Discordant Chronic Comorbidities: Final Paper Outline

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ABSTRACT
Abstract goes here.

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

General Terms
Theory

Keywords
ACM proceedings, LaTeX, text tagging

1. ABSTRACT
- W4

2. INTRODUCTION
- Problem - lack of studies on patients with discordant chronic conditions, lack of tools for individuals with comorbidities to manage their conditions
  - Promise - develop a tool to help individuals with discordant chronic comorbidities manage their health
- Obstacle - more conditions make things more complicated, these people are sick so harder to study and treat
- Technology Hole - have papers on diabetes, multimorbidities, medication management, self-management, apps but none on comorbidities and these other categories
  - Few studies have looked at designing technology to effectively support patients with comorbidities in managing their diseases.
  - More to disease management than just medication management, but most apps just focus on medication management
- Solution - develop a tool to help people with discordant chronic comorbidities manage their conditions
- Contribution - in this paper we make the following contributions:
  - Study and collect data about individuals with comorbid chronic conditions
  - Identify barriers to these patients successfully managing their conditions
  - Developed a tool to help people manage all aspects of their conditions

3. 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 have been done focusing on patients with multimorbidities or 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 diabetes, multimorbidities, self-management, medication management and adherence, and mobile applications.

3.1 Diabetes
Several studies have explored the process of managing Type 2 Diabetes, and the different aspects of managing the condition. An individuals ability to successfully manage diabetes has several components at play, including their ability to adhere to treatment regiments, their attitudes and beliefs towards their disease and treatment regiment, their knowledge of the condition, their ethnicity and culture, their language ability, their financial resources, other comorbidities they may have, and their social support system [21]. These factors are similar to many of the challenges faced by patients with other chronic conditions, and can be used to determine the likelihood of an individual being able to successfully manage a single chronic condition.

Another explored field is the use of mobile applications in managing Type 2 Diabetes. While overall patients found diabetes management applications to be useful tools, the vast majority stopped using the app after a few weeks. Common

reasons for stopping were that the app produced negative emotions, especially after entering what was perceived to be a negative value, and that the app was too much work and not worth the amount of time required to properly use it [14].

3.2 Multimorbidities

Multimorbidity, the presence of two or more chronic illnesses in an individual, can create difficulties in managing and treating these illnesses. Bayliss et al. [1] 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. 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 to aid them in successfully managing their conditions, and being more willing to see non-physician medical professionals such as nurses, chiropractors, nutritionists, physicians assistants, or others to supplement their care [24]. Several studies have focused specifically on managing the multiple medications patients with multimorbidities are often prescribed. Doyle et al. [6] 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. [29] 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 [10], 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 these patients often being unsuccessful in managing their diabetes [15]. 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 [27].

3.3 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 [8]. 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 patients physiology, symptoms, physical and emotional functions, their personal health perceptions, and their quality of life [17]. 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 [18].

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. [28] found that 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 [19]. 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 [20].

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 [13].

3.4 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 [11].

For patients with Diabetes, medication adherence is an important aspect of treatment. Nkansah et al. [23] 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 [5]. In studying various methods to find the best medication management system, Granger et al. [9] 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.

3.5 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. [25] 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 [12]. In studying ways to encourage consistent interpretation of data, Pernencar et al. [26] 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.

4. METHODS

This study was aimed at unveiling the needs, resources, support measures and health care goals required to effectively support DCCs patients manage their health. This section describes the aim of the study and research questions, participants recruitment, study design, data collection and data analysis procedures used.

4.1 Related Work

As a first step to understand type 2 diabetes patients with discordant chronic comorbidities, a collection of about 40 papers about previous research done in the area were read. In order find the right materials, key words such as diabetes, medication management, self management, multimorbidity, and comorbidity were used for a search in Google Scholars. These searches resulted in finding some useful articles. After finding some useful articles, we also created citation trees. Making use of backward and forward references from Doyle et al. [6], for example, lead to finding more useful articles.

4.2 Aim of Study and Research Questions

The presence of discordant chronic comorbidities (DCCs) with a higher symptom burden than an index disease (Type 2 diabetes) is likely to have a negative impact on the management of both index disease and other conditions a patient may have. Patients with DCCs face many challenges when trying to meet the recommended treatment goals. Thus, in order to support and empower them, we seek to understand appropriate design intervention based on their needs, experiences and their health care providers' recommendations. The purpose of this study was, therefore, to understand patients' perspectives on how DCCs impact the management of type 2 diabetes and was guided and supported by the following investigative major and specific research questions: RQ1; How do discordant chronic comorbidities impact the management of type 2 diabetes? RQ2; How do patients prioritize the management of type 2 diabetes and other DCCs that they may have? RQ3; How can technology be used to support and/or empower DCCs patients to effectively manage their conditions?

4.3 Participant Selection

Participants were recruited for this study through our contacts, by face-to-face interaction, use of flyers and local connections. We used purposive sampling strategy to recruit patients who met the following criterion: i) were between the ages of 25-65-we chose this age group in order to eliminate young participants who are still depending on their parents for medical decision or older adults who may be assisted living facilities; ii) expressed an interest in the study and were willing to take photographs and participate in interviews and iii) self-reported to being type 2 diabetic and had at least one additional chronic condition such as arthritis, body joint pain, or depression. Patients who had limited consent capabilities and major communication problems were excluded from the study. Participants were provided with an overview of the study and assurance of confidentiality. Written consent was obtained from participants prior to the commencement of the study; participants received compensation of 15 dollars for participating in the study. All participants had the option of reading the consent form or having it read and explained to them; our study was approved by institutional review board (IRB). A total of 16 patients were invited to participate in the study. Five of them identified themselves as males, and nine as females. One participant identified as gender-fluid, and another participant identified as agender. Ages broke down as 25-34 years old: N=5, 35-44: N=1, 45-54=7, 55-59: N=2 and 60-65: N=1. 15 participants completed the study, and 1 was unable to continue with the photo taking activity after filling out the questionnaire due to medical complications.

4.4 Study Design

In this study, we met with participants two times. In the first meeting, we met participants for approximately one hour to obtain their consent, fill out a questionnaire and

give directions for the photo elicitation activity. The participants were also briefed on how to use cameras and safety tips on taking photographs in the community. Participants without smartphones were given disposable cameras in this meeting. Participants were asked to take at least 20 photographs over a 2-week period, of which some should reflect positive aspects of their lives, some negative or challenging aspects and others items that they normally use to manage their conditions including resources they usually consult. We provided minimal instructions to ensure that participants exercise control over what to shoot and what to narrate about the photographs in a manner representative of their experience. As to the participants who did not have their own smartphone, we met with them to collect the disposable camera that we provided approximately 24-48 hours before the second meeting.

In a second meeting, we met for 60-90 minutes to review a participant photos and asked participants questions about the photos and debrief them and brainstormed ideas not covered in the photos. The meeting was conducted in a quiet and safe place most convenient for participants, with participants presenting the photos and narrating their meaning to the interviewer. We asked general questions such as "Why did you take that picture?" or "Can you tell me more about this picture?" or "How does the item in this picture help you or discourage you from managing your condition?" All interviews were audio recorded and verbally transcribed for analysis.

4.5 Qualitative Methodologies

In this study, a mixed method approach was adopted to investigate how DCCs patients prioritize the treatment and management of their health. Structured questionnaire/survey and photo elicitation interviews were used to gain a deeper understanding of patients' needs, support measures, health care goals and resources required to effectively support DCCs patients to manage their health. Surveys helped foster descriptions and insights of participants' perspectives, views and behaviours towards the treatment and management of type 2 diabetes and other DCCs [22]. Photo Elicitation Interviews (PEI) was used as an interview process in which the participants and researchers discussed participants' photographs together; the participants' photographs acted as "conduits to narratives" which elicit significant experience from the participants' point of view [16]. PEI gave the researchers an opportunity to uncover underlying aspects from participants' lives through interviews and their expressions when using photos. PEI also gave participants an opportunity to elaborate on their responses and share further their experiences.

4.6 Data Coding and Analysis

Exploratory data analysis longside ranking and scoring [4] was used to analyze the surveys' data. Sets of patients' options, strategies, and/or opinions were categorized and ranked in groups and clusters for easy interpretation and coding. Qualitative content analysis was also used in order to guide the description of both verbal and visual data from photo elicitation interviews [7]. Data codes were identified and categories were created as they emerged. This method helped capture the patients' needs, treatment practices. behaviours, and resources they normally use to manage their health. The analysis process involved reviewing interview questions with photographs to understand the data in context and coding alongside the respective transcripts [2].

For each interview with participants, the researchers listened to the audio recording to review the session, including the photographs discussed with each participant, field notes, and reflection of brainstorming session. Each photograph was numbered and marked based on the order it was discussed and its relevance to participants. Both typed transcription of individual interviews and associated photographs were used as the raw data for creating standard themes using affinity diagrams. The themes were iterated on several times through discussion and exchanges of analytical notes between researchers until the themes reached a point of saturation [2].

5. FINDINGS

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6. DISCUSSION

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7. REFERENCES

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