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## Creating Conditions for Patients' Values to Emerge in Clinical Conversations: Perspectives of Health Care Team Members

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### Abstract

Eliciting, understanding, and honoring patients' values—the things most important to them in daily life—is a cornerstone of patient-centered care. However, this rarely occurs explicitly as a routine part of clinical practice. This is particularly problematic for individuals with multiple chronic conditions (MCC) because they face difficult choices about how to balance competing demands for self-care in accordance with their values. In this study, we sought to inform the design of interventions to support conversations about patient values between patients with MCC and their health care providers. We conducted a field study that included observations of 21 clinic visits for patients who have MCC, and interviews with 16 care team members involved in those visits. This paper contributes a practice-based account of ways in which providers engage with patient values, and discusses how future work in interactive systems design might extend and enrich these engagements.

### Keywords

Values; multiple chronic conditions; patient-provider communication

### ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous; J.3 Life and Medical Sciences: Health

## INTRODUCTION

There is widespread agreement that delivering high quality patient-centered care means health care providers should understand and honor patient values [19]. Understanding values is especially important in care for individuals with multiple chronic conditions (MCC), such as diabetes, coronary artery disease, osteoarthritis, and depression. These individuals face challenges when the symptoms or treatment of one condition has an adverse impact on the self-care of another condition [3]. Making matters worse, individuals with MCC often disagree with members of their health care team on priorities for self-care and health outcomes [16,31,36], which leads to lower patient satisfaction and poorer health outcomes [29].

Values elicitation is not a routine part of clinical practice [8,20,37]. This is a problem because for patients with MCC and their providers to reach shared priorities for health care, they must communicate about patients' values. In this paper we adopt the definition of values from Friedman et al. [11]: "what a person or group of people consider important in life." Previous research on the incorporation of values in clinical practice has adopted narrower definitions of values. For example, literature on eliciting patients' values examines tradeoffs patients perceive between potential health outcomes [9]. This leaves out other aspects of patients' values that may give important context to patients' health care priorities. There is an opportunity for designers to support patient-provider communication in new ways that help patients and providers reach shared understanding of patients' values, more broadly construed. This support could lead to agreement between patients and providers on priorities for health care and ultimately improve patient health outcomes.

To better support patient-provider communication, we need to understand the circumstances under which providers elicit and honor patients' values. We conducted a field study with 16 members of care teams of patients who had MCC. The field study included observations of clinic visits and follow-up interviews with providers to understand how they understand patients' values and incorporate them into care assessment and planning. We found that care team members sought to understand the extent to which patients' health issues affected the things they valued. We also found that care team members attempted to persuade patients to change behaviors by communicating how health risks threaten patients' values. We uncovered practices by which team members created contexts in which patients could feel comfortable sharing their values, and ways team members negotiated localized practices for eliciting and communicating about patient values. We discuss implications of these findings for the design of interactive systems.

## RELATED WORK

### MCC: A Rich Context for Patient-Provider Communication

Care for patients with MCC provides a rich context for studying how to incorporate patient values into patient-provider communication for two reasons. First, providers find care guidelines difficult to navigate for patients with MCC because care guidelines for one condition may conflict with guidelines for another condition [10]. One proposed solution is to move away from disease-specific guidelines and toward patient-important outcomes [26]. In this kind of approach, providers work with patients to understand patients' goals and limitations and tailor care to those goals, rather than applying disease-specific guidelines without considering interactions among illnesses. Second, care for patients with chronic conditions is commonly performed by an array of different health care professionals [32,33]. Care teams often include a primary care physician (PCP), plus one or more medical assistants, nurses, pharmacists, social workers, and specialists. This means we must attend to potential differences in communication between patients and providers in different roles. It also means we need to understand communication among providers as one factor that could influence communication between patients and providers.

## Related Perspectives on Values

**Values in Design Research**—Le Dantec et al. [22] argued that designers should seek to discover values as phenomena situated in and enacted through particular contexts. While early publications in value-sensitive design (VSD) suggested a set of 12 potentially universal values of ethical import [11], later publications clarified that VSD did not intend to make strong claims regarding the universality of values [5]. More recent work by Houston et al. [18] has adopted the stance of viewing values as local to specific design contexts (as opposed to universal), and not as fixed entities but aspects of practice that are produced and reproduced in action (following theories of practice [27]). In this paper we adopt the perspectives of Le Dantec et al. [22] and Houston et al. [18] to examine how patient values emerge in clinical practice.

**Broadening Clinical Perspectives on Values**—Previous work in health services research has adopted narrow perspectives on values. For instance, Laiteerapong et al. [21] studied values elicitation in terms of patients' preferences among discrete options suggested by healthcare providers in a controlled setting at a single time point. Other studies have aimed to understand how providers elicited patients' concerns during patient visits, but have focused on health outcomes over values more broadly defined (e.g., understanding and treating physical function rather than patient's desire to be able to attend a grandchild's baseball game) [9]. Grant et al. [13] showed that patients want providers to understand their medical and non-medical concerns, but that providers may resist incorporating non-medical concerns in patient care practices.

This prior research in health services potentially hides a range of contexts in which patients' values emerge naturally in conversations with providers, and potentially leaves out aspects of patients' values beyond preferences. There is a need to better understand how care team members understand and incorporate values into health care practices.

## Supporting Patient-Provider Communication Through Interactive Systems Design

Supporting patient-provider communication is an active area of research in the design of interactive systems (e.g., [34,35]). Previous work has approached the problem from several angles. Some research examined and sought to improve remote communication through the use of secure messaging and patient portals [30]. Other studies have assessed the effects of technology on the quality of face-to-face interactions between patients and providers [6,7], and have explored design interventions to improve these interactions, such as providing shared access to health information during conversations [28]. While there has been a steady stream of research in HCI to support patient-provider communication, little work has explicitly examined the degree to which this communication incorporates patients' values.

Our prior work has explored MCC patients' perspectives on communicating with providers about values [23]. Herein, we extend this work by adding providers' perspectives. To enable better care for patients with MCC, we need to understand the circumstances under which care team members can elicit and honor what is important to patients in their daily lives. This understanding can provide insight for the design of interventions to encourage care team members to routinely elicit and honor patient values during patient care.

To address this evidence gap, we posed the following research question: How do care team members of patients with MCC engage with patients' values in the course of clinic visits?

By using the word "engage" in this research question, we remain open to the potential range in practices through which care team members come to understand patients' values (e.g., purposive elicitation, review of previous visit notes), and potential ways that understanding values shapes care team members' practices (e.g., inquiring about patient health concerns, making suggestions for patient self-care.)

## METHOD

We conducted a field study with clinical care team members who care for patients who have MCC. We observed patient-provider interactions during 21 patient visits and interviewed 16 different care team members following those visits. Study procedures received institutional review board approval at Group Health Research Institute.

### Participant Recruitment

Participants fall into two categories: clinical care team members and patients. Care team members included nine PCPs (D1-D9), six medical assistants (MA1-MA6), and one otolaryngology specialist (S1). There were 16 patient participants (P1-P16). We also included 7 informal family caregivers who attended visits with patients (CG3, CG7, CG8, CG9, CG12, CG13, CG16). All participants were recruited from an integrated healthcare system in the Pacific Northwest region of the United States.

We recruited this group of participants through a series of steps designed to ensure voluntary participation from all care team members as well as patient participants. Our first recruiting step was to contact the clinic manager for clinics within the integrated health care system to get permission to conduct observations and interviews in the clinic. After receiving permission, we attempted to enroll all clinic staff members who interact with patients with MCC. Commonly these staff included PCPs, medical assistants, registered nurses, clinical pharmacists, diabetes educators, and social workers.

Next, we identified patients whose PCP was enrolled in the study. We required patients to have diabetes and at least two of the following common chronic conditions: depression, osteoarthritis, and coronary artery disease. We chose these conditions because they are more likely to require self-care than other conditions, and because self-care for these different conditions can conflict. We only enrolled participants who were not receiving help from a professional caregiver. To enroll caregiver participants, for each patient who enrolled we asked if there was anyone they lived with who helped manage their health care, and who attended their visits to the clinic.

### Clinic Visits

The field study was organized around clinic visits for 16 patients. Patients participated in one visit, except for P1 (2 total visits), P4 (2), P6 (3), and P8/CG8 (2). Thus, the total number of visits observed was 21. The visits took place in seven different clinics, all of which were part of the same integrated healthcare system. The clinics provided outpatient

primary care, along with other services such as specialty care (e.g., ophthalmology), pharmacy, radiology, or urgent care.

Each clinic visit included up to three parts, depending on care team members' availability: 1) observation of pre-visit preparation by the PCP, 2) observation of the patient encounter, and 2) semi-structured debrief interviews with clinical care team members who interacted with the patient. To schedule clinic visits we monitored clinic schedules for upcoming visits between enrolled patients and their PCP. When such a visit was scheduled, we contacted the patient (and caregiver, if applicable) to obtain permission to observe the visit. Then we contacted the patient's PCP and any other clinical care team members who were likely to interact with the patient during that visit to get their permission to observe the visit.

If the PCP was available, the observation began when one or two researchers observed the PCP while they prepared for the visit with the patient (part 1). This commonly lasted around 5 minutes while the PCP reviewed the patient's medical record on a computer in the PCP's office. Next, observation of the patient encounter began when the patient was called from the waiting room and continued until the patient left the clinic (part 2). One researcher followed the patient through each part of the encounter. This typically involved observing the rooming process, in which the MA escorted the patient from the waiting area to the exam room, an initial conversation between the patient and MA, and then a conversation between the PCP, patient, and caregiver (if applicable). The length of observations ranged from 30 minutes to 2 hours. The researcher took handwritten field notes to capture actions performed and the content of conversations between patients, caregivers, and care team members. Field notes were typed and expanded following each clinic visit.

Debrief interviews were conducted in person in a private office in the clinic or remotely by phone, depending on care team members' availability (part 3). Wherever possible, interviews were conducted in person, but at times care team members' schedules did not allow it. Also, depending on availability, interviews were conducted with individual care team members or in a group. In practice, interviews never included more than the physician and the medical assistant for the visit. Interviews typically lasted between 15–30 minutes. Interviews followed a semi-structured interview guide to elicit care team members' perspectives on: visit objectives (i.e., patients' concerns, care team members' concerns, how well these concerns were addressed); patient values (i.e., how well the care team member felt that they understood the patient's values, how visit objectives related to patient values); factors that helped or hindered communication about patient values, either during the visit or in general; and communication among care team members. At times interviewers referred back to events observed during the visit to ground the topics of the interview in observed events. Interviews were audio recorded and transcribed verbatim using a professional transcription service. Every participant (patients, caregivers, and care team members) received \$50 for participation in a clinic visit.

## Analysis

Interview transcripts and field notes were analyzed in Dedoose [38]. Two of the authors (AB, CL) analyzed the interview transcripts using thematic analysis [15], which included open coding, focused coding, and writing up themes that emerged in the process of coding.

During open coding, AB and CL read through transcripts and field notes, generated and applied provisional codes, and met regularly to refine the codebook. During focused coding, AB and CL coded the transcripts using the finalized codebook, met regularly to discuss and clarify emerging themes, and wrote up themes for use in the paper. Throughout this process, all authors participated in analysis meetings to discuss emerging codes and themes.

## FINDINGS

We designed the field study to uncover care team members' perspectives on how they engage with patients' values over the course of clinical visits. Here we discuss the four themes that emerged from our analysis of field notes and interview transcripts.

### Judging Impact of Health Concerns on Patient Values

In every visit, we observed PCPs listening to patient concerns and making decisions about how to address those concerns. One factor PCPs considered in making these decisions was how much the patient's health affected things the patient valued. Sometimes even when a patient had not introduced the value on their own during a visit, the PCP asked the patient about their values in order to judge the gravity of patient health concerns.

One example occurred during a conversation between D4 and P1. D4 had been P1's PCP for many years, so she was familiar with P1's values, including her faith: "*Her involvement in her faith, in her church: those are things that are important to her and they definitely drive what she does.*" During the visit P1 said she felt fatigued due to getting up to use the restroom several times at night. D4 sought to understand the extent to which incontinence was affecting P1's life. D4 did this by asking P1 if she had to get up to use the restroom during church. Similarly, when D4 was discussing hearing loss with P1, she asked if P1 had "*trouble hearing [the] pastor.*" D4 drew on her understanding of P1's values to gather information about P1's health concerns and judge the extent to which the concerns were affecting the things P1 valued.

Another example occurred when P4 visited D5 because he was experiencing neck pain. D5 conducted a physical exam of P4's head and neck to determine the nature of the pain. During this exam D5 also asked P4 what he had been doing recently. First D5 asked questions to determine potential sources of the neck pain, such as when the pain began and if P4 remembered doing anything in the days before the pain that might explain it. Then, D5 inquired about whether the pain affected P4's ability to chauffeur his in-laws. In previous conversations D5 had learned that P4 valued supporting his in-laws by helping them get around town. D7 said:

"One of the things I know about him is he does, for instance, do a lot of driving, I believe of his in-laws...so it was on my mind in terms of just his, again, kind of day-to-day lifestyle, so I was trying to take that into consideration of, 'Okay, you know, what—how can we approach this to kind of make sure that he is able to maintain his usual day-to-day life and overall function that way.'"

These examples illustrate how care team members judged the extent to which patient health concerns affected things patients value.

## Communicating Medical Concerns in Terms of Values

During pre-visit observations and post-visit interviews, PCPs often told us they perceived patients' health risks differently than patients did. Sometimes PCPs feared long-term and life-threatening consequences, but expressed that patients did not appear to perceive the gravity of the risk. In these cases, often PCPs believed that action by the patient was warranted, such as monitoring blood sugar and changing diet. PCPs described having difficulty convincing some patients of the importance of taking these actions. One common strategy providers used was to communicate the medical concern in terms of patients' values. By referencing patient values, PCPs aimed to communicate medical concerns in a way that captured patients' attention and convinced them of the seriousness of the risk.

For D3, understanding and referring to her patients' values made her feel more effective as a physician and helped her communicate her own motivations to her patient:

“I feel like I'm definitely a better doctor with them because I know what's important to them and I can use that. Not use it like in a manipulative way, but use it in a way to remind them, ‘Hey, I want to make sure that you're able to go on this trip and see your family and I want to make sure that you're well while you're there so I think we should do this, this, and this to get you ready for that...I know that's important to you and I want to help you and this is how I see I can help you with that.’”

Providers believed that relating patient values to health risks facilitated successful conversations about treatment and self-care. Although some thought that communicating the severity of health risks, such as a heart attack, could convince some patients to better manage self-care, explaining how health risks might threaten a patient's ability to pursue their values was felt to be a more persuasive avenue for getting a patient's attention. This was especially relevant to conditions that may be asymptomatic. In one interview, D7 and MA4 discussed how they sometimes struggled to convince patients of the seriousness of health concerns because the risk seemed “*too remote*” (D7). However, by communicating how the physical symptoms of neuropathy, a complication of diabetes, could worsen and have a direct impact on activities a patient valued, D7 could discuss the consequences of self-care in more concrete terms:

“It's more firepower for me just to get them to do the stuff I want them to do... Check your sugars, that stuff. It's like, ‘Listen, you know the numbness and tingling in your hands? You like to fish, right? So if the diabetes is not under control, it's going to get worse so now it's going to interfere with the fishing.’ Because I can talk about heart attacks and strokes—yeah, it'll scare them a little bit but...It doesn't scare them enough...because it's something remote. It doesn't mean anything now. But if you can get them something that's happening now like, ‘Oh, my feet are really painful because of the neuropathy,’ then we can talk and I have a point of saying, ‘Your blood sugar needs to come down if it's not getting better.’”

The purpose of expressing health concerns in terms of potential impacts on patient values was to motivate patients to change their attitudes and behaviors toward self-care. For

providers, understanding and referring to patient values facilitated more persuasive communication about the seriousness of certain health risks that patients might not perceive to be as concerning.

### Encouraging Patients to Share Values

Care team members used strategies to encourage patients to share things they value. Some PCPs and MAs described how they began interactions with patients with an open floor to invite patients to share anything on their mind.

For example, D5 described his strategy for learning about what's important to patients:

“...trying to start visits with not just going directly into medicine...and, hopefully, that, even subconsciously, for them lets them know that they can...talk with me about things, not just diabetes numbers or things that way. So even if that means that, in the future, they feel more comfortable bringing something up, so try to keep a low key, not just, ‘Okay, we gotta get this done right away,’ type of approach.”

D5 believed that this approach created a context in which patients felt comfortable sharing what was important to them. The excerpt indicates that D5 saw this as a process of building rapport that stretches over time. He acknowledged that sometimes patients may not feel comfortable bringing something up, and that his actions in a given visit could help the patient feel comfortable raising the issue later on. Other providers also acknowledged the temporal dimension to patients' willingness to share. Providers perceived that building trust with a patient over time would encourage the patient to share things important to them that might be difficult to elicit otherwise. For example, D2 learned about one of P10's key values during a visit we observed:

*“...just like hearing him talk about it...it's why I get behind every day, but like the chatting too, I think is really important just because it builds your relationship and then later they do share things easier...it wasn't like I had to drag out of him that he's lived a good life and he's fine dying. Like he—this just comes out, you know? And I think that that comes over time...you don't like specifically ask them, are you okay if you were to die tomorrow? I mean if you do that, that does not go well...I just think it's the caring about them as a person too and not just their disease I think helps with that kinda thing.*

D2 changed her approach to treating P10's diabetes after he shared he was “*fine dying*.” She put him on insulin to keep his blood sugars lower while enabling him to eat the sweets she knew he enjoyed. In this case, D2 understood P10's values regarding the end of his life as well as his values regarding day-to-day management of diabetes. Over time, D2's strategy of caring about the patient as a person allowed her to develop this understanding of the patient's values, and this understanding shaped her approach to caring for the patient. In another example, D3 underscored the importance of strong relationships with patients for understanding what's important to them:

“That's the goal is that you would be able to have a long-term, trusting relationship with a patient where they feel like they can safely share with you. And there's a lot of confidences that are shared in primary care. And we can have a huge impact.



And sometimes the impact isn't even medical. Sometimes the impact is more social.”

Care team members wanted to encourage patients to share values, and they perceived that patients would be more likely to share values if they built strong relationships with them. Because of this, care team members perceived a cost to pushing patients too hard to change attitudes or behaviors toward self-care. Care team members told us about times when they faced a choice between pushing a patient and preserving their relationship with the patient. For example, D1 said she decided not to push P9 to take a medication because she didn't want to risk P9 “*shutting down*.”

“I never order a medicine if they're not gonna take it...I think she even picked it up [last time D2 ordered the medication], but just never took it. So to me that says she's not gonna take it so I don't push her...if they're like, ‘Well, I'm not sure’... maybe then I push more, if I feel like there's an opening...I do think she'll be better off if she can lose weight, so right now I don't think it's an urgent thing. It's not gonna directly affect her life; ten years from now maybe...But, yeah, I just felt like if I would have pushed it, she would have just shut down. So I just kind of brought it up, planted the seed and then I'll bring it up again next time.”

Because of the perceived costs of spoiling relationships with patients—costs that included diminishing the likelihood of the patient sharing values and closing off avenues to potentially persuading patients to change behavior in the future—providers sometimes chose to pursue strong relationships with patients instead of pushing for patients to adhere to medical objectives in the short term.

### Local Practices for Values Communication Within Care Teams

The way care teams communicated with each other about patients' values played a part in how patients' values became incorporated into patient care. In this section we describe how care team members engaged with patient values in the context of a collaborative, team-based environment.

Within each care team, we found that members in different roles usually engaged differently with patients to understand their values. D3 perceived that MA3 was more social with patients than she was as the PCP because the MA's agenda was more open:

*“I think that they [patients] feel more like a visit with the MA is maybe a little bit more social. And so sometimes they will be a little bit more forthcoming because there can be a little bit of chit chat going on while you're getting vitals and just kind of typing a few things in. Whereas usually when the provider comes in, we're like, okay, I already know this is what we're doing today...I've got my agenda. Whereas when the MA goes in, it's more of the open agenda.”*

However, we didn't see a consistent pattern in values-related communication by role. In contrast with D3's explanation of MA4's communication with patients, MA6 lamented that her approach was mechanical and didn't allow for open conversation: *“I feel like sometimes just kind of a robot, a machine...like we're told to do certain things. We have to do them within a minute or two and fit it all in. There's really no room for anything extra, really.”*

These findings suggest that care team members' role is a factor in values communication, but role alone might not explain differences in communication. Members of each care team negotiated their own, localized approaches to values communication. These approaches often involved some form of specialization and division of labor in relation to values communication. For example, MA4 would filter what she learned from each patient and communicate that abbreviated message to D3 based on what she believed the doctor needed to know about the patient. MA3 believed this would help the doctor by communicating key information without requiring the doctor to spend valuable visit time eliciting the information.

Care team members in different roles faced challenges communicating with one another about patients' values. Sharing between team members raised a dilemma. On one hand, the care team member who learned of the information may want to share it with other care team members in order to improve the patient's experience and support other values-oriented practices (e.g., judging seriousness of concerns, communicating risk). On the other hand, care team members didn't want to violate a patient's trust if the patient had thought they were sharing the information in confidence. D2 discussed this in terms of her access to the notes mental health specialists write when they see one of her patients:

“Sometimes I hate that though because they didn't tell me, so I don't always know that they want me to know that...like you get a certain level of trust. And if I know they've shared it with me I'm fine with it, but if it wasn't me...it's hard to know because some of them assume you know. So it's a touchy subject and I guess I feel like when I do read that stuff, I kind of tread lightly and don't say: oh, I know this happened, you know, and see if they bring it up.”

Thus, different care team members used different communication approaches, which elicited information about patients' values to varying degrees. Different care teams developed localized practices for communicating with each other about patients' values. However, patients' expectations regarding information sharing was not always clear to providers.

## DISCUSSION

Our findings represent a novel, practice-based account of ways in which care team members engage with patients' values. The first two themes pertain to ways in which care team members employ knowledge of patient values during patient encounters. The final two themes demonstrate strategies care team members use to develop an understanding of patients' values. This account is a contribution to DIS because it provides a grounded, naturalistic view of an area of concern to designers of interactive systems (e.g., [34,35]): patient-provider communication. The following discussion makes additional contributions to DIS by relating the findings to prior work in interactive systems design and suggesting new avenues for future design.

### Encouraging Communication About Patient Values

In the first two themes we identified two ways in which providers applied knowledge of patient values to personalize patient care: providers judged the extent to which patients' health concerns affected patient values (theme 1), and providers communicated their

concerns for the patient's health in terms of patient values, making those concerns salient for the patient (theme 2). Recent research in health services has called for providers caring for patients with MCC to elicit patient values and incorporate those into patient care. Our findings show that providers do this, but our findings also suggest that providers' views on patients' values may be limited to the utility of values for providers' medically-oriented goals. This may leave out values that providers do not perceive to be directly related to health care concerns. Our prior work [23] suggests that this communication boundary between patients' medical concerns and patients' values is reinforced by patient perceptions of what providers want to know. In that study, patients often did not disclose values freely because patients did not perceive their values to be pertinent to their health care. Thus, patients withheld some values from providers, or discussed those values with other people, such as religious leaders. There is an opportunity for future design to support providers and patients in overcoming this boundary.

**Support for Providers**—Providers seek to understand what's important to patients, but the scope of providers' interest in patient values may be limited. Future design work could encourage providers to dig deeper into the things that matter to patients in their daily lives. One challenge in encouraging this is providers already have limited time with patients [12], so adding additional discussion during visits may take away from other aspects of patient care. Prior work has focused on eliciting patient values before visits with health care providers so patients are primed and prepared to discuss these things during the visit. Lyles et al. [25] designed a tablet-based tool for patients with MCC to use prior to encounters with PCPs. The tool elicited discussion topics from patients in six categories: “new problems/symptoms,” “old problems/symptoms,” “medicines,” “need something from the doctor,” “stress at home or at work,” “a personal concern or other”—and prompted patients to prioritize these topics for the upcoming encounter. Our findings suggest the need to extend tools like this in two ways. First, they could elicit patient values instead of just patient concerns for the visit. Prior work offers some preliminary categories of patient values [4], including principles (e.g., religious faith), relationships (e.g., family), emotions (e.g., sense of accomplishment), activities (e.g., gardening), and possessions (e.g., woodworking tools). More work is needed to validate these categories and test whether including these in elicitation tools would help care team members understand patients' values. Second, designers could explore how and when such instruments should be deployed. For example, our findings showed that care team members specialize in how they engage with patient values. MAs and PCPs may engage with patient values to different degrees depending on the local arrangements of that care team. Therefore, elicitation tools could be designed with multiple care team roles in mind, and could enable care teams to fit such tools into their existing localized arrangements.

**Support for Patients**—Many providers may want to know about patient values, but patients choose not share their values with providers because they do not perceive their values to be pertinent to their health care. Future design work could educate patients about why providers want to understand their values. This could be incorporated into existing patient education programs, such as the Chronic Disease Self-Management Program (CDSMP). CDSMP is a series of group workshops developed by Lorig et al. [24] for

individuals with chronic illness. The workshops are held in medical and community settings (e.g., senior centers, libraries) and cover subjects such as evaluating available treatments and communicating with members of their care team. Our findings suggest that education about communicating with care team members could include reasons why care team members want to know about patients' values.

### **Balancing Trust in Relationships with Communication Among Team Members**

Our findings revealed that care team members may face a dilemma between keeping values information private to respect patient confidentiality and sharing values with other care team members to facilitate the personalization of patient care (theme 3). We did not observe care team members explicitly asking patients if it was okay to pass along things that patients shared, nor did we observe patients stating whether they expected care team members to share what they learned or keep it private. The practices we observed for navigating this dilemma are localized and negotiated on an ad hoc basis. Patients retained little control over how the information they shared was discussed among care team members.

Prior work has examined the relationship between patient privacy concerns and patient willingness to disclose information to health care providers. A recent study showed that patients concerned about the security of health information stored in electronic health records are more likely to withhold health information from their providers [1]. Typically, the storage and portability of data about patients is viewed positively, enabling coordination of patient care across care contexts. For example, it is valuable for instructions that were conveyed to a patient following discharge from the hospital to be visible to the patient's PCP before the patient visits the PCP to follow up on hospital care. However, to our knowledge there has been little to no research on the tension between maintaining trust in dyadic patient-provider relationships and communication among members of a patient's care team. Our findings suggest that patients and care team members may have different expectations about the documentation and sharing of patients' values. More work is needed to understand and develop best practices for establishing patient preferences for documenting and sharing their values, and subsequent work is needed to understand how the design of interactive systems like electronic health records can represent patients' sharing preferences to care team members.

### **Supporting Concordance Despite Different Priorities**

In this section we discuss our findings in relation to recent work by Bagalkot et al. [2] and Grönvall et al. [14] that called for concordance as a design ideal in HCI. Drawing on a report by Horne et al. [17], they defined concordance as "a patient-doctor negotiation process that gives the patients equal importance." In health services, the definition has evolved from concordance as an endpoint (patient and provider having reached shared priorities for care) to concordance as a process (ongoing engagement between patient and provider as equal collaborators) [17]. Concordance emerged in response to models of compliance or adherence (hereafter, adherence), in which the patient's behavior was judged by how well the patient adhered to the plan put forth by the care provider. Advocates of concordance critiqued the adherence model as paternalistic, privileging the provider's perspective and aims over the patient's.

We agree that concordance is a worthy design ideal for supporting patient-provider relationships. Our findings show connections between patient-provider communication about values and patients and providers enacting concordance. Providers recognized that a strong patient-provider relationship is a context in which patients feel comfortable sharing their values. Sometimes providers pulled back from pressing their own medically-oriented goals when those goals conflicted with the patient's values. One first step toward supporting strong relationships despite potentially discordant priorities for health care could be to facilitate communication about patients' values. However, enacting concordance in practice comes with complications. Thorny issues emerge when patients' values are directly at odds with providers' goals. For example, D2 gave up on persuading P10 to stop eating sugary desserts when she learned that he was "okay with dying." Would we expect D2 to engage P10 differently if P10 had been much younger, or much healthier? What does it mean to support a strong patient-provider partnership when the patient's values pose an extreme risk to their health? Future work is needed to explore how to handle these tricky cases when designing interactive systems to support concordance.

### Limitations and Future Work

There are several limitations to this study that suggest the potential for future work. It is possible that participants behaved differently during observations and interviews based on their perception of the purpose of the study. The recruitment methods we used (letters, emails, phone calls) and the consent forms participants signed contained language expressing our goal in this study. We described this goal as seeking to understand how to improve communication between patients and providers about what was important to the well-being and health of patients. We did not explicitly include this language in interview or observation protocols, although several interview questions covered the topic of what was important to patients' well-being and health. We cannot rule out the possibility that the language used in recruitment materials, consent forms, or study protocols shaped participants' behaviors and responses. Future work could examine this possibility in more depth.

We also cannot rule out that patients withheld values during this study in the same ways they reported in [23]. It is possible that our view of patient-provider communication about patients' values was biased by this withholding. Future work could explore this by analyzing differences in the types of values patients share at home [23] versus types of values they share during the clinic visits.

Future work could also systematically explore how patients with MCC communicate about values with different types of health care providers. In the section on "Local Practices for Values Communication Within Care Teams," we shared evidence that patients behaved differently with care team members in different roles (i.e., MA vs. PCP). There is an opportunity to investigate in more depth how patients interact with different roles within care teams, as well as how they interact with providers across different care teams (e.g., ophthalmologists, pain specialists, physical therapists, or psychologists).

We acknowledge the possibility that providers' background and experience caring for patients with MCC could affect how they interact with patients. We did not collect this

information as part of the study design, so it is difficult to comment on how care team members' experience levels influenced our findings. To some degree, the results sections "Encouraging Patients to Share Values" and "Local Practices for Values Communication Within Care Teams" addressed the topic of provider experience. The former addressed how the strength of a provider's relationship with a patient shaped how they surfaced and honored the patient's values. The latter addressed how care team members' level of experience working with each other shaped their local practices with regard to patient values. Future work could explore in more depth how the background and experience of providers shapes how they interact with patients. For example, it is possible that changes in medical education might result in newer providers engaging with patient values differently than providers who have been practicing medicine for longer.

## CONCLUSION

We contribute a grounded, naturalistic account of the practices by which care teams engage with patients' values. These practices include personalizing care in terms of patients' values and creating strong relationships to encourage patients to share values. These findings imply some avenues for encouraging routine communication about values, such as extending values elicitation instruments for providers to elicit a broader range of topics, and educating patients about the ways providers use patients' values to personalize care. These findings also revealed that care team members sometimes face a dilemma between communicating with other team members about patient values and protecting patient privacy. Finally, these findings extend an ongoing conversation in the design community regarding concordance as a design ideal by pointing to some challenges we face in supporting concordance in practice.

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