and take a holistic approach as they adjust to their changed lifestyles. The app will walk a patient through the process of setting a realistic goal, breaking it down into small, achievable steps, and working to reach that goal. The app will provide a patient with tips and motivations, which will allow them to achieve their goals and make strides in improving their quality of life.

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