Design and Care for Discordant Chronic Comorbidities: A Comparison of Healthcare Providers’ Perspectives

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ABSTRACT

Care and support of discordant chronic comorbidities (DCCs) are challenges not only for patients but also for their healthcare providers. DCCs are health conditions in which patients have multiple, often unrelated, chronic illnesses that may need to be addressed concurrently but may also be associated with conflicting treatment instructions. Previous studies show that patients with DCCs reported multiple challenges. Here, we conducted interviews (N = 8) and focus groups (N = 7) with healthcare providers to obtain providers' perspectives. We compare the challenges and views reported by patients and healthcare providers. We suggest design guidelines and technology-mediated ways to address convergent and divergent issues between patients and providers. We recommend future exploration of strategies to simplify and better understand how treatment choices for one condition may impact another and how that exacerbates DCCs care costs.

CCS CONCEPTS

• Health care information systems → Health informatics;

KEYWORDS

Discordant chronic comorbidity; provider perspective; patient perspective; decision making and prioritization; collaboration; design strategy; treatment plans

1 INTRODUCTION

Globally, approximately one in three adults suffer from multiple chronic conditions [18]. In the US, one in four people have multiple chronic conditions, and such conditions are on the rise among the older adults [15]. This increase exerts pressure on healthcare systems [30], which is made even worse by discordant chronic comorbidities (DCCs), which are situations in which a patient has multiple, often unrelated, chronic illnesses. DCCs need to be addressed concurrently, yet they are associated with conflicting treatment instructions, which causes providers to struggle with determining what is right for their patients. To ensure effective care and adequate quality of life for patients with DCCs, healthcare providers constantly adjust patients’ healthcare plans. Further, to ensure that everyone has all relevant information, providers must continuously discuss treatment options with their patients and with other healthcare professionals attending to the same patient. However, several factors frustrate the coordination of these processes, including rigid provider workflow, inadequate communication, disease interactions, and treatment costs. To the best of our knowledge, healthcare systems are not equipped to simultaneously facilitate these activities [4].

Currently, there are studies on supporting patients self-manage their healthcare [35, 36, 40]. For example, there are technologies that support self-reflection [9] and there are online communities being used to: i) provide advice for patients who are navigating through multiple treatment plans (e.g., diet, exercise, and medications) [33, 34], ii) support patients negotiating with the healthcare system [12, 24], and iii) support patients coordinating between multiple providers [2, 10, 12]. However, these studies do not discuss how multiple providers can collaborate or how to reduce conflict between multiple treatment plans. Further, studies barely mention promoting trust and collective decision-making processes that may involve weighing patients’ concerns, values, and financial capabilities.

Ongwere et al. [43] explored patients’ perspectives on the challenges of managing DCCs, which further substantiated this high-level analysis. This study with (N = 16) patients illuminated the complexity of treating DCCs resulting from patient-provider trust and communication issues as well as from the inadequate coordination between healthcare providers treating the same patient. A significant subset of the findings in Ongwere et al. focused on the
challenges patients experienced in working with multiple providers to treat their multiple conditions. In particular, this study’s findings showed that patients complained about several problems, including: i) the lack of communication between providers, ii) the providers’ reliance on them (the patient) for that communication, and iii) the difficulty of prioritizing different parts of their overall treatment plan. Findings from that patient study informed the work reported in this paper. We are particularly interested in the challenges providers see when treating patients with DCCs and how those challenges may be overcome. Thus, we conducted a two-part study to investigate healthcare providers’ perspectives on: i) the challenges providers face while supporting patients with DCCs, ii) providers’ understanding of patient challenges and support strategies, and iii) design opportunities for the care and treatment of DCCs. Here we present the results of our two-part study, a comparison of patients’ and providers’ perspectives, and propose design implications of those findings. The first part of the study was a semi-structured interview of providers (N = 8) to explore the challenges in providing care to patients with DCCs. The second part consisted of two focus groups (N = 7) in which those same providers explored potential design directions to overcome these challenges.

The contributions of this paper to personal health informatics communities are the following: i) An initial presentation of providers perspectives on the challenges affecting patients with DCCs and potential strategies to address those challenges, ii) A comparison of patients’ and providers’ perspectives on care and support of the DCCs, iii) A presentation of design opportunities for care and support for DCCs in areas where patients and providers agree or disagree; and in areas where providers agree or disagree with each other.

We present design suggestions to be considered by designers when creating new tools. These tools could be used by both patients and providers, however, the majority of the design suggestions are aimed at users that are patients.

2 RELATED WORK

Despite the increased number of patients with DCCs, few studies have examined the needs and challenges these patients face [42]. Due to the inadequate amount of research done on DCCs, this related work section discusses the care and support needs of patients with multiple chronic conditions, the barriers to patient-provider communication and collaboration, and the role of technology in facilitating the care and support of multiple chronic conditions. We then provide a justification of the need for technological tools and strategies to support the care of DCCs.

2.1 Care and Support Needs of Patients with Multiple Chronic Conditions

Reporting and communicating patients’ information is a major concern among providers. Patients’ information is predominantly shared on paper, by phone, or by email [38]. For patients with multiple chronic conditions, this information often accumulates rapidly and is easily lost or forgotten, or becomes a burden for providers and patients to maintain, share, and interpret [38]. In an attempt to address these issues, current healthcare systems have adopted the use of electronic health records (EHRs) and personal health records (PHRs) to more effectively share patients’ medical information. However, to use these tools, healthcare providers currently need to be in the same healthcare system. There is an opportunity to explore alternative ways of integrating and sharing patients’ records across multiple healthcare systems. In fact, healthcare providers encourage their patients to coordinate and share appropriate information with multiple healthcare providers [48]. However, reports by Roderick et al. [48] show that patients are often overwhelmed by the information they receive from healthcare providers during discussions, written notes, and prescriptions. Further, Ongwere et al. [43] showed that patients with DCCs were selective about what they share, because the information is either too much for them or they are not well prepared to share the information according to healthcare providers’ expectations. Unfortunately, little work has been done to adjust providers’ expectations of their patients and to reduce patient anxiety and uncertainty.

Balancing multiple plans is another issue consistently reported in current literature. At present, patients with multiple chronic conditions are provided with relaxation or breathing time to cope with the intensity of their treatment plans [16], other studies, however, promote the use of distractions (e.g., hobbies and social activities) to give patients emotional breaks [54]. Although these strategies might help reduce intensity, they have only a short-term effect. Finding the right balance between a patient’s multiple treatment plans remains a challenge and calls for the understanding of not only providers’ opinions, but also patients’ perspectives. We see a research opportunity in exploring strategies that facilitate and motivate patients to effectively achieve their treatment goals while addressing the impact of multiple recommendations from various providers.

Multiple costs also create an additional burden on patients with multiple chronic conditions. [55]. Higher costs emerge due to disease interaction and fragmented healthcare systems [43], and the need for patients with multiple chronic diseases to continuously acquire treatment records. These patients often experience fluctuating and complex disease trajectories, leading to constantly changing treatments. In the US, the healthcare systems are designed to provide care on a disease-by-disease basis; this strategy does not favor patients who have multiple diseases [54]. Some clinical practice guidelines try to accommodate multiple chronic conditions. However, these guidelines are also drafted in the context of a single chronic disease [52]. Hence, patients with multiple illnesses still face increased costs. The literature has talked about these challenges, but there is little regarding tools to help address challenges associated with managing multiple costs. There is an opportunity for designers to explore tools to minimize the impact of multiple treatment costs and its consequences to patient treatment adherence and quality of life.

2.2 Barriers to Patient-Provider Communication and Collaboration

Handling the multifaceted information that patients collect is another concern. They frequently seek support from multiple sources (e.g., peers, friends, family, and online support groups) [20] that are often inconsistent with their healthcare providers’ recommendations. Ongwere et al. [43] suggested that patients be equipped with
the necessary knowledge to evaluate their choices. Further, Berry et al. [5] designed systems that allow a clinician to evaluate patients’ data, collaborate with a specialist, and adjust their patients’ treatments. However, we have yet to see systems or strategies that help healthcare professionals instantly evaluate information that patients collect elsewhere. Nonetheless, we see the usefulness of the Internet of Things (IoT) and mobile health applications in sending prompts to clinicians for professional advice based on the information patients collect [23]. Also, some online support groups include professional moderation to promote consistency of shared information [53]. Although these strategies are necessary to facilitate collaborations with and among providers, they do not exclusively address complex interactions caused by the multifaceted data that patients with DCCs collect throughout their care.

Trust issues and reluctance to share information form another barrier to patient-provider communication and collaboration. Caring for patients requires moderate levels of interaction among healthcare providers. Indeed, Reddy et al. [47] explored the use of a shared information system used to facilitate interactions between patients with multiple chronic conditions and their healthcare providers. They recommended providing information in multiple representations to accommodate the different providers who are seeing the same patient. Lim et al. [31] conducted a qualitative study of patients with multiple chronic conditions and found that they often withheld information from providers when communicating about their health and well-being. Patients frequently disclosed information they deemed pertinent to share but were worried about the consequences of sharing and the influence of interpersonal relationships with providers [25, 31, 43]. We have yet to see studies addressing trust issues between patients with DCCs and their healthcare providers. Thus, there is an opportunity to build that trust and craft tools to present the required information in a format that providers, patients, and other stakeholders can easily understand.

Another barrier is diverging patient-provider values and concerns [3]. Providers’ concerns are often related to professional issues, including diagnosis and care in accordance with medical standards, while patients are concerned about their identity, hopes, and fears [3]. These concerns and values shape how patients communicate their personal information and also influence the support they receive. There is an opportunity to explore strategies that balance individual care, values, and concerns with and among providers, and then to explore providers’ perspectives, practices, and tools to bridge the patient-provider gap, create trust, and facilitate the effective sharing of information.

2.3 Role of Technology in Facilitating the Care and Support of Multiple Chronic Conditions

Multiple conditions often prevent patients with DCCs from achieving the required treatment goals. For example, their pain or depression may hinder their ability to perform sufficient exercise. These patients need a motivation to track and adjust their treatment routines. In fact, Li et al. [29] explored patients’ rehabilitation management and found that monitoring subtle changes enables clinicians to better plan procedures tailored to individual patients. Other studies are exploring the design of tools to monitor and support patients with single chronic conditions. For example, Mougiakakou et al. [37] designed a platform to monitor the treatment of patients with type-1 diabetes and provide decision support and risk assessment. Al-Taee et al. [1] proposed a mobile health approach to remotely collect and monitor patients’ data and provide tailored feedback on a smartphone platform. The goal of this platform was to utilize patients’ current and historical data to support the self-management of diabetes and enable real-time clinical interaction as well as provide feedback tailored to patients’ personal needs. Finally, Chang et al. [8] developed a context-aware interactive mobile-health system that provides real-time, two-way communication between diabetes patients and caregivers by utilizing IoT. The IoT system keeps track of a diabetic patient’s blood sugar values and sends a reminder to the patient and caregivers when records are abnormal. However, these systems are designed to support patients with single chronic conditions.

There is also an opportunity for researchers to explore how these approaches can be enhanced to support patients with multiple needs. Examples of such studies may include those that share information across patients’ care settings and exchange expert knowledge. Indeed, there are systems that facilitate patient information sharing, including the use of online platforms [50] and emails [39] to exchange patients’ information and coordinate care among providers.

While some researchers have looked at the enhancing communication between the patients and their support network [22] and empowering direct interaction among peer patients [19], others, including Jordan et al. have designed portals that facilitate remote communication between patients and their peers and patients and clinical providers [14]. These designs focus on informing clinicians about the patients’ symptoms and caregivers’ activities so that providers could partake in shared decision-making remotely. There is also a use of electronic health records (EHRs) and personal health records (PHRs) to share patients’ medication histories.

Although there are studies focusing on ensuring continuous communication between patients and their peers, caregivers, and providers, a few studies promote continued communications between healthcare providers who attend to the same patient. Furthermore, the idea of portals as discussed in Jordan et al. will not work because it is not in the provider’s workflow.

The EHRs or PHRs solutions may potentially work, but then the same EHRs and PHRs should be adopted across every clinical setting to support this collaboration. In fact, some EHRs have text messaging capabilities [49] however, these capabilities do not work across different EHRs.

Theoretically, setting interoperability standards across EHRs could allow different EHRs to be adopted across different clinical settings, however, in reality, setting and implementing interoperability standards is very difficult. Creating a standard that supports all EHR models would be challenging. And since interoperability standards will always favor some EHR designs over other EHRs, setting interoperability standards has many political and business implications.

We see the potential need for further exploration of design strategies to facilitate quick and continuous communication with and
among providers and patients to reduce the occurrence of treatment conflicts and overwhelmed patients, as well as facilitate shared decision making.

3 METHODS

This paper reports on a two-part study with healthcare providers, consisting of an interview (N = 8) and focus group study (N =7), respectively. All participants, but one, participated in both parts (Table 1) and were recruited from a community-based behavioral care center and local healthcare system. The Institutional Review Board (IRB) at our university approved the study.

3.1 Participant Selection

We recruited from two healthcare centers and we only selected health care providers who self-reported dealing with conditions that matched our recruitment criteria. See 1. We also used snowball sampling. To ensure that we had providers with some experience in treating DCCs, we focused on providers who reported treating type-2 diabetes and common DCCs associated with type-2 diabetes (e.g., depression, chronic kidney disease, or arthritis). We excluded healthcare providers who did not treat patients with type-2 diabetes and one of these DCCs. We provided participants with an overview of the study and assurance of confidentiality, after which we obtained written consent. Each participant received $10 gift card for their participation.

3.2 Data Collection

3.2.1 Interview. The study aimed to gain a deeper understanding of healthcare providers' perspectives on DCC patient care. To this end, we conducted a semi-structured interview, drawing on the themes from the Ongwere et al. patients study [43] on the challenges of managing DCCs. These themes included: i) the patients' following of treatment plans, ii) the relationships between providers, iii) the treatment priority-setting process, and iv) the preferred information sources. We chose these themes because patients identified them as issues that have a substantial impact on DCCs care. We met participants once in person to obtain consent and perform a semi-structured interview. We conducted interviews in a quiet room in a healthcare facility. The interviews were audio recorded and transcribed for subsequent analysis.

3.2.2 Focus groups. After the interviews, participants were invited to participate in one of two focus groups. We used the focus groups to more thoroughly explore the themes that emerged during the interviews. While the interviews addressed challenges and strategies for managing DCCs, the focus groups revolved around brainstorming design opportunities to effectively support the complex care of DCCs. We used the focus groups to identify and brainstorm strategies that can be used to address the concerns highlighted in the provider interview study [32]. We conducted the focus group sessions (FG1 FG2) in a quiet room at a healthcare facility with 3-4 participants in each session. Participants in each focus group were randomly selected based on their availability. A lead researcher facilitated these sessions, which lasted 45-60 minutes. Questions for the focus group were chosen to address themes highlighted in both the providers’ and patients’ studies. After reminding providers that we were particularly interested in their experience with patients with DCCs, we asked if they used any form of technological strategy to help their patients. We also asked them about balancing conflicting diseases, communicating with other healthcare providers, and understanding how different conditions may interact. After learning about their current strategies, we discussed how to improve those strategies or create new ones.

3.3 Analysis

We used a thematic analysis [7] and affinity diagramming [21] to analyze interview and focus group data. We systematically segmented the data and broke the audio transcripts into exemplary quotes, each of which contained a key thematic point. Our team (N=3 researchers) inductively organized these quotes into new categories to identify major themes. We iterated on the codebooks until we reached satisfactory inter-rater reliability (Cohen’s Kappa of 0.78 and 0.82 for interviews and focus groups, respectively).

From the interview results, we identified six major challenges, including: i) support networks providing unreliable and discouraging information, ii) providers’ trust in their patients, iii) treatment goal setting, iv) resource constraints, v) disease and drug interactions, and vi) high treatment costs. The results from the interviews influenced the focus group discussions, which focused on strategies to navigate these identified challenges.

The interviews and focus group discussions highlighted the following themes, which are further discussed in our findings section. These themes include: i) providers’ rigid workflow is barrier to DCCs care and support, ii) provider trust and communication is another challenge, iii) DCCs disease and drug interactions make prioritization difficult, iv) health care providers’ varying treatment preferences complicates treatment of DCCs, v) patients’ support networks could be feeding patients discouraging information, and vi) DCCs treatment costs are higher compared to single chronic conditions.

Figure 1: Analysis Process

Showing how the transcripts were broken into exemplary quotes (white papers) and then categorized into major themes (posted notes)
Table 1: Summary of study participants.

<table>
<thead>
<tr>
<th>Interviews</th>
<th>Medical Position</th>
<th>Medical Specialty</th>
<th>Patients (Monthly)</th>
<th>Knowledge about DCCs</th>
<th>Focus groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>Registered nurse</td>
<td>General internal medicine</td>
<td>28</td>
<td>Knowledgeable</td>
<td>FG2</td>
</tr>
<tr>
<td>P2</td>
<td>Health coach</td>
<td>Psychiatry disorders</td>
<td>30</td>
<td>Knowledgeable</td>
<td>FG2</td>
</tr>
<tr>
<td>P3</td>
<td>Health coach</td>
<td>Mental disorders</td>
<td>10</td>
<td>Knowledgeable</td>
<td>FG1</td>
</tr>
<tr>
<td>P4</td>
<td>Registered nurse</td>
<td>Out patient surgery</td>
<td>120</td>
<td>Very knowledgeable</td>
<td>FG1</td>
</tr>
<tr>
<td>P5</td>
<td>Director of integrated health</td>
<td>Clinical &amp; Social work</td>
<td>1400 (overseas)</td>
<td>Very knowledgeable</td>
<td>FG1</td>
</tr>
<tr>
<td>P6</td>
<td>Certified pharmacy technician</td>
<td>Pharmacy</td>
<td>100</td>
<td>Knowledgeable</td>
<td>FG1</td>
</tr>
<tr>
<td>P7</td>
<td>Registered nurse</td>
<td>Geriatric</td>
<td>150</td>
<td>Knowledgeable</td>
<td>FG2</td>
</tr>
<tr>
<td>P8</td>
<td>Medical doctor</td>
<td>Psychiatry</td>
<td>70</td>
<td>Very knowledgeable</td>
<td>–</td>
</tr>
</tbody>
</table>

4 FINDINGS

In their study, Ongwere et al. [43] confirmed that patients with DCCs struggled to prioritize and balance often-conflicting treatment plans they received from multiple providers. In this paper, we seek to learn the thoughts of the providers, and we focus on the impact of continuous DCC interactions. We show how DCCs are complicated for providers to treat.

4.1 Providers’ Rigid Workflow is a Barrier to DCCs Care and Support

To identify the problem(s) and best course of action during an office visit, providers need to extract and distill both the big picture and details of a patient’s life and health. The problem with this directive is that patients with DCCs often present multiple issues that providers are not able to cover in a single session. As one provider elaborates:

“Having to multiple conditions gets confusing, it gets hard for [patients], we’re not able to cover all of those in one session, and so some get forgotten [next time around].” -P1

The current healthcare system requires healthcare providers to attend to a different patient every 15 minutes [13]. Providers are not given extra time with patients with DCCs. Providers are expected to spend the same amount of time to examine patients with DCCs as they do for patients with a single chronic condition. One participant elaborates:

“You may think, but really, it is hard for [doctors] to get the extra time for patients who come with multiple problems.” -P5

Several providers acknowledged how the healthcare system fails its patients. As one sympathetic health provider (health coach) said to a fellow healthcare professional:

“I think it’s too much for [doctors because] they can’t even see the patients in a timely fashion because of their tight schedule.” -P2

Due to time constraints, some providers delegate some of their patients to other healthcare support professionals within the same clinical facility.

“Asking the colleague take over some patients surely relieves that pressure. We always try help each other tackle our [patients] caseloads.” -P1

However, according to some other providers, delegating patients (especially those with DCCs) is detrimental. One of the disapproving participants said:

“When a patient is delegated to healthcare providers who already have heavy workloads are that patient is easily forgotten or is relegated to a lower priority.” -FG2

Participants instead focused on discussing strategies they have used to optimize office visits. For example,

“Helping patients develop check list and/or symptoms diaries.” -P1

Diaries and check lists help patients organize their observations and thoughts, while also ensuring those observations and thoughts are not forgotten. Thus, less details are missed when patients report to their doctor. So that, when a patient goes to their doctors’ office;

“[Patients] go in there knowledgeable, know what you are talking about, know exactly what to say to the doctor.” -P8

To better use diaries and checklists, providers suggested that patients should be trained. Patients should be trained to record only vital disease observations, opposed to less essential observations. Patients should be trained to be both direct and precise when communicating their needs, and to avoid:

“[…] talking about what happened a year ago[…] go in, this is what is going on today, this is what I need and make them their own advocates.” -P8

Providers believe that patients who are readily prepared with vital details, allow a provider and a patient more time to discuss treatment options and also makes a patient knowledgeable about their health.

4.2 Provider Trust and Communication is Another Challenge

Throughout our study, we saw provider-patient trust and communication issues. Providers required patients to coordinate and share their treatment plans with other providers. One provider was quoted saying:

“I would suggest things and I always say discuss this with your diabetic doctor.” -P1

Despite providers requiring patients to take responsibility for sharing their healthcare information, some providers believed patients were not always truthful or omitted details of their medical histories. For example, in one focus group, providers complained that:
A brief summary listing the patient’s disease symptoms, prescriptions, experienced side effects, and questions may help streamline the patient assessment and make the visit more efficient. Most of the providers suggested that patients should present the information they collect elsewhere in:

<table>
<thead>
<tr>
<th>Challenges/Barriers to DCCs support</th>
<th>Strategies identified and/or used by providers</th>
</tr>
</thead>
</table>
| Providers’ rigid workflow is barrier to DCCs care and support | - Delegate some of their patients to other support professionals  
- Help patients prepare discussion points and checklists for recalling vital details  
- Prepare patients become their own advocates |
| Provider trust and communication is another challenge | - Encourage patients to provide detailed information  
- Simplify and streamlines patients’ information sharing |
| DCCs disease and drug interactions make prioritization difficult | - Set and supervise DCCs treatment plans  
- Used motivational interviewing to understand patient’s view of the problem  
- For some cases, participants explored patients’ family histories to ground treatment decisions |
| Health care providers having varying treatment preferences complicates patients with DCC treatments. | - Discussed and shared thoughts, individual treatment strategies and suggestions with each other  
- Adopted the use of decision support and reporting tools i.e MEPS or PQRS  
- Some (health coaches) attended patients’ doctors’ appointments and helped to advocate for a patient in these meetings |
| Patients’ support network could be feeding patients discouraging information | - Provided patients formal guidance before they can proceed with suggestions, they get else where.  
- Were receptive to ideas that patients support network suggest and advised patients accordingly  
- Evaluate the patients’ support network |
| DCCs treatment costs are higher | - Direct patients to places to find cheaper options |

Table 2: Challenges and Future Design Opportunities to Support Patients with Discordant Chronic Comorbidities (DCCs)

DCCs care challenges and strategies categorized in three themes, prioritizing ans balancing treatment plans, rigid healthcare provider work-flow and non-adherence.

4.3 DCCs Disease and Drug Interactions Make Prioritization Difficult

Given the continuous disease and/or drug interactions associated with DCCs, the challenge of supporting complex treatment plans was a popular topic. For example, providers complained about drug interactions worsening patients’ health:

“There are adverse drug effects [...] and certain monoamine oxidase inhibitors for depression and steroids for arthritis often interact in dangerous ways.” -FG2

These drug interactions often have adverse effects in DCC patients, causing patients to experience dramatic disease changes and more severe symptoms. As one provider attested:

“Our [patients] can change drastically from day to day, so they can feel really great one day, and the next day, be extremely depressed, psychotic, or manic.” -P5

Some providers acknowledged that the constantly changing conditions, not only make providers’ jobs more difficult, but significantly burdens their patients. For example:

“Treating diabetes is one thing, but when so many [patients] have chronic cytology, chronic foot issues, and numbness and tingling, [Patients] just feel bad in general and that changes every time [patients] come. It is difficult for [patients] and for us.” -P8

These constantly worsening symptoms interfere with providers’ abilities to effectively observe and decide on the most effective treatment plan for a patient. Some providers believe such symptoms lead to other severe conditions, such as major mental illnesses, among patients with DCCs: One provider explains:

“I know a lot of chronically ill people have depression as a result of their illness.” -P1

"A patient is not always going to tell you the truth. And all [healthcare providers] can do is reach out to [other healthcare providers] or anyone who is involved with that patient.” -FG1

P3 was specifically frustrated about how patients shared inadequate information and did not share treatment plans across providers:

“There is too much involved, and [patients] just don’t want to give everything.” -P3

Patients with DCCs often gather fragmented pieces of information, some of which may be essential in decision making. When patients do not to share all of this information, problems arise. In fact, providers maintained that inaccurate records cripple them in setting appropriate treatment goals. As one participant elaborated:

“You have two different doctors who are trying their best to do what is right for [a patient], but [patients] don’t have or don’t want to share all the information.” -P3

Further, for the information that the patient was able to share, providers were frustrated by the formats at which patients shared this information. As P5, who often consults patients’ records, stated:

“There are lots of formats to get patients’ records, but [providers] do not want fifty reams of paper, [providers] want […]”. -P5

Most of the providers suggested that patients should present the information they collect elsewhere in:

"[a] summary of what occurred, what the major issues are.” -FG1

A brief summary listing the patient’s disease symptoms, prescriptions, experienced side effects, and questions may help streamline the patient assessment and make the visit more efficient.
Other providers think the unstable symptom changes associated with DCCs create treatment interference and make it difficult for them to help a patient complete a desired treatment plan. P7 explains:

“some of the symptomatology, like active hallucinations can really create some major interference.”

The providers attempt to address these issues by continually setting and supervising DCCs treatment plans, [which] requires [providers] to continuously observe patients’ symptoms and treatment side effects.” -P5

Others, however, believe that it is important to understand the patient’s view of the problem, and use motivational tools and patient input to guide the treatment plan, and:

“to figure out what motivates [patients], what [patients] are willing to work on, what do [patients] want to work on.” -P4

Doing this helps them understand patients’ priorities, other preferences, and major concerns. This allows providers to find a middle ground and identify a treatment plan that minimizes impacts on the patient and results in increased patient compliance. Regarding novel symptoms, when verifying treatment decisions, one provider would explore patients’ family histories just in case

“[the symptom] is something that’s been coming through the blood line, or is [symptom] just something new with them?” -FG1

4.4 Healthcare Providers Having Varying Treatment Preferences Complicates Treatment of DCCs

As expected, providers treat patients according to their specialty, experience, and background, resulting in them paying attention to particular symptoms and disease cues when making treatment decisions. When attending to a patient presenting both arthritis and depression symptoms, P4 believed that physical limitations take precedence:

“I know a lot of chronically ill people have depression as a result of their illness. And I do not think that we can fix the mental part until they get to feeling better physically.”

On the contrary, P3 felt that mental issues must be addressed first:

“Understanding how our [patients] are feeling mentally is going to affect how they feel physically, so just really finding a way to help [patients] feel their best mentally, that way [providers] could improve [patients] physically.”

Providers felt their area of expertise was the most critical to address first, and thus wanted to prioritize their own treatment plans. To address these differences, participants discussed the importance of discussing and sharing thoughts, individual treatment strategies, and suggestions, acknowledging that there is no lone expert for a DCC patient’s care. One participant explains how this process should proceed:

“[Providers] need to be working in tandem with other care providers. So, everybody kind of brings a specialty, or a niche to the table that then informs the treatment planning process and the care.” -P8

Another suggestion is to encourage healthcare providers to take advantage of decision support and reporting tools such as the Physician Quality Reporting System (PQRS) or Medical Expenditures Panel Surveys (MEPS) to reduce errors and omissions. In fact, one participant explained that

“having a meaningful use and standards for prescribers, like PQRS and MEPS and some of these things, helps to improve patient evaluation.” -P5

The hope is that, if well used, these tools would inspire the healthcare professional to be more thorough when evaluating patients. Health coaches reported having attended some of their patients’ doctor’s appointments and helped advocate for a patient in these meetings and also maintained the communications with patients’ specialists. In fact, P2 reported that:

“so [they] like to attend those appointments and be in communication with those providers.” -P2

Through this use of office visits, they gather information and make sure that all other providers are aware of what medications the patient is currently on, and they help patients follow those recommendations.

4.5 Patients’ Support Networks could be Feeding Patients Discouraging Information

Currently, when managing single or multiple chronic conditions, connectedness matters for both patients and healthcare professionals [17]. In this study, however, we see providers taking a different view of the impact of patients’ support networks (both social and professional). Mainly family, friends, and peers make up a patient’s social support network, and other providers form the patient’s professional support network. Providers consider some of the patients’ social support networks to be giving demotivating information. One provider gave an example of what one of their patients said:

“I went out with so and so and they told me their wife had this or their husband had this and he died and cousin so and so had this.” -P5

Because of such advice and comments, providers think that their patients are often fearful and are skeptical of accepting treatment plans that providers find to be helpful and will seek other professional support. This other professional support can also be problematic for providers when it suggests treatment that the providers are not aware of or conflicts with a patient’s current treatment plan. P6, for example, explained how

“sometimes [their] patients don’t like what they’re getting prescribed by [them], so they will go seek elsewhere to get what they want...They go to people who don’t know a thing about [patient] history. And they collect these long lists, and they come and say, ‘so and so told me to do this, they told me to stop this one’”

Providers interpret this as a refusal to continue on a prescribed treatment plan and worry that such decisions may cause medication complications, over- or under-medication, and non-adherence. Also, two different patients with DCCs may not be affected the same way
and a patient’s support network may not be aware of it. For example, one provider elucidates:

“If you have a blood sugar of seventy, somebody may be passed out, somebody else may still be functioning well.” -P7

Providers believe that if a patient insists on consulting their support network, then that support network should be evaluated and patients should receive formal guidance before implementing any treatment ideas received elsewhere.

“We need to talk to them about the type of support they get, this support must be evaluated.” -P7

Some providers were receptive to these ideas patients brought from their support network and others tried to explain why these ideas may or may not apply to their patients:

“[..] try to meet them where they are at and find out why they are clinging to this information.” -P6

As such, creating an opportunity for patients to explore the benefits of these ideas or learn how these ideas may not be applicable to their condition, allows patients to be more engaged in setting treatment goals. One provider believes:

“as a clinician, [a provider’s] goal is to making sure [they] understand, what the patient says they’re motivated for.” -P5

And together providers should translate the patient’s understanding into setting treatment plans that a patient is comfortable trying.

4.6 DCCs Treatment Costs are Higher

In the current healthcare system, managing any treatment is often expensive. These expenses are even higher for patients with DCCs, as P8 explains:

“It’s a hot mess. I mean, I think everyone is just, struggles with costs and, that’s hard for probably you and I to manage, and so when you factor in a lot of other conditions, that makes it even more of a challenge.”

More costs emerge due to DCCs’ disease interactions and varying provider treatment recommendations as mentioned in section 4.3 and 4.4 respectively. Providers are worried about how these costs interfere with their ability to support patients with DCCs. For example, P8 described why it is difficult to help some patients, especially those of low socio-economic status, to follow complete treatment plans:

“When patients are told to go call [a specialist], and then [the patient] finds out there’s a fee, then [patients] don’t have that money, [a patient] just give up and do what they want to do.”

It was noted that most of these patients often avoid consulting specialists or skip treatments in an attempt to minimize the costs of their medications. Thus, patients wait until their situation gets worse before they start to seek medical attention.

“It just gets worse and worse and it creeps up on them and then it takes something huge to bring them into the hospital.” P1

For some providers, the solution to patients’ financial challenges was to help patients with DCCs minimize the treatment cost. One strategy, as they explained, was to

“direct [a patient] to a place where medication is less expensive to go to.” -FG1

5 DISCUSSION

Through our findings, we noticed providers were concerned about patients’ actions and interpersonal interactions (i.e., with peers, family and friends, and other healthcare professionals). Yet in their work exploring patients’ perspectives on the care of DCCs, Ongwere et al. [43] reported several concerns about the patient-provider relationship. In this section, we compare these perspectives and highlight areas where healthcare providers and patients in Ongwere et al. had converging views or diverging views concerning communication challenges, prioritizing DCCs treatments, the role of the patients’ support networks in DCCs care process and financial cost burden. We then suggest design strategies to reconcile the two views to reach a middle ground.

5.1 Comparison of Providers and Patients Perspectives

5.1.1 Inadequate Communication. Many problems with effective care of DCCs stem from a lack of communication with and among a patient’s multiple providers. However, there is a difference in opinion regarding whether patients agree or refuse to share their medical history. Here, providers claim most patients do not want to share all their medical information and altered or omitted details of their medical histories. In contrast, patients in Ongwere et al. claim they were willing to share their records freely, but some patients selectively shared their records because they feared judgment by their providers or losing their insurance, and others felt their providers were not interested in certain aspects about their health behaviors. Ongwere et al. also showed patients actively engaged in finding creative strategies to share their records with their multiple healthcare providers. For example, when patients struggle to remember clinical terms and procedures used, some patients carry their medication lists – showing all their treatment histories every time they go to various doctors’ offices. However, our findings show that providers often get frustrated when patients present these long lists of paper records during doctors’ office visits.

5.1.2 Prioritizing DCCs Care Burdens. Effective care of DCCs often requires a patient to prioritize different conditions to set achievable goals. We see a consensus on why prioritization of DCCs care is a challenge and how patients are being asked to do multiple treatment plans which often are conflicting. First, both providers (in our study section 4.3) and patients in Ongwere et al. say healthcare providers’ varying preferences creates conflicts. Providers suggest that patients receive conflicting advice because specialists prioritize different symptoms (i.e. one provider may believe physical symptoms should be prioritized and another may insist that physical problems cannot be fixed until mental problems are addressed). In Ongwere et al. patients reported being overwhelmed when providers prescribed treatment plans without considering
the potential conflicts with prescriptions written by their other providers [43]. Second, providers and patients agree drug interactions complicate prioritization and DCC care. Providers reported in section 4.3 of the study, that drug interactions cause adverse effects in their patients with DCCs, and make patients experience dramatic disease changes and severe symptoms. In Ongwere et al., patients complained about how their medications had a complex regimen, increased chances of overdosing and severe symptoms [43]. The constant changes in patients’ symptoms interfered with providers’ abilities to observe and prioritize treatments for their patients. Further, because of these symptoms, patients are unable to prioritize their care as they should, and others were unable to implement recommended treatment plans. Finally, another challenge to prioritization of DCCs that is mentioned in both studies is constraints within the healthcare system. Providers are time-constrained and some do not get enough time to thoroughly evaluate their patients in one meeting and make informed treatment decisions. The communication among providers is also challenged and it is difficult for them to consult other specialists located in fragmented settings. Just like the providers in Ongwere et al., patients stressed that they struggled in making DCCs treatment choices because i) time-constraints made some providers difficult to reach, some provide even push their patients away, ii) inadequate coordination among healthcare providers introduced confusion on how patients should prioritize the instruction they get from different providers. [43].

5.1.3 Patients Support Network Introduces Complications in the DCC Care Process. First, providers and patients disagree as to whether patients’ support networks provide detrimental information. Section 4.5 shows healthcare providers being critical of how patients use the information they receive from their support network. In contrast, patients in Ongwere et al. believe support networks frequently provided social support, emotional support and other DCC care strategies that were difficult to find elsewhere [43]. Providers assert that the advice patients’ receive from their support networks complicates DCCs care. Providers insist that patients and their support network are not aware that patients with DCCs are not affected in the same way as patients with a single disease. Reports in Ongwere et al. show patients are aware of this difference and often consult multiple support sources before formulating strategies to meet their specific needs [43]. Second, providers and patients disagree as to whether patients’ support networks compromise patients’ willingness to medicate. Our study reports how providers reported that patients refuse to implement a prescribed treatment plan or undergo procedure because of experiences they hear from their support network. Providers believe such information is often discouraging, frustrating and demotivating for patients with DCCs. On the contrary, in Ongwere et al., patients see this information as a useful insight. They want to be told that it is going to be “okay,” but they prefer to know how things may go wrong before they get better. That way when they experience bad reactions or outcomes, the patients are not surprised or in denial. [43].

5.1.4 DCC Treatment Costs are Higher. Finally, providers and patients agree on how the cost of managing DCCs is higher [43]. Providers reported that costs often interfered with providers’ ability to help some patients complete treatment plans. Patients in Ongwere et al. also reported that they were greatly burdened by the costs of their prescribed treatment plans.
5.2 The Design Strategies

5.2.1 Supporting Collaboration Among Providers is Key. In our findings, we report that healthcare providers prescribe varying treatment preferences. The impact of this variance is worsened by inadequate communication and collaboration with and among a patients’ healthcare providers. Such patients receive conflicting treatment plans and become overwhelmed. It is crucial that all decisions made by the patient or any provider be brought to the attention of every member of the DCC care team so that members avoid prescribing treatment plans that conflict or overwhelm a patient. Presently, there is a wide adoption of EHR [51] portals, and emails to exchange information and review patients’ records online [26, 27]. However, systems are often located in different platforms/clinical settings and do not facilitate the sharing of medical records. This lack of true interoperability frustrates effective collaboration across platforms [55] and consequently, the care of DCC patients, who often see specialists using different EHRs [43]; but technology can alleviate these issues by supporting seamless DCC care. Sample designs can allow bidirectional communication and local integration between care providers. In particular, we recommend tools to facilitate networks among multiple providers and reduce overly burdensome requests on patients.

For example, tools that coordinate care and quick responses among providers, such as a tool that is similar to a bidirectional pager. The original request could be programmed to invite a simple “yes” or “no” response. Similarly, the response could be designed to allow another provider to simply confirm or disagree with a course of action. The tools may also allow a responding provider to enter an alternative recommended course of action, if they so desire. These tools could also be designed to identify and flag conflicting or potentially overwhelming treatment recommendations for further consultative evaluation. Some US research medical centers (e.g., the Mayo Clinic and the Cleveland Clinic) are already moving in this direction by calling for in-person collaborative patient monitoring and assessment [11]. These centers frequently organize meetings where clinical specialists, primary doctors, nurses, and patients meet to discuss a patient’s conditions, questions, and treatment plans [11]. Nevertheless, for DCC patients who see specialists located in different clinical or geographical environments, such in-person collaboration will be very costly and difficult to coordinate. Hence designers need to figure out a way to simulate that practice remotely. At this point, we don’t know the solution, but that is what we want to accomplish. We recommend the following design considerations: First, how can we create and coordinate structures that adapt such in-person consultative meetings between healthcare providers and a patient. What is happening in those consultation rooms? What tools do providers use while communicating and consulting with a patient and among other specialists? Could tools be developed to support these interactions? Systems should be built to replicate best practices between specialists doing face-to-face consultation. These systems should also strive to implement these best practices in an asynchronous format. The second consideration involves exploring technologies that emulate and facilitate collaborative practices to resolve conflicts, ambiguities, and continuous disease changes, which are either not addressed or aggravated by the current fragmented US healthcare system. In the case of DCCs, consider the following questions: How might one provider’s interpretation of a patient’s symptoms and other information be made available to others who are addressing different diseases in the same patient? Should these tools consider these differences in providers’ interpretations, or should they adopt a specific format? Is there any scaffolding in place that helps the provider understand things they are not currently able to understand? Further, once a decision is made, how might this information be shared with other providers in the patient’s network? How might we determine whether that decision is critical and requires immediate review, or whether the decision can be reviewed at a later meeting between a provider and patient? If a provider is making the decision, how can we share that decision among providers? Could this decision be confirmed by the other providers? Strategies should be designed to create real-time or near real-time cycles of decision-making. For example, a system might allow an initial provider to make a decision and then assign another provider to evaluate its impact. If the evaluation is negative, the system may allow the evaluating provider to suggest changes or allow the initial provider to reassess and adjust their original decision. Optimally, these real-time or near real-time cycles of decision-making would occur before a patient implements a particular treatment plan.

5.2.2 Supporting a Participatory Decision-making and Prioritization Process. One of the major concerns brought by both patients and providers is patient non-adherence to treatments recommendations. In section 5.1 we show how providers and patients attribute this failure to multiple and often conflicting treatment recommendations, higher costs of managing DCCs and resource constraints in the healthcare system. Providers are trying to push away their patients because of time constraints and we need systems to help stop that practice: for example, systems that streamline doctor’s office visits to reduce time pressure on healthcare providers 3. Systems could be designed to alleviate this pressure on both providers and patients and allow them flexibility to prioritize treatments. There are already tools designed to support people in picking their daily tasks intelligently and spending time on the high-value activities that keep them moving forward [6]. In healthcare, there is a wide adoption of EHRs Web services equipped with risk-prediction algorithms designed to leverage patient-specific data and perform multiple computations to estimate the relative benefits of alternative treatment options [45]. From these, a patient is provided an individualized option. Even with the current use of such tools, prioritizing is still a challenge in, and is further impacted by, continuously changing symptoms [44]. This problem is even worse for DCC patients, whose treatment information is challenging to find in any centralized location, and the unstable nature of their symptoms makes it difficult to achieve accurate predictions because such models are not intended for multiple conditions, especially DCCs. Tools need to be designed to not only help clinicians prioritize, but also incorporate multiple delivery strategies.

For example, tools need to allow patients to choose course of action and implement that action, while identifying which actions should be evaluated by a caretaker or healthcare provider. If an action is flagged for review, caretakers or providers should be able to evaluate the course of action and give recommendations.
Some deliveries could be by physicians, while others by a patient, a caretaker or a patient’s family member. All done together to effectively navigate the daily decisions patients with DCCs have to make. Thus the goal of a provider here is to map standard clinical procedures to a patient’s physical, mental and financial situation, including what motivates a patient. The provider would use that information to make treatment choices that are acceptable, financially considerate, realistic and are aligned with the scope of clinical practice. Further studies are required to explore how social technical tools can be designed to support this process. Further, such systems should include financial considerations in the decision-making process and empower both healthcare providers and patients to navigate through financial constraints. For example, we suggest integrating treatments covered by a patient’s insurance and other treatment alternatives that may work for a patient’s situation. For instance, instead of taking medications or subscribing to a paid service, a tool may suggest a local activity group that a patient may consider joining. Are there some habits that can be adopted without substantial fees? For DCCs, there is a need to make financial implications pertinent to both patients and providers when making treatment plans.

5.2.3 Building Trust is Key in Enhancing Patients’ Information Sharing. As noted earlier, patients selectively share information for fear of judgment by their providers or losing their insurance. [43]. This selectivity frustrates providers. Other studies confirm these challenges [51, 53]. We are still unclear, however, whether this problem can be alleviated by the use of social-technological tools, such as patient information tracking and monitoring tools. If social-technological tools can be used to glean more information from patients, do these systems implicate thematic human-computer interaction concerns, such as the patient’s privacy and information security? Some patient activities have legal implications. Thus, such concerns may be highly pertinent to patients but may not be of great concern to healthcare professionals. Patients resist telling their providers the whole truth, such as the self-medications they are receiving, because they fear consequences. The whole truth may include details of illegal activities [43]. Designers should identify the specific consequences that these patients fear. Tools must be designed to bring into awareness what the law requires the physician to report and what is protected by doctor-to-patient confidentiality [43]. The app must make this explicitly clear and avoid prompting patients to share information that may lead to future consequences. There are additional reasons that dissuade patients from sharing information with their doctors. When doctors complain about their patients not sharing information, as reported by Ongwere et al. and others [51, 53], patients may be trying to be respectful of their doctors’ time or may feel doctors are not interested in knowing the information [43]. If that is the case, an application could help a patient review multiple facts about their condition and determine what needs to be shared with the provider, such as glucose level, body (feet, skin) changes, or daily eating habits. The app can present the provider with a list that allows them to select what they want to address with the patient; but if any other item in the list gets the provider’s attention, they choose to discuss that item as well. To the best of our knowledge, there are not enough tools at present that can prepare both patients and providers for such meetings. Patients can also use the same tool to talk about their goals and limitations, and the worst outcomes they want to address. The platform would make patients’ information available to their providers perhaps in a slightly different view for each specialist. We recommend further exploration on how to best present this information to multiple providers without compromising its meaning and how a patient may lead that process.

5.2.4 Turning a Patient’s Social Support Network into Social Workers is Essential. Although, DCCs patients find their support helpful [22, 42, 43, 56], it is important to note that, DCCs care is highly complex. What works one day may be fatal at a later date and these support networks may not be professionally equipped to notice such alterations. Communicating and managing these changes could be resolved in the the same system suggested by providers in section 4.5 and also in [28, 41, 46](the system in which providers monitor and evaluate the input received from patients’ support networks). However, this system would consume more time from already overburdened providers and these actions could infringe on a patient’s personal space and privacy.

Designers need to explore strategies and design systems to leverage the trust between patients and their support network by turning persons in a patient’s support network (a family member or a caretaker) into a social worker. The application could empower them to monitor a patient, interpret a patient’s treatments, and evaluate what a patient gathers from other persons in a patient’s social and professional network. When a patient meets with their healthcare providers, this family member or caretaker could share the collected information and constructively add to the discussion. We believe that building tools that help a family member or caretaker support a patient, whom they both advocate for and love, is great start toward achieving effective care and support for patients with DCCs.

5.3 Limitations

Through this study, we worked with seven healthcare providers who attend to patients with type-2 diabetes and arthritis and/or depression. For care and support of discordant chronic conditions, there are many other different disease combinations and we did not identify if certain issues are more prevalent with certain disease combinations compared to others. Although the sample size in this study is acceptable due to the challenges of recruiting a large number of providers, further studies interviewing more providers may be beneficial and provide more diverse insight.

6 CONCLUSION

In this study, we discussed healthcare providers’ perspectives on challenges supporting and navigating the care of DCCs. We compared these perspectives with the perspectives of patients with DCCs presented in Ongwere et al. [43]. The providers discussed in more detail what a patient can do to improve both their treatment and their condition. They show that patients who experience severe symptomatic comorbidities often had higher treatment burdens and levels of non-adherence. The inadequate coordination among healthcare providers during goal-setting process also complicates patients’ care. In this paper, we provide provisional design guidelines to address both convergent and divergent issues reported in the two studies. We also highlight, first, the need for
future research to explore technology-mediated ways of influencing healthcare provider expectations for their patients and rectifying the divergence of opinions highlighted in the prior sections. If conflicts do arise, there should be ways to address and deal with them, keeping in mind the logistics required to facilitate that process. A second research opportunity is exploring strategies and models to simplify and better understand how treatment choices for one condition may impact another.

REFERENCES


