ABSTRACT
Patients with discordant chronic comorbidities (DCCs) have multiple, often unrelated, chronic illnesses with opposing treatment instructions that need to be addressed concurrently. While many tools are available for a single chronic condition or a set of well-defined health behaviors, there is a lack of tools designed to support patients in managing multiple conditions whose suggested treatments may be in opposition to each other. This paper reports on a 2-week photo elicitation interview study of 15 patients with type-2 diabetes and either depression, arthritis, or end-stage renal disease. Participants discussed the barriers they encountered in managing their health and strategies they used to overcome those barriers. Our findings highlight the difficulties faced by patients with type-2 diabetes and DCCs, including adjusting to having multiple health problems, maintenance of their support networks, and financial concerns. Here we present design implications grounded in the current literature as well as the results of our study. Our work points to a new, novel strategies for care and treatment not only of DCCs but also of other complex conditions.

ACM Classification Keywords
H.5.m. Ubiquitous, pervasive, and mobile interaction (HCI)

Author Keywords
Discordant Chronic Comorbidities; Healthcare Providers; Care and Treatment; Type-2 Diabetes and DCCs; Self-management

INTRODUCTION
The International Diabetes Federation (IDF) 2017 estimates show that there are about 425 million people ages 20-79 with diabetes worldwide and by 2045 there will be 629 million people living with the disease [2]. In the US, reports from the Center for Disease Control (CDC) [14] show that one in four Americans have multiple chronic conditions and over 29 million people have type-2 diabetes. The majority of those patients have at least one additional chronic condition and approximately 40% have three or more chronic conditions [14, 25].

Chronic conditions are diseases that last five or more months, such as type-2 diabetes, arthritis, and depression. Due to the extended nature of these conditions, healthcare providers entrust patients to play an active role in their care and treatment. However, patients, especially those with discordant chronic comorbidities (DCCs) -which are multiple, often unrelated, chronic illnesses with opposing treatment instructions that need to be addressed concurrently [37], frequently struggle to successfully adhere to their complex care and treatment routines. This situation leads to patients’ increased risks of developing severe health complications and a lower quality of life [1, 23, 37, 51]. DCCs create difficulties for both healthcare providers and patients when attempting to help or manage patients conditions. Patients with DCCs often need frequent general practice consultations, complex and structured care, as well as increased coordination between different health care providers to ensure their quality of care and treatment [1, 23].

Although the challenges of managing multiple chronic diseases are well explored in the recent literature, the plethora of the available tools, apps, wearable and sensing devices only support the care and treatment of a single chronic disease. With the exception of work on the elimination diet, where foods causing the adverse effects in a patient are identified by removing and subsequently re-introducing specific foods to the diet [45], to the best of our knowledge, no tools have been designed to support them in managing both their type-2 diabetes and at the same time any additional conditions.

In this study, we aimed to uncover barriers faced by patients with type-2 diabetes and DCCs. We discuss design implications grounded in the finding of this study and the current literature with the goal of exploring alternative design strategies to support the care and treatment of type-2 diabetes and DCCs. We guided our research using the following investigative research questions: i) How do DCCs impact the management of type-2 diabetes? ii) How do patients prioritize the management of type-2 diabetes and DCCs? iii) How can technology support patients with type-2 diabetes and DCCs in managing their health and well-being? To explore these questions, we performed a 2-week photo elicitation interview (PEI) study with 15 participants who had type-2 diabetes and a DCC (either arthritis, depression, or both). In fact, the majority of the
participants reported 3 or more conditions, including end-stage renal disease, stomach valve disorders, breathing problems, and kidney problems among others as shown in (Table 1). We specifically chose patients with arthritis and/or depression because, as patients with arthritis experience excessive pain, they are vulnerable to or fear injury, and lack the motivation to engage in physical activity. Yet as part of their of their type-2 diabetes treatment, they need to exercise despite the pain. Depression, on the other hand, often leaves patients with no energy and forces them not to perform regular type-2 diabetes management activities, such as regular blood sugar testing, which they find overwhelming. The co-existence of these acute conditions leads to an increase in anxiety and makes it hard for patients with type-2 diabetes to maintain healthy diets, activity levels, and medication, and consequently impacts their blood sugar levels [51]. Due to the functional and mental limitations, and the financial stress that depression and/or arthritis causes to patients with type-2 diabetes, they are more likely to make choices that may exacerbate their conditions.

We used PEI because photographs sample images shown in (Figure 1) portray the intimate dimensions of participants’ social-life/behaviors, routines, and patterns. Using these photos as a conduit to initiate discussion about participants’ personal experiences provided us with deep and meaningful insights. We identified a set of barriers participants faced when managing their conditions and strategies that they used to attempt to overcome these barriers. This paper presents the findings and key takeaways that can be used to address the complex needs of patients with type-2 diabetes and DCCs. We start with an overview of the related work. We then describe our methods and present our research findings. We conclude with a discussion of design opportunities to help patients with DCCs in managing their conditions.

The following are our contributions to personal health informatics, design, and HCI communities:

- present 8 healthcare barriers faced by patients with type-2 diabetes and DCCs, 5 of which are similar to those affecting people with single chronic conditions and 3 are mainly specific to care and treatment of type-2 diabetes and DCCs.
- discussion of 10 design implications to help patients with type-2 diabetes and other DCCs to prioritize their care and treatment plans and communicate with their multiple healthcare providers. Although 4 of the 10 design considerations are similar to those used to help patients with single chronic conditions, we suggested additional features to these design ideas in order to meet needs specific to the care of DCCs. Six design considerations are mainly targeted for type-2 diabetes and DCCs.

**RELATED WORK**

Studies in HCI and personal informatics have examined the impact of chronic conditions, the ways in which patients manage chronic conditions, and the tools developed for the management of single chronic conditions. To the best of our knowledge, a few studies have focused on patients with multiple morbidities, but next to no study have looked at patients with type-2 diabetes and other DCCs. Due to the inadequate amount of research done on DCCs, this related work section discusses i) technological interventions used to support health care and well-being, ii) self-management tools, iii) and type-2 diabetes management tools. We then use this discussion to support the need for tools to help patients with DCCs to prioritize their care and treatment and communicate with multiple providers.

**Technological interventions**

There has been a growth in recent research aimed at exploring the role of technologies in supporting people to better manage their health. For example, Connelly et al. designed a dietary monitoring app (DIMA) to support patients receiving hemodialysis in adhering to their recommended dietary regimen [9]. Similarly, researchers and technicians have designed several applications to help patients keep journals of their experiences [11], set goals and milestones for their physical activities [10], and support and enhance social sharing [13].

Mei-Ying Wang et al. developed “Wedjat” a mobile tool to alert the patients about potential drug-drug/drug-food interactions and plan a proper intake schedule [48]. Salgia et al. [39] proposed a smart pillbox to help patients take the required medicine in the right proportion at the right time. The pillbox is equipped with an alarm clock, a light-based slot sensor, and a GSM module that alerts patients and their healthcare providers. There are a growing number of medical reminder health applications, making them a promising tool to help reduce non-adherence to long-term medications. However, Santo et al., in their randomized controlled trial study to evaluate the feasibility and effectiveness of medication reminder apps on medication adherence, found limited evidence to suggest that the medication reminder apps are effective in ensuring adherence among patients [41].

Researchers have done extensive work on price comparison tools, such as, for example, sites “goodrx” that are dedicated to comparison shopping for drugs [5]. There are other dedicated portals, including meta-shopping sites from Amazon and Google express that are meant to address issues related to drug prices. Patients with DCCs benefit from these initiatives; however, patients with morbidity require multiple prescriptions and procedures that go beyond just identifying the cheapest drugs. Patients with DCCs could also benefit from understanding their insurance options, generic and/or alternative medications, diets, or exercise. Similarly, the major pioneering websites such as CureTogether [6] and PatientsLikeMe [15] have made an important stride towards crowd-sourcing health care management strategies.

However, most of these applications support patients to perform a single task or monitor the progress of a single condition. Similarly, the online communities have focused deeply on areas of patient-powered research networks and crowd-sourced dietary, exercise, and medications strategies. Although, patients with DCCs can benefit from participating in these communities, crowd-sourcing diet, exercise, or medical advice is an entirely different matter than crowd-sourcing the mixing of medications and their potential side effects that patients with type-2 and DCCs need. For a patient with type-2 diabetes and DCCs, incorrectly balancing insulin and steroids, could prove potentially fatal. Also, most of the patients with DCCs
have specific needs they either do not understand or do not know how to fully explain and therefore are able to find healthcare in these online communities that require direct patient interaction. In this paper, we argue for exploration of ways to personalize advice and present it to patients who may possibly have trouble articulating conditions they have and/or need in the online platforms. We also suggest a need to crowd-source the mixing of medications and their potential side effects.

Self management tools
In personal informatics, self-management skills help empower patients to research and find more information about their health and better understand their disease and treatment[31]. As patients with multiple chronic conditions, they need to take an active role in managing their health. To do so, they need to be equipped with relevant knowledge, skills, and tools to facilitate their self-care. Funnel et al. [16] recommend the design of applications for patients’ needs, goals, and life in order to improve clinical outcomes and quality of life. Nunes and Fitzpatrick [35] suggest a need to enhance self-management practice with caregiver/support work collaboration. In their work interviewing and observing patients living with Parkinson’s, they found that collaboration enables the different self-care activities to take place and builds a good quality of life. This approach may help patients with type-2 and DCCs to coordinate and seek emotional, tangible, or informational support from their support network.

However, current studies do not define how to validate the impact of support network actions. We suggest integrating strategies to understand variations in DCCs healthcare utilization and adherence to their multiple healthcare goals and the impact of support network actions. This can be done by adopting the burden of treatment theory model [32] to define what actions each patient, provider, and support network can do and continuously track the interactions between these actions.

To further analyze the quality of the self-management, we turn to Bandura’s theory of self-efficacy beliefs. Bandura et al. [3] suggests a model detailing the foundations for human motivation, well-being, and personal accomplishment. The model highlights the importance of reflecting on a patient’s previous experiences or experience of observing others, social persuasion, and emotional or mood states. We use this model to suggest the design for motivation, personal accomplishment, reflection, and improvement in a patient’s ability to self-manage their multiple conditions [26]. We also learn from Lorig’s [27] prior work on empowering patients to i) make decisions, ii) find and utilize relevant resources, iii) communicate with their health care providers, and iv) take action to improve their health. We expand these strategies by reporting on the patients’ with DCCs experience, and strategies.

Type-2 diabetes management tools
There has been extensive work done on creating tips, tools, and technologies to help patients with type-2 diabetes manage their health. Some of these tools make use of smartphone apps to help patients better manage insulin [44], provide blood glucose monitoring tips [46], and enhance fitness tracking [20]. These tools provide a one-stop support for tips, tools, and technologies for patients with type-2 diabetes and improve A1C and diabetes self-care.

For example, the Glucose Buddy app helps to guide a patient through the activities of recording and monitoring glucose, medications, carbohydrate intake, and A1C and provides patients with tailored reminders [47]. However, to attain the effective management of daily carbohydrate intake, a separate app is required in addition to Glucose Buddy. Mamykina et al. [28] developed a web and mobile diabetes detective (MODD) to support patients with diabetes in exploring new ways to control their blood sugar levels and track their activities. In many cases, both Glucose Buddy and MODD could be beneficial in the care and treatment of multiple conditions. However, they do not address issues related to drug/disease interaction or physical or mental limitations. For example, patients taking insulin for diabetes and steroids for inflammatory conditions face severe challenges in blood glucose management, as steroids counteract insulin. In addition, patients with DCCs often manage a high volume of information, visits, and self-care tasks [50] but the current tools do not fully help them coordinate, synthesize, and reconcile the health information they receive from multiple providers. Due to the many conditions patients with DCCs have, they are forced to sporadically tweak their care and treatment plans. We suggest a need for tools to motivate their self-efficacy, advocacy, and personalized expertise/awareness.

METHODS
This study sought to uncover barriers faced by patients with type-2 diabetes and DCCs and suggest design implications to help patients in navigating the care and treatment of their health. We used questionnaires and photo-elicitation interviews (PEI) to investigate how patients with DCCs navigate the care and treatment of their complex health conditions. We designed the questionnaire to elicit participants’ views, insights, and behaviors towards care and treatment of type-2 diabetes and other conditions they may have [34]. The photos we collected during PEI activity helped us to gain a deeper understanding of participants’ needs, support resources, and healthcare goals that participants used to manage their health and wellness. We discussed participants photos during the interviews, while the photographs acted as “conduits to narratives” that elicited the significant experience from the participants’ point of view [24].

Participants
We recruited participants through our personal, social and professional contacts, face-to-face interaction, flyers, and local connections. We used a purposeful sampling strategy to recruit patients who met the following criteria: i) were between the ages of 25-65, 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 or depression or both. 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 a compensation of $15 for participating in the study. All participants had the option of reading the consent form or having it read and explained to them. A total of sixteen patients were invited to participate in the study, five of whom identified themselves as males and nine as females; two participants identified as gender-fluid. Fifteen participants completed the study, but due to medical complications, one participant was unable to continue with the PEI activity after filling out the questionnaire. The study was approved by the Indiana University Institutional Review Board (IRB).

Study Design
The researchers met with participants two times. In the first meeting, the research team met participants for approximately one hour to obtain their consent, have participants fill out a questionnaire, and give directions for the photo elicitation activity. The researchers also used this meeting to brief the participants on how to use cameras and on safety tips for taking photographs in the community in this meeting. The researchers gave participants without smartphones disposable cameras.

For the photo-taking activity, participants were asked to take at least 20 photographs over a 2-week period, some of which should reflect positive aspects of their lives, some negative or challenging aspects, and others that should be of items that they normally use to manage their conditions, including resources they often consult. The research team provided minimal instructions to ensure that participants exercised control over what the photos capture 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, a researcher met with them to collect their disposable camera approximately every 24-48 hours. The photo content was similar across the smartphone and disposable cameras users and there was no noticeable difference in the content they captured. However, we also observed that patients who used disposable cameras tended to capture more of their household tools and indoor experience while those with smartphones also documented their outdoor activities, tools, and social network.

During the second session, the researchers met with participants for 60-90 minutes to review their photos, ask them questions about the photos, and brainstorm other information not covered in the photos. The meeting was conducted in a quiet, safe and most convenient place for participants. The participants presented the photos and narrated their meaning to the interviewer. The researchers asked leading questions to engage participants in discussing their experience. Questions asked in interviews included i) why did you take this picture? or ii) can you tell us more about this picture? or iii) 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. Two participants used the disposable cameras to take photographs that were developed in a photo studio for interviews and analysis. P13 was blind and did not take the photos. Instead, P13 wrote down the items and the aspects they used to manage their health and then discussed them with the research team during the PEI interview. Similarly, P12 had stomach problems and could not hold a conversation for more than 2 minutes; the research team sent P12 an email prompt to discuss why he/she/they took photos and how the photos related to P12’s health. After receiving participants’ response via an email prompt, the researcher sent follow-up questions for items that needed a more detailed explanation.

Analysis
The research team employed a variety of techniques to analyze the results. First, with the goal of understanding and characterizing the health management behaviors and practices of balancing the conflicting needs patients with DCCs, the researchers systematically examined participant use of photos to discuss barriers and strategies during the PEI interview. Then the research team analyzed responses to the questionnaire to understand how participants balance the management of their various conditions by mapping individual health issues to the number of times they commented on a strategy that addressed a specific health care issue. Finally, we used the grounded theory approach to allow themes to emerge [42]. The audio transcripts were broken into quotes, each of which contained one key point. A team of 6 researchers inductively organized these quotes into categories to identify major themes. These themes were further categorized into subcategories and were used to create a codebook that generated codes. The research team refined the codebook using Dedoose qualitative analysis software. The lead researcher trained the Dedoose data for inter-rater reliability testing, while the other research team members took the tests. We conducted 3 iterations of data analysis using Dedoose. In each iteration, we discussed the codes and the respective excerpts, re-defined some, merged some and created new ones. The first test conducted on excerpts was generated from P1-P4 data, the second test on P4-P8 data, and the last test on P9-P15 data. The results of the three tests enabled us to refine our codebook.
We asked participants to contextualize their practices relating to various doctors’ offices or pharmacies. One participant shared that ‘every medical professional that I go to’ reported carrying their medication lists every time they went to other providers. However, the majority of patients often share critical medical information they receive from their specialist doctors. Health care providers often depend on primary doctors to discuss prescriptions suggested to them by other providers. This lack of consistent and coordinated communication often leads to the prescription of opposing treatment plans. There were also trust issues between patients and their health care providers. Some patients specifically talked about not sharing other supplements and alternative medications they were using for fear of judgment. Some thought that their doctors might not find it important and so decided not to share with them: ‘I think, my Psychiatrist does not need to know my alternative medications, plus I don’t want to lose my insurance so I don’t have to tell him, I only tell him what he needs to know’. P3.

Communication with and amongst medical providers

One major concern participants face is the lack of adequate communication and coordination amongst different medical providers. This lack of consistent and coordinated communication often leads to the prescription of opposing treatment instructions including conflicting diets and management plans. Participants felt that their healthcare providers normally prescribe care and treatment plans without considering the potential conflicts with prescriptions written by their other providers. For example, P13 said: ‘So I’m talking to my kidney doctor, and he sees [the prescription from a diabetes doctor]. He goes, why are you taking B-vitamin and cinnamon? And I go, well, my diabetes doctor suggested that I take this. Oh, you don’t need that. He [kidney doctor] is going based on what his labs say’. Indeed, 14 participants mentioned a lack of communication among medical providers as a major concern.

Participants P3, P7, P11, and P13 reported being asked by their primary doctors to discuss prescriptions suggested to them by their specialist doctors. Health care providers often depend on their patients to share critical medical information they receive from other providers. However, the majority of patients often do not recall or remember clinical terms and procedures used. Because of the complexity of managing DCCs, 8 participants reported carrying their medication lists every time they go to various doctors’ offices or pharmacies. One participant shared that ‘I always keep a list of medications, a list of all my doctors, a list of how long I have been in the hospital, and I provide that to every medical professional that I go to’. P1. Not all participants took such initiatives and reported having taken conflicting medications and/or over-medicating themselves, consequently exacerbating their health.

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Care and treatment goals

Lack of adequate communication between providers cripples participants’ ability to effectively manage the critical aspects of their care and treatment including polypharmacy and prioritizing their illness. Here we discuss participants thoughts about these issues.

Polypharmacy

Adapting and adhering to care and treatment plans require a participant’s extreme knowledge when dealing with polypharmacy. Twelve participants reported challenges and complications as a result of taking multiple medications. Because of multiple conditions, a majority of participants reported having a complex medication regimen, as exemplified by one participant: ‘So all of my medications are basically a production you have to master two different combination, there are those you have to take before others, those that require you to eat food first, those that you have to take for a day or days depending on how you feel, you need to constantly call for help’. P9. The routine of taking so many medications can become a daunting burden that increases the chances of overdosing or missing out important medication steps.

Prioritizing illnesses and treatment

The complications of polypharmacy are worsened by inadequate coordination amongst medical providers, consequently

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Education</th>
<th>Occupation</th>
<th>Other Diseases</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>45-54</td>
<td>High school</td>
<td>Disability</td>
<td>Lung disease, Depression, Back pain, Fibromyalgia</td>
</tr>
<tr>
<td>P2</td>
<td>25-34</td>
<td>Attended high school</td>
<td>Disability</td>
<td>Depression, Fibromyalgia, Back &amp; leg pain, Arthritis, Headaches, Club foot</td>
</tr>
<tr>
<td>P3</td>
<td>55-59</td>
<td>Associate degree</td>
<td>Disability</td>
<td>Depression, Fibromyalgia, Sleep problems, Back pain, Chronic fatigue, Arthritis, Post-traumatic stress disorder, Thyroid</td>
</tr>
<tr>
<td>P4</td>
<td>45-54</td>
<td>College graduate</td>
<td>Disability</td>
<td>Arthritis, Manic depression</td>
</tr>
<tr>
<td>P5</td>
<td>55-59</td>
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<td>Disability</td>
<td>Depression, Breathing problem, Chronic pain, Chronic fatigue syndrome, Blood issue atrophy foot</td>
</tr>
<tr>
<td>P6</td>
<td>45-54</td>
<td>High school</td>
<td>Retired</td>
<td>Chronic pain, Arthritis, Osteoporosis, High blood pressure, Kidney problem, Acute tendonitis, Cerebral palsy</td>
</tr>
<tr>
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<td>25-34</td>
<td>Bachelor degree</td>
<td>Server</td>
<td>Asthma, Arthritis, Post-traumatic stress disorder</td>
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<td>P8</td>
<td>45-54</td>
<td>High school</td>
<td>Production</td>
<td>High blood pressure, Stroke history, Seizures/Epilepsy</td>
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<td>25-34</td>
<td>Master’s</td>
<td>Chemist</td>
<td>Major depressive disorder, Headaches, Migraines</td>
</tr>
<tr>
<td>P10</td>
<td>45-54</td>
<td>Attended high school</td>
<td>Disability</td>
<td>Depression, High blood pressure, Thyroid</td>
</tr>
<tr>
<td>P11</td>
<td>25-34</td>
<td>Attended college</td>
<td>Student</td>
<td>Major depressive disorder &amp; Depression, Arthritis</td>
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<td>Masters</td>
<td>Runs a business</td>
<td>Depression, Arthritis</td>
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<tr>
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<td>Retired</td>
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<td>High blood pressure, Liver disease, Depression, Back pain, Osteoarthritis, Kidney stones, Fibromyalgia, Restless leg syndrome</td>
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<td>High School</td>
<td>Disability</td>
<td>Depression, High blood pressure, Arthritis</td>
</tr>
</tbody>
</table>

Table 1. The prevalent chronic conditions/diseases reported by the DCCs participants.

FINDINGS

We asked participants to contextualize their practices relating to DCCs care and treatment. The following themes emerged from our analysis of the data: i) communication among medical providers, ii) care and treatment goals, iii) lifestyle choices, iv) importance of peer support, and v) financial concerns. We describe the barriers patients face in each of these themes and discuss the strategies participants currently used to mitigate these challenges.

Participants felt that their healthcare providers normally prescribe care and treatment plans without considering the potential conflicts with prescriptions written by their other providers. For example, P13 said: ‘So I’m talking to my kidney doctor, and he sees [the prescription from a diabetes doctor]. He goes, why are you taking B-vitamin and cinnamon? And I go, well, my diabetes doctor suggested that I take this. Oh, you don’t need that. He [kidney doctor] is going based on what his labs say’. Indeed, 14 participants mentioned a lack of communication among medical providers as a major concern.

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Polypharmacy

Adapting and adhering to care and treatment plans require a participant’s extreme knowledge when dealing with polypharmacy. Twelve participants reported challenges and complications as a result of taking multiple medications. Because of multiple conditions, a majority of participants reported having a complex medication regimen, as exemplified by one participant: ‘So all of my medications are basically a production you have to master two different combination, there are those you have to take before others, those that require you to eat food first, those that you have to take for a day or days depending on how you feel, you need to constantly call for help’. P9. The routine of taking so many medications can become a daunting burden that increases the chances of overdosing or missing out important medication steps.

Prioritizing illnesses and treatment

The complications of polypharmacy are worsened by inadequate coordination amongst medical providers, consequently
introducing confusion over how participants prioritize the instructions they get from different providers. Thirteen participants reported difficulty in prioritizing their multiple demanding healthcare and treatment plans. They often had to follow specific diets, exercise routines, medication regimens, and care and treatment protocols that were prescribed by multiple often uncoordinated healthcare providers. In most cases, participants found themselves overwhelmed and unable to follow these conflicting plans. For example, a diabetes diet and end-stage renal diet prescribed by a patient’s endocrinologist and nephrologist contained conflicting information, as described by one participant: “But on a renal diet, you have to look at the vegetables and say, I cannot have raw spinach. You know, I have to limit raw spinach. But you know, a diabetic doctor says to eat a big spinach!”-P13.

There was a mention of a challenge managing conflicting provider recommendations. Participants reported being often forced to make a decision that resulted in them favoring one condition over another. They struggled to strike a balance between illness and stayed in certain care or treatment plans because they conflicted with other plans or disease symptoms they had. Some participants ended up focusing on a single aspect of their healthcare and foregoing everything else. One participants noted: “The stomach value disorder is the root of my other health issues [arthritis, heel spur, poor diet and lack of exercise] at this time, it has complicated my type-2 diabetes because I cannot eat many of the natural, healthy, low carb foods that I normally would eat, I can’t easily balance it with other plans either”-P12.

Many participants tended to employ one of three strategies to find a balance between their conflicting healthcare plans: i) recalling their prior experiences to inform their current decisions (“I can occasionally take a vitamin or supplement for a day or two with food, such as fish oil, but then it hurts too much to continue after a day or two”)-P12, ii) seeking help and reliable and detailed medication information including side effects from their peers or other trusted online medical sources, and iii) trial and error to experiment with balancing the different treatment requirements. Other participants, however, were overwhelmed with this balancing process and relied on case managers or health coaches to prioritize their focus.

Life style choices
Most strategies that participant used to strike a balance or prioritize the care and treatment of their illness were reflected in individual patient’s lifestyle. In this section, we discuss how lifestyle impacts adherence and patients’ ability to find a new normal.

Adhering to lifestyle and self-management routines
Even when participants were empowered to prioritize their care and treatment plans, there was a perceived need to support them to continue on those plans. Nine participants reported difficulty in adhering to specific care and treatment regimens, as well as diet, exercise, and self-monitoring. Eight participants reported problems with learning how to adhere to the clinical and non-clinical aspects of their treatment.

DCCs often require changes to diet and exercise as part of an overall health plan. Such transitions can be a difficult transition for patients, as it may require them to learn new skills, limit the amount of food they eat, track their sugar levels, and balance other multiple health plans. One participant described these skills and the importance of learning them: “To stay in control is what is going to keep you from going blind or from losing a kidney. You know, you have to be disciplined and diabetes sucks”-P9. Participants who were successful in adjusting their lifestyle along with their medical routines experienced noticeable health benefits such as weight loss, lower blood pressure, or a reduction in symptoms.

While the rewards are high, it is often difficult for participants to make this transition (and find a new normal routine). When transitioning, participants have to become accustomed to monitoring their symptoms in order to help manage and understand their disease. For type-2 diabetics, this activity takes the form of monitoring one’s blood sugar, which typically involves a patient sticking themselves in order to record their glucose levels. This is often difficult for patients with arthritis or fibromyalgia who experience intense body pain, since those with depression and mood swings often lack the motivation to monitor sugar levels. Participant P6 discussed how important it is to treat healthcare management as a full-time job: “The sooner you [a patient] realize that it’s a full-time job and you are going to have to dedicate so much time to control various conditions”. Once a patient with type-2 diabetes is able to get into this routine, they are able to better manage their conditions and more effectively handle any medical situations that may arise.

Establishing a new normal
While confronting the struggle of balancing the complex and sometimes conflicting advice from multiple providers, participants also faced an additional barrier such as coping with the mental and physical limitations particularly imposed by depression, arthritis, or other DCC. Participants discussed the need to come to terms with an altered lifestyle and emphasized the importance of realizing the impact that chronic conditions will have on one’s life. As an example, participant P7 described the importance of knowing their physical and emotional stimuli and hobbies and utilizing them to overcome their health issues: “Learning how to re-contextualize your life, things you enjoy and how you have been doing for a while, was immensely important”. It is important for patients to find ways to reach a sense of normalcy within their new realities in order to be able to successfully manage their chronic conditions.

Some participants reported having had to relearn life skills such as walking after the major surgeries. Having gone through unpleasant life experiences, participants reported having to continuously find a new normal. This participant described their motivation to adapt to what a new phase in life had to offer: “I try to build upon each day I’m a lot better than where I was a year ago, but I try to do something a little different each day”-P5. This is true for patients with single chronic conditions, as well; they too have to identify their new normal and then make specific behavioral changes. However, this process is often intense for patients with DCCs because, first, they are overwhelmed by multiple healthcare and treat-
ment issues they have to address at the same time, and second, it takes a longer and more complicated process for DCCs to achieve a short new normal.

**Importance of support, particularly peer support**

Patients need support while balancing, establishing, and maintaining a new normal. Participants reported establishing and maintaining various support networks to help in adjusting to their health conditions.

Social networks provide participants with a sense of belonging, act as a distraction from their conditions, and redirect them to focus on something else, such as playing games, knitting, or crocheting. For example, one participant discussed their knitting group: "About half of people I knit with also do have other forms of anxiety or depression, so I can kind of commiserate with them" -P6. Participants often turned to their support network for management strategies and support in understanding the difficulties of living with chronic illnesses to find emotional and spiritual motivation. One participant mentioned being challenged by their doctor to rethink their life choices. Some participants, on another hand, mention not being able to get most of their questions answered through these existing support groups. If patients had two diseases they may have had to seek support from 2 different support groups, one for one condition i.e the first disease was for type-2 diabetes and the other for depression. They have to go to multiple sources that sometimes do not provide the answers to their specific needs, as one participant discussed: "Sometimes I can not find all the information I need in most of these platforms; they deal with issues that do not apply to my diabetes and depression, so I spend time reading medical books and searching WebMD and then try to put this idea together" -P7.

Another discussion had to do with participants finding very useful insights from their peers with a single chronic condition. As one participant elaborates: "Sometimes I want them [peers] to tell me it is gonna be ok and I’m going get out of it, but sometimes I just want them to let me know that, yeah, that sucks, that really, really sucks and I did it too and it took me hell of a long time to get past it" -P7. These participants are able to share techniques and understand the pain of going through related problems. But most of all, they were able to provide emotional support and assurance. Patients with single chronic conditions also face the same challenges reported in this section; however, patients with DCCs have to consult multiple support groups to have their needs addressed. This process often is complex and overwhelming.

**Financial concerns**

Another barrier that participants faced in successfully managing and prioritizing the treatment of DCCs is the financial difficulties associated with treating multiple chronic conditions. While sometimes clinical costs of seeing multiple health care providers and taking various medications are partially covered by a patient’s insurance, the majority of patients with DCCs fear that if their insurance coverage is changed, they may no longer be able to afford all of the medications in the amount that they need. As a result, some worried participants do not take medication as prescribed. For example, one participant stated that: "Often I try to stockpile all of my supplies[just in case insurance coverage changes]. I use infusion sets and cartridges longer than I should. I try to use less insulin" -P9. This practice among patients often leads to complications including increased hospitalization and poor quality of life.

**DISCUSSION**

From our study, we found that multiple aspects affect the participants with DCCs, ranging from financial constraints to physical and associated mental health issues. These issues are multi-level; not only are they patient-centered, but they also reflect on the healthcare providers.

Some of these findings are consistent with those reported in the care and management of single and multiple chronic conditions. For example, in their work examining how individuals make sense of online information, Nakij and Mamykina found that informational needs can at times lead to contradictory priorities for online health community members [33]. Similarly, studies by May et al. [32] on rethinking what it means to be a patient in the age of chronic multimorbidity demonstrate a need to better understand the resources that patients draw upon as they respond to the demands of the burdens of illness, the burdens of treatment, and the ways these resources interact with healthcare utilization. In other studies, Mei-Ying Wang et al.[48] used a mobile tool to alert the patients about potential drug-drug interactions and plan a proper intake schedule. There is also extensive work on drug price comparison tools [5] and platforms that facilitate crowd-sourcing health care management strategies to address issues related to patients financial concerns [15, 38].

This paper builds upon these findings and highlights the need to support patients in i) building trust and joining health care collaborations ii) conceptualizing care and treatment strategies and resources, iii) maintaining a healthy lifestyle, and iv) navigating through medical and financial systems. We also identify several strategies supporting specifically patients with DCCs in navigating through the unique challenges they face in managing their complex illnesses. Below we discuss these strategies in further detail and point out implications for the design for patients with type-2 diabetes and DCCs.

**Medical provider interactions**

Health care providers play a vital role in the care and treatment of chronic conditions. They help set goals, monitor patient progress, follow-up on patients’ adherence, and provide clinical advice accordingly. To effectively execute these roles, health care providers often require patients’ commitment, relevant information, and trust. Below, we discuss design implications to enhance collaboration between patients with DCCs and their multiple healthcare providers.

**Facilitate doctor-to-doctor communications**

In our paper, we see evidence of a lack of communication between medical providers who treat the same patient with DCCs. Such miscommunication results in confusion and conflict in prioritizing patients, care, and treatment plans. Studies in HCI and personal health informatics have addressed issues related to ensuring effective communication between healthcare providers and patients. For example, while some researchers
have looked at the enhancing communication between the patients and their support network [21] and valuing and empowering direct interaction among peer patients [19], others, including Jordan et al., have suggested the design of portals that facilitate remote support and communication between patients, their peers, and clinical providers [12]. These designs focus on informing clinicians about the patients’ symptoms and caregivers’ activities so that providers could partake in shared decision-making remotely [12]. There is also documented use of electronic health records (EHRs) and personal health records (PHRs) to share patients medication histories [40]. Although, most studies have looked into ensuring continuous support for patients communicating with their peers, caregivers, and clinicians, only a few studies have focused on the benefits for continued communications between healthcare providers who attend to the same patient [18].

In this study, we believe that the challenges of provider-to-provider communication is due to a healthcare provider’s rigid workflow. Integrating that workflow into other providers’ plans can be a deal breaker. For this reason, the portal solution as suggested by Jordan et al. may not work because it is not in the provider’s workflow. The EHRs or PHRs solutions might work, but there is a need to adopt and duplicate EHRS/PHRs in every clinical setting to support this collaboration. Some advancements in this direction has already been made since there is text messaging in a single EHRs [40], but it does not work across clinical boundaries with different EHRs.

We propose two sets of solutions to issues related to provider-to-provider communication. First, we propose to design a tool to facilitate provider-to-provider communication and take the burden off the patients. To do this we recommend first to understand what healthcare providers want. Do they want to have direct communication with each other? or would they rather have a patient be that conduit? If they want to include a patient with DCCs in their communication loop, what do they need to communicate? Do they want their information to be explicit?

Second, we propose to design a tool that supports the patient as an integral player in provider-to-provider communication. We hope to support them so as to reduce the barriers we have identified in our findings. However, we also recommend that the healthcare providers recognize whether patients are or want to be in this part of the communication. Do patients want to be and are they capable? Is there a limitation to their being in this loop? What should be done to support patients being part of this communication? How do we design technologies to support them as much as possible, so that they do not have to rely on memories alone? Patients should be equipped with the information they need so that when they meet other providers they can just share that information with them. We do not have the answers to these exciting questions at the present, but we suggest them for further future exploration.

Report substances patients use for self-medication that were not prescribed by doctors

Our findings under the communication with and amongst providers category show two issues; one, patients are not sharing information with providers sometimes because of issues of trust and sometimes because of the difficulty in communicating such complex information. Another aspect is that there is simply a lot to communicate and such an abundance of information makes communication harder. It becomes a burden for patients to communicate everything.

The importance of patients’ information sharing is well documented in current studies; for example, Halamka et al. [18] explored the use of EHRs and PHRs to share patients’ medical history, medication lists, routines, and allergies with providers who are within the same healthcare system. Similarly, Sands and Halamka [40] used online systems to share patient information. Although it is significant to share information across providers, these approaches do not capture several types of important patient-generated information, including the use of alternative therapies, medications, or supplements that patients with DCCs often tend to engage in.

To address this issues, we recommend two design areas for further exploration. First, how can we design tools to facilitate trust so that patients with DCCs don’t feel like they are going to get in trouble if they are communicating something illegal? For example, patients may not know what the law regulates the physician to report or not. How can we design technology to facilitate that trust so that patients can be open? Do they not trust providers because they are afraid of the judgment? ii) Are they afraid of not getting treated? iii) Are they afraid of not getting insurance? iv) Are they afraid of getting in trouble with the law? There are so many reasons why they may be afraid to share this information. Further studies need to be conducted to understand what this reason is and then discern what kind of regulatory body in the area, they leave in so that they talk to someone that has a mandatory report for if they have to report to someone. Designers have to be careful of exposing patients to situations where they may share information that will get them into trouble. There may be circumstances where doctor-to-patient confidentiality can or can not deal with law enforcement, so such tools need to make really clear whether or not it acceptable to share the information with providers because it won’t be reported to the law enforcement. Different countries have different laws that regulate these kinds of the activities and communication and what patients and providers need to be aware of when relating the proper information.

Second, with regards to the complexity of tracking and sharing multifaceted information that patients capture across their conditions, including the advice from their support network that is often completely different, confusion may arise because they use tools that are different from those they used to interact with healthcare providers. We suggest a need to create a quick bridge between health care providers and support networks so that the advice they get from their peers can be verified by the physicians with the app benefits.

We are excited about fostering trust between patients and their providers in handling complicated ethical situations and learning from patients’ experience including using non-prescribed medications (legal or not) and listing all patient’s drugs (legal or illegal, prescribed or not). In this phase of our research, we find this issue of patient’s trust and privacy to be sensitive and
requiring further exploration. We reserve this investigation for future work.

Care and treatment strategies
In our finding under care and treatment goals, we learned that patients with DCCs had very complicated health care management routines that they were not able to adhere to. This situation is particularly difficult and much more challenging than a single condition or two conditions that can be treated in the same way. The prioritizing between two different conditions is a challenge to the patients with DCCs; as result, they tended to focus on one single condition.

In personal and clinical health informatics, there is substantial work done in supporting effective clinical decisions and drug reconciliation in clinical settings [43, 48, 39]. Detecting conflicts between medications is one of the features of Clinical Decision Support Systems. However, challenges still exist when it comes to addressing issues relating to patients’ lifestyle, concerns, sporadic disease trajectories, and the mental and physical limitations that DCCs struggle with. One important need is for tools that address a patient’s personal and specific needs. In other studies, the patient’s personal healthcare management skills, knowledge, and motivation have been promoted as a key to effective self-management [6, 15]. As such, patients with DCCs can be empowered to learn and master their disease trajectories, project risks, and utilize necessary resources including rich information to effectively navigate through the care and treatment of their complex illnesses. Because setting priorities and optimal goals for DCCs is often a big challenge, patients’ skills and knowledge can be instrumental in achieving effective decisions.

In personal health informatics, there is a fair amount of work done in enabling a patient to be their own health detector, by enabling them to reflect on their conditions [29], gather data about their conditions for purpose of feedback from peers and clinicians [30], and elicit self-directed behaviors independent of clinical or peer insights [36]. Patients under clinical provider supervision often try out new strategies and experience new symptoms before they receive another treatment plan at their next appointment [17]. The problem with this situation is that because of clinical workflow, people really don’t want to wait for that long and won’t try out different things in time. There is a need for a more expedient way to facilitate this process and make faster iterations with providers specifically. How can the providers see what patients tried and failed while they waited for the next appointment? There is a need to create tools that fit in the current clinical workflow, find new ways to allow for an easy and quick exchange of the information and provide a faster iteration. For example, in the current workflow, when a patient calls the doctor’s office, the nurse re-routes the information to the doctor and then calls back a patient after some time. There should be the way to process the information quicker electronically, finding a system that i) allows for smooth and quick information exchange, ii) improves the clinical workflow from the beginning and reduces the amount of time spent going through multiple messages left by patients every day, and finally, iii) understand affordable clinical workflow and how they can be integrated.

Motivate lifestyle changes
Our findings under lifestyle choices suggest that similar to people with single chronic conditions, patients with DCCs also experience challenges related to finding a new normal. However, for the patient with DCCs, how they make changes to lifestyle or identify and adapt to the new normal it is a lot longer and more complicated task because if they tweak one thing (for example medication strategy), then something else has to be addressed, and then something else again.

Also, as suggested by our participants, similar strategies have been documented for the care and treatment of single chronic conditions which are basically how to change the lifestyle and establish the new normal. For example, Marie Clark’s study [8] discusses the development of lifestyle self-management intervention that helps to reduce fat intake and increase physical activity levels. While this intervention was designed based on a psychological model of health behavior change, it does not look at the long-term, complicated process that patients with DCCs undergo.

To support these patients, we propose exploring and deriving tools, strategies, and techniques that keep patients with DCCs motivated. For example, tools are necessary that help them see a bigger picture while working on a small piece. This design strategy can be informed by constructs from social cognitive theory [4], i.e., by designing tools that support patients to achieve specific, measurable, assignable, realistic and time-related goals. As such, a patient can be empowered to look at various aspects of their health as opposed to only one condition, and then: i) break them down and make steady progress, ii) stay motivated for long processes and tweak small things over longer period, and finally iii) keep the big picture in mind while focusing on a small change because they can’t do it all at once while at the same time balancing many different ones.

Care, treatment, and social support
Our findings under importance of support, particularly peer support show that participants with DCCs seek information from different support groups while also benefiting from interacting with people who have only one chronic condition. However, it was also noted that those people who have a single chronic condition didn’t necessarily understand the complexity of multiple chronic conditions. Thus, the participants with DCCs had to consult multiple resources with an attempt to seek strategies specific to their needs.

Current work in HCI and personal health informatics encourages the design and implementation of tools to coordinate interactions between patients and their support network. For examples, Min-Je et al. [7] analyzed the strength of individual features in predicting a patient’s social support need and found that users seeking emotional support tend to post more on online health support networks. These practices can also help patients with DCCs to expand their support network and seek support for their individual needs. We also believe that if someone has a single disease they may have very important information to share with the patients with DCCs. They may have techniques or understand the pain of going through the same problem and have helpful information about it. However, these patients may have a challenge filtering this information.
because they have no idea of how to handle other things patients with DCCs are still undergoing, but still patients with a single chronic condition are a very good resource. Nevertheless, what we think is a major issue here is that people with a single condition might not be good at understanding how to handle multiple support recommendations, and, to the best of our knowledge, current tools are not addressing this issue explicitly.

As our results show, patients hope to gain advice from peers and online support groups who are skilled and experienced in managing conflicts in healthcare and coordinating different healthcare providers with an effort to avoid making conflicting treatment plans for their DCCs. This process involves learning not only about the single disease, as they do in current online platforms, but about multiple conditions and applying that knowledge to evaluate risks and prioritize them when a conflict arises and also manage multiple providers. We believe that these circumstances substantially affect how patients seek and implement their care and treatment plans. For that reason, we need to be aware of these differences to understand DCC management. We suggest the design of tools that not only facilitate the understanding of specific conditions and the complexity of those conditions. Further, there is a need to: i) support groups with the same one exact combination of chronic conditions, for emotional support and have intimate knowledge of the disease process, ii) support groups of people who also have multiple chronic conditions could be different ones, but they understand how much harder it is to manage them and understand the challenge of having multiple providers to communicate and understand the emotional and physical and financial drain of balancing multiple chronic conditions.

Care and treatment financial strategies
The results of our study under financial concerns show that the existence of DCCs makes it difficult for patients to afford standard treatment procedures or other non-clinical strategies that could enable them to manage their health effectively. Like the people with single chronic conditions, patients with DCCs experience similar financial concerns. However, for patients with DCCs, the financial concerns are often exasperating because patients are basically getting multiple sets of expensive requirements. DCCs complicate the care of co-existing chronic conditions and often force these patients to forego other important aspects and/or procedures of managing and treating their conditions.

To address this issue, the current studies suggest a need to engage policymakers in policy-making discussions to support patients with complex medications plans [22, 37, 49]. There is also extensive work on price comparison tools, for example, sites such as "goodrx" that compare shopping prices for drugs [5], or others such as meta-shopping sites ranging from Amazon to Google Express that provide patients with details about where they can find more affordable drugs. While there are many price-comparison websites for travel, groceries, electronics, and entertainment, there has yet to be portals dedicated to helping patients discover affordable mixing care and treatment plans.

In the US we need to make the financial aspects both transparent and part of the decision making process. For example, when patients with DCCs are setting goals, they would benefit from seeing the financial aspects upfront and weighing whether or not they can afford them instead of choosing goals and then failing to afford the implementation. Any health tool that is targeting the US or a similar population that has a financial model for health care needs to include these considerations as part of the model. For example, i) if it is a tool for drug/medication management, it should also have to include insurance company rates, charges, and coverage so that patients can know how much it is most likely going to cost; ii) if it is a tool that helps with exercise, then we recommend including suggestions for meeting specific exercise goals incorporated with the cost of performing that activity and iii) better yet, if it is a nutrition tool that suggests recipes based on the patients’ health constraints, it should include how much they are most likely going to spend in their area.

Limitations
Through this study, we worked with patients suffering from type-2 diabetes (Index disease) and arthritis and/or depression, other combinations. As with additional discordant conditions, there are many other different combinations from which we expect similar issues to arise, but we need further work to make sure whether the issues our study uncovered are due simply to the combinations we chose or because they are more widespread.

CONCLUSION
We have presented the results of a 2-week photo elicitation interview study of 15 patients with DCCs. Our findings suggest that patients with DCCs face many difficulties, including those specifically related to managing their diseases, seeking social support, and addressing financial concerns. Prior studies have primarily focused on the management of single chronic illness, and have devoted less attention to the challenges patients with multiple conditions may face. Furthermore, research on multiple chronic conditions is still in early stages and, to the best of our knowledge, has yet to suggest any potential design direction to support patients with DCCs. We discussed directions for future designs, including i) exploring ways to report substances patients use for self-medication that were not prescribed by doctors, ii) promoting lifestyle changes, iii) crowd-sourcing medication side effects, iv) raising awareness about the long-term effects of particular conditions through social learning, v) designing systems for alternative medication plans and affordable drugs, and vi) facilitating doctor-to-doctor communication. These designs will help empower patients with DCCs, reduce the burden of living with multiple chronic conditions, and improve the quality of life and well-being for these individuals.

ACKNOWLEDGMENTS
We would like to thank all the participants. In addition, we are indebted to Centerstone Blooming, Indiana for allowing us to recruit from their clients.
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