Design for Discordant Chronic Comorbidities(DCCs): a DC^3 Model

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Abstract. Patients with complex conditions and treatment plans often find it challenging to communicate with multiple providers and to prioritize various management tasks. The challenge is even greater for patients with discordant chronic comorbidities (DCCs), a situation where a patient has conditions that have unrelated and/or conflicting treatment plans. We present results that highlight these challenges from two studies. The first is a photo-elicitation study with patients with DCCs (n=16), and the second is an interview study of health providers (n=8). In an attempt to address these challenges, we introduce a model that captures the different stages of synthesizing information about symptoms and suggested medical treatments, decision making around possible treatment plans including prioritizing different portions of the plan, and implementing their plan. This model is iterative, such that changes in a plan can impact symptoms and necessitate revisiting the plan. We call this model the Discordant Chronic Condition Care (DC^3) model.

Keywords: contextual model, care and treatment, type-2 diabetes, discordant chronic conditions, information sharing, · decision making

1 Introduction

Treating and managing Discordant Chronic Comorbidities(DCCs) is a major challenge in health care [18, 19, 17]. DCCs are when two or more conditions have unrelated or even conflicting treatment plans. For example, depression, arthritis, and end-stage renal disease are discordant to type-2 diabetes [21, 18]. Patients with DCCs must often coordinate between multiple providers and each provider prioritizes the specific condition they are treating. These competing priorities make it difficult for patients to know how to create a treatment plan that is best for their particular situation [18]. For example, a patient with type-2 diabetes and arthritis may work with one provider to control their diabetes symptoms while simultaneously working with another provider to control their arthritis symptoms. As such, changes in the treatment plan for diabetes can negatively impact the maintenance of arthritis. This exposure to disease and treatment interaction requires a patient with DCCs to have a lifetime engagement with the healthcare system. There is a continuous need to change strategies as a patient goes through unstable cycles, with an attempt to find a new normal [18]. In fact, these periods of stability are often quite short for patients with DCCs, since treatment for one condition may be contraindicated by treatment for another condition.

There is a body of work in the Human-Computer Interaction (HCI) and Personal Informatics, that emphasizes the design and implementation of tools, models, and frameworks to support the management of chronic conditions. For example, i) a holistic framework describing patients' complex and diverse cancer journeys from diagnosis through survivorship [13, 10], ii) a five-stage model (Stage-based Model of Personal Informatics Systems) for understanding how people use personal informatics tools and barriers people face in each stage [15], iii) a lived informatics model for personal informatics that captures the practices of self-trackers to help change behavior, encourage or maintain an activity, or motivate individuals to self-track [8], and iv) a tool, the mobile diabetes detective (MODD), designed to facilitate reflection and problem-solving in diabetes self-management [16]. However, these current approaches and tools are limited to helping patients manage a single chronic condition and do not support patients with DCCs [24, 18]. Furthermore, these current technology tools and models do not consider the complex interactions and unstable disease changes experienced by patients with DCCs.

We provide three main contributions in this paper: i) we investigate the health management challenges of patients with DCCs, including the perspectives of healthcare providers, ii) we propose a conceptual model that represents a process of sense-making and decision making for treating DCCs and seeks to address the challenges of managing DCCs, and iii) we discuss design implications that address complexities of DCCs care.

2 Background

Current studies have explored and designed models that inform and support the design of tools that track, monitor individual patients' behaviors, and promote sense-making and decision-making among patients and healthcare providers. However, these models are not capturing the complexity of DCCs. Here, we discuss the examples of those models and their limitations when it gets to care of complex interacting conditions.

First we discuss Personal Health Informatics models and tools that support decision-making and adherence. A model of shared decision-making consists of four key elements: i) at least two participants(i.e., the physician or multiple clinicians, patient, and family members) are involved in the decision-making process; ii) participants engage in all steps of the treatment decision-making process; iii) information is shared prior to the shared decision-making, and iv) both participants agree to the decision. The model highlights three major constructs [4]. The first construct is information sharing between clinicians (i.e treatment options, risks, benefits, and patients' histories). The second construct is equal participation/contribution to the treatment priorities by patients and their providers, and in some instances, family, caretakers, or other healthcare providers also contribute to this discussion process [4]. At the end of the discussion, options are presented, including those that are not being considered for a patient to pursue. Finally both patients and providers agree on the best course of action. During the setting and implementation of this course of action, goal setting and self-efficacy constructs play a major role. For example, they are being used to design tools that facilitate patient engagement. [2, 1]. Patient engagement tools include self-monitoring and receiving behavioral reminders [22]. Patients can now be engaged by self-management technological tools (heart rate monitors, blood glucose monitors and medication reminders)[13, 5, 16].

The second consideration for models in HCI and personal health informatics is Li et al.'s five-stage model. Inspired by the TTM, Li et al. developed a model that characterizes how people transition between five stage (i.e., preparation, collection, integration, reflection, and action) of their personal informatics tracking needs and describes the iterative nature of these information tracking stages and the barriers that prevent transitions [15]. This model was later expanded to include two phases of reflection, and discovery and maintenance [15]. These new phases allowed individuals to ask different types of questions in each phase. However, the model did not adequately account for the daily activities of self trackers. To address this challenge, Epstein et al. expanded the five stage model and created "a lived informatics model of personal informatics" which adequately characterizes the integration of self-tracking into everyday life by individuals. A set of studies in diabetes care are exploring the design and implementation of social technological interventions that i) support patients in tracking and collecting relevant information [6], ii) facilitate reflection and problem-solving, and iii) help patients make healthy dietary and exercise choices [5].

Third, Mamykina et al. [16] used their self-reflection and problem-solving tool (MODD) to develop a diabetes self-management model with steps that include i) identifying problematic glycemic control patterns, ii) exploring behavioral triggers, iii) selecting alternative behaviors, and iv) implementing these behaviors while simultaneously monitoring behaviors for improvement.

Finally, in cancer management, Hayes et al. proposed four stages of caring for cancer patients [10]. These stages include: i) screening and diagnosis, ii) initial information seeking, iii) acute care and treatment, and iv) no evidence of disease or chronic disease management. This work has informed the design of interventions including the *"cancer journey framework"* and associated *"my journey campus"* intervention used to help patients with breast cancer navigate through their healthcare needs from diagnosis to survivorship [13]. My journey campus provides a list of tools that i) accompany people on their healthcare journeys, ii) accommodate shifts in patients' needs, and iii) motivate patients and increase patients' energy levels and goals in the different stages of their journey [10].

In this section, we show that there are personal health informatics models that strive to i) inform the strategies and tool designs used to empower patients in becoming active agents of their health; ii) help engage patients in activities that promote exercise, diet, socializing, medication management, and symptom reporting while also helping patients monitor their own physical and emotional status and make incremental goals; and iii) support patients with chronic diseases with setting and adjusting their treatment plans. While existing models focus on people's readiness to change and provide actionable steps for different stages, we have yet to see work that focuses on people's ability to reengage and iterate when complications occur due to complicating events that are common with DCCs, such as multiple contradicting recommendations and interactions between goals. Future work is needed to explain how people can simultaneously handle multiple decisions within and across different stages of behavioral change. Furthermore, the increase in multimorbidities, especially when the conditions are conflicting (DCCs), require healthcare and healthcare systems to shift their traditional focus from individual conditions to approaches that account for a patient's multiple health needs [23, 14, 17]. This paper introduces such a model.

3 Methods

3.1 Data collection

In prior work,[18, 19] we conducted two studies to understand the challenges of caring for and supporting the care of discordant chronic comorbidities. In the first study [18], we distributed questionnaires and conducted a photo-elicitation interview (PEI) with patients with DCCs. We investigated how patients with DCCs navigate the care and treatment of their complex health conditions and uncovered challenges faced by patients with type-2 diabetes. Fifteen participants completed the study (participants were recruited until we reached data saturation [9]). The participants 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 as having type-2 diabetes and at least one additional chronic condition, such as arthritis or depression or both.

In the second study [19], we conducted interviews and focus groups with healthcare providers attending to patients with DCCs. In this study healthcare providers included; physicians, health coaches, nurses, psychiatrists, clinical and social workers, and pharmacists. The interview focused on gaining a deeper understanding of healthcare providers' perspectives on DCC patient care. The focus groups focused on the challenges identified during the interviews and brainstorming strategies and opportunities to effectively support the complex care of DCCs. Eight healthcare providers participated in the interview study. Seven of these providers participated in a focus group study. Only healthcare providers who self-reported treating type-2 diabetes and common DCCs associated with type-2 diabetes (e.g., depression, chronic kidney disease, or arthritis) participated in the study. Given difficulty in recruiting healthcare providers, eight(N=8) participants is an acceptable number for these types of studies [7, 12]. The Institutional Review Board (IRB) at our university approved the both studies.

3.2 Analysis

The research team employed a variety of techniques to analyze the results from the two studies. First, to understand patients and providers perspectives about the DCCs care needs, we used a thematic analysis [3] and affinity diagramming [11] to analyze patient and provider data. We systematically segmented the data from each study and broke the audio transcripts into exemplary quotes, each of which contained a key thematic point. Our team of six (for patients study) and three (for providers study) inductively organized these quotes into new categories to identify major themes.

From the patient study, five themes emerged from our analysis of the data. The second study, highlighted five themes. Themes from the patient study and provider study were further categorized into subcategories and were used to create a codebook that generated final codes. The research team refined the codebook and conducted iterations of data analysis. In each iteration, we discussed the codes and the respective excerpts and created new ones, resulting in the following three themes: i) information gathering and comprehension, ii) decision making when determining treatment plans, and iii) implementing treatment plans. For details about the methods, participant selection, and study design, please see [18] for the patients' study and [19] for the healthcare providers' study.

4 DCC Challenges

In this section, we describe the challenges that are specific to patients with DCCs based on our work with patients with DCCs [18] and their healthcare providers [19]. We summarize these challenges in three distinct stages identified in our prior work: i) information gathering and comprehension, ii) decision making when determining treatment plans, and iii) implementing treatment plans. See (**figure: 1**) Below we discuss these stages in detail, all statements come from the prior work.

4.1 Information gathering and comprehension

Patients must constantly take in new information and determine if it necessitates a conversation with one or more of their providers. The new information may come in the form of new symptoms or diagnoses. For example, if a patient experiences new information (a symptom), it may be severe enough to prompt a patient to report it to their provider, resulting in a treatment plan change; however, sometimes a symptom may simply be an inconvenience to the patient and the patient may determine that reporting the information to a provider would not be worth the risk of upsetting the current balance. Other reasons patients intentionally do not to share information with providers include that

Fig. 1. Treating multiple conditions in isolation can lead to unexpected interactions.

> *In the iterative analysis of the patients' and providers' data, we observed that changes in the treatment plan for one condition often negatively impact the control of the other condition. Leading three-stage management (i.e., information gathering and comprehension, decision making when determining treatment plans, and implementing treatment plans) cycle for each of their conditions.*

the information might negatively impact their insurance coverage, or because the patient believes the provider would not be interested in knowing the information. There are also times when patients unintentionally neglect to share relevant information. This is typically because patients have difficulty with clinical terms and procedures and cannot remember all the relevant information.

Regardless of the reason why, providers view the patient altering or omitting details as frustrating the provider's ability to accurately assess the health and treatment plans of their patient. Providers also complain that information is sometimes shared in an unhelpful manner. For example, the information may be presented in the form of a large disorganized pile of paper records from past doctors' office visits. This practice also frustrates providers.

4.2 Decision making and setting treatment plans

To better manage DCCs, patients and their providers have to prioritize different conditions to set achievable goals. However, setting these priorities can be challenging. One primary challenge is that different healthcare providers have different treatment preferences. In particular, healthcare providers typically feel that the condition they are treating should be the priority. For example, a healthcare provider who treats patients for diabetes asserted that mental health issues cannot be addressed until a patient's diabetes is under control. Whereas another healthcare provider insisted that mental health issues keep patients from taking care of their physical health, so mental health should be the priority. These different views result in conflicts in the decision-making process [18, 21].

Another issue is treatment plan (i.e, prescriptions such as drugs, lifestyle, assistive devices, and therapies) interactions complicate prioritization. Complex interactions cause adverse effects in patients with DCCs, such as rapid and severe changes in symptoms. Although providers recognized this complexity, they pointed to several reasons it was difficult to overcome. First, the rapid changes in symptoms and disease progression interfere with providers' abilities to observe and prioritize treatments for their patients. Second, providers are constrained for time and do not have enough time to thoroughly evaluate their patients and make informed treatment decisions. Third, patients react differently to each combination of treatment plans, so providers use trial and error with each patient. This is much harder when a patient is treating multiple conditions. Finally, providers are not able to easily consult their patients' other providers located in other healthcare systems, which inhibits providers from reconciling their patients' treatment, including therapies and prescription medicines. This is especially true for patients and providers in our studies, where mental health providers reside in different healthcare organizations than physical health providers.

Finally, even when a treatment plan is set, the cost of managing DCCs is higher and patients are not always able to afford and complete the treatment plan prescribed to them. Providers and patients agree that the cost of managing DCCs is higher [18, 19]. Costs often interfered with providers' abilities to help some patient's complete treatment plans. Patients are greatly burdened by the costs of their prescribed treatment plans.

4.3 Implementing treatment plans

Patients with DCCs often have a complex treatment plans (i.e medications, therapy, procedures and tests). This complexity increases patients' chances of getting overwhelmed and some patients even experience worse treatment outcomes, which in turn affect patients' abilities to implement or adhere to such prescriptions. Healthcare providers think that this non-adherence is made worse when providers prescribe treatment plans without considering the potential conflicts with prescriptions written by their other providers or the burden it imposes on patients. Even if treatment plans for different conditions did not conflict, patients are often overwhelmed with the quantity and complexity of treatment protocols.

When implementing an agreed upon treatment plan, patients are also frustrated by constant side effects. When confronting the struggle of balancing the complex and sometimes conflicting advice from multiple providers, patients also face an additional barrier such as coping with constantly changing symptoms and drug interactions imposed by another DCC. Healthcare providers also think that patients are not capable of implementing complex treatment plans. This issue arises when the patient tries implementing a treatment plan and new and often worse symptoms emerge. This issue also arises because a patient's mental capability or energy levels are too low to proceed with a complex treatment plan. Moreover, patients also sometimes experience negative side effects when implementing a new plan. Thus, a patient must be on the lookout for both positive and negative changes in their health. These changes may necessitate the patient to terminate a current treatment plan and return to the decision-making stage and alter the treatment plan.

Another challenge in treatment implementation and adherence results from patients' support networks. We noticed conflicting perception between patients and providers regarding the impact of patients' support networks. Healthcare providers claim that patients' support networks are a significant cause of patients' poor treatment decisions and lifestyle choices and often compromise patients' willingness to medicate. For example, some healthcare providers think that some patients refuse to implement a prescribed treatment plan or undergo the recommended procedure because of the miss-information patients receive from their support networks. However, patients find the informational support they get from their support network helpful. Patients learn from their peers' experiences –both what worked and what did not work for them. The healthcare providers were particularly against their patients learning from and changing their treatments based on the opinions of their peers because every patient with DCC has unique experiences. Current studies suggest that some patients can be experts about their conditions [8]. Patients (peers) can provide perspectives as experts from their unique experience and knowledge [20].

5 Discordant Chronic Condition Care (DC^3) Model

In a prior section, we show how care and management of DCCs requires simultaneous coordination of multiple aspects of a patient's health in which one change in management of one disease may negatively impact another disease. This added complexity can potentially lead to shorter times of stability and longer periods of detective work and changing treatment plans. Alongside the challenge of implementing a complex treatment plan, it can be difficult for patients with DCCs to even track down the underlying source of a particular symptom, given their multiple conditions and numerous medications and management tasks. For patients with a single disease (e.g diabetes or cancer), the diagnosis process is often simplified: it's either yes or no. While patients with DCCs always need to ask "but which one?". If a patient has DCCs, they need to deal with the confusion created by disease interactions and conflicting advice between multiple healthcare providers. In addition, providers often want the patient to prioritize the condition they are treating, and there are no mechanisms for helping the patient prioritize different aspects of their treatment across conditions or providers. Indeed, prioritization is often ad-hoc and haphazard. Further, patients are frequently used as the conduit for de-facto communication between providers, resulting in frustration on all sides. We use these observations to introduce the Discordant Chronic Condition Care (DC^3) model (**figure: 1**). The DC^3 model recognizes DCCs complexities and incorporates key strategies for i) assessing and addressing the complexity of DCCs care, ii) adapting to an individual's varying goals and needs, and iii) working closely with healthcare providers who understand the disease and the patients who are living with DCCs.

The DC^3 model identifies 3 major stages:

- Comprehension: a patient encounters a new symptom, condition, information or advice that requires an interpretation and contextualization to their

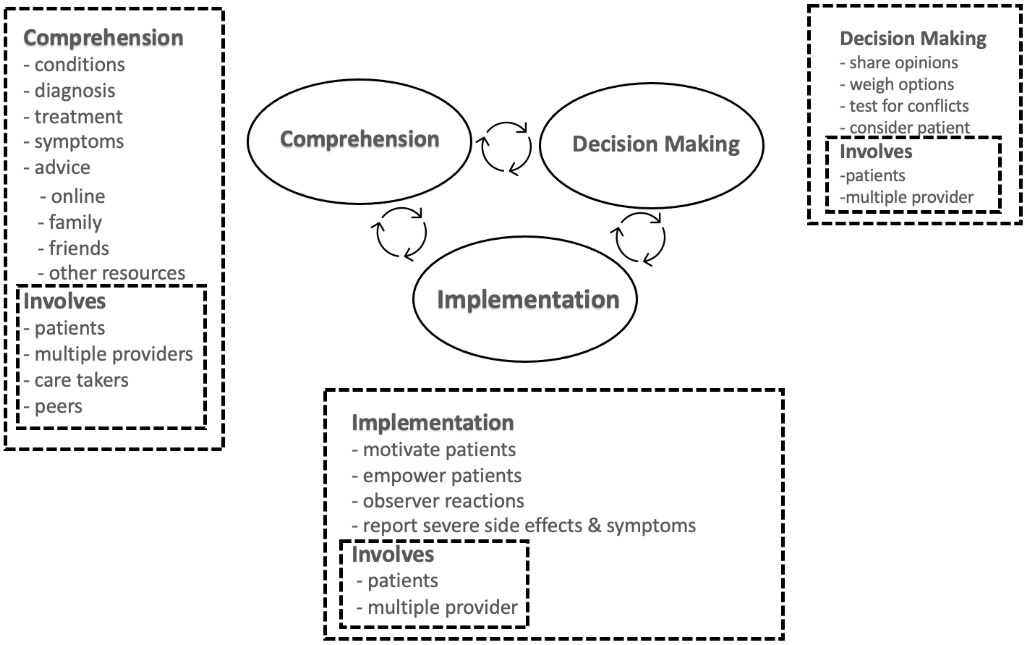

Fig. 2. DC^3 model for DCCs.

We use the information presented by patients with DCCs [18] and their health providers [19] to develop diagram that simulates three stages of management (DC^3 model): i)information comprehension, ii) treatment plan decision making, and iii) treatment plan implementation. Other additions to the diagram include accounting for all stakeholders (patients, providers, and patients' support networks (friends, family, and peers)) and the iterative nature of the DCCs care process

current health condition. This process of interpreting the new input often requires the patient to communicate with providers to fully understand the implications and decide if a change in treatment should be considered. The comprehension stage identifies a need to support patients in recording any potentially relevant information (Takeaway #1), and support providers in filtering that information to focus on the most urgent and relevant (Takeaway #2). This will help address the challenges caused by the complex information patients collect. Further, this process of supporting patients and providers may include identifying information sources and multiple facts for all of the patient's conditions and sharing of that information with and among multiple healthcare providers.

- Decision making: based on the understanding of the new information, the patient and providers must decide if they will modify the current treatment plan. Additional information may be sought (e.g. further tests), and a cost/benefit analysis performed. Patients may decide the potential risks of changing their treatment plans are too severe, such as upsetting their other conditions and balancing the conflicting advice from multiple providers. The decision making stage suggests a need to i) help patients navigate conflicting advice and prioritize different aspects of their treatment plans (Takeaway #3) and ii) support patients and providers in recording, reviewing, and starting/stopping treatment plans including therapies and prescription medicines (Takeaway #4). This will allow patients to prioritize their daily tasks intelligently and spend time on high-value treatment plans. It should provide patients an avenue to identify what types of decisions require professional consultation and what types of decisions can be initiated and implemented by the patient themselves. Further, it allows patients and providers to keep track of treatment plans including therapies and prescription medicines that were stopped and why they were stopped.
- Implementation: after a new plan is formulated, the patient needs support in executing the plan, including monitoring the outcome of the changes and communicating that information to their multiple providers. A change in health status may move the patient to the first stage where the cycle may begin again. The implementation stage needs to: First, help patients break down larger treatment goals into smaller, achievable tasks reflecting the patient's capabilities to help patients address the difficulty of adhering to complex treatment plans (Takeaway #5). Second, consider a patient's unique cognitive capability, energy level, and external resources available to that patient to implement a plan. This will help patients who are failing to adhere to their treatment plan because of negative side effects or severe mental, physical or environmental limitations (Takeaway #6). Third, support patients to digest and process new information received from their support network and seek a second opinion from a healthcare professional. This will help reduce any negative contributions of patients' support networks in patient non adherence (Takeaway #7). Finally, costs should be brought to the forefront so that a patient and their healthcare providers can reduce the risk of a patient failing to afford an agreed upon treatment plan or procedure (Takeaway #8).

6 Discussion

Throughout this paper, we present results from two studies that led to the DC^3 model. This section compares the DC^3 model with some existing models and frameworks and discusses how the DC^3 model might be used to influence the design of tools to support patients with DCCs.

6.1 Comparison of DC^3 model

The DC^3 model suggests a lens for designers looking to support individuals with multiple complex needs and can be differentiated from others in the following ways:
First, the DC^3 model focuses on the fact that two or more single diseases go in parallel and have complex interactions. The DC^3 model could help designers focus on disease interactions that complicate DCCs care. This is not the case in the care and support of single chronic diseases. It is true that some single chronic diseases are extremely difficult to manage because of conflicts between symptoms. For example, with respect to epilepsy, patients are confronted with choosing between having seizures or having the ability to think fast. Likewise, patients with Parkinson's may have to choose between feeling nauseous or having better motor skills. Despite that, if a patient has a single disease, they are aware of such conflicts. However, if a patient has DCCs, they need to deal with the confusion created by disease interactions and conflicting advice between multiple healthcare providers.
Secondly, compared to other models - such as the cancer management models[10], the journey framework [13], a lived informatics model of personal informatics [8], and TTM - the DC^3 model suggests strategies necessary to generate a rich understanding of when a patient needs change. The model also suggests the input on how designers might develop solutions to match an individual's needs. The DC^3 model does not specify endpoints of diagnosis and cure, or pre-contemplation and termination of behavior, as patients with DCCs will likely live the rest of their lives with these conditions. Instead, the model contains the general cycle of information seeking, decision making, and implementation present in the diabetes model, and also recognizes that there are multiple diseases to manage. The detective work involved must balance many potentially conflicting factors. For this reason, patients may stay in one stage for an extended period of time, or even backtrack to a prior stage before being able to move on to the next stage. The DC^3 model represents the complexity and time-consuming process of continuously having to comprehend new symptoms, information, and advice. In addition, the DC^3 model also accounts for the modification of treatment plans, including how to prioritize and implement different plans that may come from different providers, while monitoring for changes in the progression and symptoms of a condition. Furthermore, The DC^3 model emphasizes the need to communicate amongst multiple providers throughout this process.

6.2 Implications for design

DCCs care is already complex, but is further worsened by multiple actors. Doctors are zooming in on certain aspects of the disease and trying to optimize that part only. They can lose focus of how the other conditions are impacting their patients and they need support in focusing on their patients' complex needs. Take as an example, the geographic aspects of a map. Maps guide us by telling us where to go; maps orient us by pointing us in certain directions; and maps place us in context and tell us what is around us. Here we discuss how the DC^3 model could inform the design of tools to support providers and patients with DCCs in seeing beyond a singular disease. These design suggestions include creating tools: for a single stage, to transition between stages, to simplify complexities, and to coordinate the treatment plans prescribed by multiple healthcare providers.

Tools for a single stage

The DC^3 model could be used to design tools to support patients with multiple conditions in individual stages of the management process. In the comprehension stage, tools could help patients organize information across multiple conditions instead of focusing on a single condition or type of data. Tools that collect symptoms, condition information and common treatments for different conditions should be created. These tools should not separate this information based on different conditions. Instead, these tools should present all of the information and symptom in a way that makes sense to a patient. In essence, we advocate for providing a view of the entire patient instead of individual conditions. Thus, when a patient reports/records a new symptom, it can be placed in the context of their other symptoms, regardless of which condition caused the symptom. Focusing on the conglomeration of symptoms and other information associated with a patient's multiple conditions reduces the probability of a patient or provider making a change for one condition without considering how that change might impact a patient's other conditions.

In the decision-making stage, tools could be created that help patients collect all of the different treatment recommendation made by their various providers and evaluate them simultaneously. While a single provider might not recommend too many adjustments to a treatment plan at once, as the combination of treatment adjustments across providers might be too much for the patient to execute. Further, by collecting all of the treatments together in one place, patients and providers can be attuned to look for possible interactions across recommendations for different conditions. Finally, in the implementation stage, tools should be created to help patients track their progress for the entire plan, and not just individual components.

Tools for transitions between stages

In addition to developing tools to help with the challenges of individual stages, tools that help patients transition from one stage to the next would be extremely valuable. Patients with complex conditions can bounce back and forth between stages when trying to determine or implement an appropriate plan. For example, a patient who has noticed a new symptom and goes to a provider to adjust their treatment plan, may be asked to record other information. This information may be used to identify whether an adjustment may impact another condition. This can take the patient back to the comprehension phase. Similarly, a patient and their provider might alter the treatment plan, only to discover, after implementation of the plan, a negative impact on one of the patient's conditions. Tools are needed to help quickly communicate with all providers and adjust the plan, without a patient having to wait days or weeks to see their various providers. In the comprehension stage, the communications with and among providers is challenged when patients alter or omit details when communicating their other providers' recommendations. Providers are also frustrated and unable to accurately assess the health and treatment plans of their patient, because their patients share information in a disorganized and unhelpful manner. We recommend the design of tools to support patients in recording any potentially relevant information (Takeaway #1), and to support providers in filtering that information into the most urgent and relevant items of information (Takeaway #2).

Tools to simplify the complexity

Patients with DCCs are differentiated from patients with a single condition in that all of the stages and transitions are complicated by the presence of conditions which may work against each other. In the implementations stage, patients struggled with complex treatment plans, were overwhelmed and often experienced worse treatment outcomes.

We recommend the design of tools to help patients breakdown larger treatment goals into smaller, achievable tasks reflecting the patient's capabilities (Takeaway #8). These complicated interactions need to be simplified so patients can easily flag them (to discuss with providers), and better understand how a treatment for one condition may impact another. Similar to having drug interaction lists that are commonly available [26], patients should have access to treatment interaction lists tailored to their conditions. This would allow potential negative interactions to be flagged contemporaneous to the provider recommending a particular diet or lifestyle change. This would allow the provider to consider if there is another recommendation that could be made without exacerbating the other condition (e.g. swimming for exercise instead of walking when a patient has arthritis).

Furthermore, in the implementation stage, the cost of implementing multiple treatment plans brings in another complexity and consequently hinders a patient's ability to adhere to the treatment plans. The financial aspect should also be included in the tools. For example, when setting treatment plans, the tool should bring the cost to the forefront so that a patient and their healthcare providers lessen the risk of a patient failing to afford a treatment plan or procedure (Takeaway #5). The tools should include what is covered by a patient's insurance and what activities can be obtained through local community groups. The tools should also include less expensive options, such as lifestyle changes opposed to expensive medications. The benefits of alternative less expensive treatment plans, such as lifestyle changes, could result in multiple positive outcomes. In fact, for DCCs, (with type-2 diabetes) not only could lifestyle lower the costs but also reduces the risk of harmful medication side effects (i.e. hypoglycemia and weight gain).

However, for DCCs lifestyle changes may have barriers too. When a patient has arthritis, increasing physical activity may be another challenge. This is another example of how treatment interactions force patients and providers to prioritize treatment plans. This situations is worse when a treatment plan interaction causes adverse side effects, and rapid and severe changes in symptoms. Tools should help the patient and providers prioritize their treatment plans and strike a balance, since the patient may need to take multiple medications. Doing so requires careful monitoring to ensure that a patient complies with the goal set with his or her provider, so to avoid worse complications. If complications occur, tools must support patients in stopping certain plans. For example, a tool meant to support patients and providers in prioritizing treatment plans should also support patients and providers in recording, reviewing and starting/stopping treatment plans. Further, these tools should also ensure that the reason for each prescription (symptom and disease) is recorded for easier review in the future, as well as linking symptoms to potential drug side effects, especially when starting a new prescription or changing a dosage (#4).

Tools for coordinating with multiple providers

The care of DCCs relies on a shared understanding of a patient's complex information. Tools that help patients coordinate communication amongst their various providers are desperately needed (as suggested in the "Transitions Between Stages" section above). While EHR can be an adequate communication tool for providers that reside in the same health system, many patients with DCCs see providers in different health systems. When this occurs, providers often rely on patients to be the conduit for communication, yet patients struggle with this role [18]. A tool that facilitates communication between providers could help prevent bad treatment choices and alleviate the frustrations experienced by both patients and providers. These tools could be similar to monitoring tools suggested in [25]. In addition, when the information is shared, these tools should have a capability to support multiple healthcare providers and patients to collaboratively digest and process new information as well as seek professional verification of the new information(Takeaway #7).

In the decision-making stage, a major concern is that different healthcare providers have different treatment preferences. Tools should be created to help patients navigate conflicting advice and prioritize different aspects of their treatment plans (Takeaway #3). We also would like to emphasize the importance of shared decision making. Tools must be created to facilitate shared decision making and allow one provider to i) gain a realistic understanding of the patient's current health status (comprehension), ii) evaluate a patient's unique cognitive capability, energy level, and external resources available to implement a plan (#6), and ii) seek the perspective of other providers attending to the same patient. For patients with DCCs, tools can also provide an overview of the patient's severe symptoms resulting from multiple interacting chronic conditions as well as progressive symptoms that may become problematic at a later time. Tools should be designed to explore each of these scenarios and best characterize patients' current situations and how their health is likely going to evolve over time before making a treatment recommendation.

We need to recognize that patients with DCCs struggle to make decisions due to conflicting treatment paradigms and conflicting professional advice. We also need to recognize that designs can help these people make better decisions despite the multiple and often conflicting recommendations they receive. How can we help these patients sort through all this information so they can formulate a plan and try that plan? Some may decide to consult their other doctors' views about a decision. Some patients may want to know the time elapse before they begin to see a change. Patients need to be aware of potential side effects and reactions, and should be informed on the recommended steps if such events occur. Most technologies used to support patients do not account for any of the above. Patients should be empowered to have these conversations and bring this knowledge to their healthcare providers.

7 Conclusion

In this paper, we present results from two studies focused on challenges that patients with DCCs and their providers face when managing multiple conditions which may have conflicting treatment plans. Challenges revolve around having multiple conditions with multiple providers, complex treatment plans in which a change in the treatment of one condition can worsen another condition, and limitations on what patients can accomplish. We use these empirical results to develop the DC^3 model intended to support the design of systems to assist in the care and treatment of DCCs. Contrary to existing chronic disease care models, DC^3 focuses on the complexity of prioritizing multiple treatment goals and explicitly acknowledges the somewhat erratic nature of DCCs in which there is not always a clear trajectory or end. DC^3 also highlights the multiple stakeholders, emphasizing the difficulties patients often have with communicating and negotiating between multiple providers who may not be sensitive to the impact their recommendations may have on other aspects of the patient's health. Finally, DC^3 recognizes that attaining a "stable state" for patients with DCCs is difficult, fraught with lengthy detective work and experimentation. This experimentation can set patients back, forcing them to revisit their plans (in consultation with multiple providers) in search of a new normal.

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