“It's good to know you're not a stranger every time”: Communication about Values Between Patients with Multiple Chronic Conditions and Healthcare Providers

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When patients’ decisions about health care priorities conflict with those of their health care providers, patients’ health outcomes suffer. Patients’ values for health and well-being influence their healthcare priorities, but recent work suggests that the values discussed in clinical settings do not reflect the full breadth of patients’ values. To address an evidence gap regarding how discussions about values occur in clinical settings, we conducted a field study with patients with multiple chronic conditions and their health care providers, including clinical observations, interviews, and home visits. We report on the extent to which certain categories of patients’ values identified in prior research were discussed in clinic visits. We then discuss how patients and providers coordinated their perspectives to establish connections among patients’ values and health concerns. These findings have implications for the design of systems to support patient-provider communication to incorporate patients’ values and promote concordant priorities for health care.

CCS Concepts: • Human-centered computing → Empirical studies in collaborative and social computing; Computer supported cooperative work • Applied computing → Consumer health; Health care information systems

KEYWORDS: Values; multiple chronic conditions; patient-provider communication

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1 INTRODUCTION

In the United States, one in four adults have two or more chronic conditions [4], and the prevalence of multiple chronic conditions (MCC) increases with age [58]. Health care for individuals with MCC is complex. Health care providers face challenges because clinical care guidelines typically are oriented

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toward single chronic conditions, and guidelines for one condition may conflict with guidelines for other conditions [26]. Individuals with MCC (hereafter, patients) face challenges because self-care for one condition may conflict with self-care or symptoms of another condition [5]. Furthermore, patients potentially face conflicts between symptoms of illness, self-care, and the demands of daily life [50]. Thus, for both patients and providers, health care for MCC can involve making difficult decisions among competing demands.

When patients' and providers' decisions about healthcare priorities do not align, patient experience and health outcomes are worse [51,56,61]. For example, Staiger et al. [51] found that higher patient-provider agreement on diagnosis, diagnostic plan, and treatment plan was associated with improvements in the patient's functional status, health status, and self-reported satisfaction. Furthermore, Zulman et al. [61] found that the probability of concordance in patient and provider priorities was lower when patients had other demands in life they considered more pressing than health, such as financial strain.

Patients' values—what they consider important or meaningful in everyday life [27]—shape decisions they make about their health care priorities [24]. Thus, it is important to support patient-centered communication between patients and providers that incorporates patients' values [33]. Recent work has described patients' [40] and providers' [8] perspectives on communication about patients' values in clinic settings. This previous work is focused mostly on interviews with patients and providers. Because what patients and providers say they do in clinical conversations can differ from what they actually do, there is a need to extend this prior work with observations of patient-provider communication in practice.

Prior work in health services has typically defined patients' values narrowly, such as a patient's preference for treatment chosen from among pre-selected options [25]. This potentially neglects the range of things patients value in their daily lives. Recent work has sought to account for the full range of patients' values in everyday life by developing a patient-centered values framework [7,41]. The framework describes a taxonomy of values based on home interviews with patients with MCC: activities (e.g., gardening, reading), abilities (e.g., mental sharpness, vision), principles (e.g., faith, self-reliance), relationships (e.g., family, friends), emotions (mood and/or embodied feelings, e.g., serenity, joy, or relief from pain), and possessions (e.g., photographs, musical instruments) [7,41]. In this paper, we applied the framework as an analytical tool to assess the extent to which patient-provider communication in clinic settings reflects the full range of patients' values.

We report on a field study with individuals with MCC and members of their health care team. We observed 16 patients and their care team members (N=15) and family caregivers (N=7) during clinic visits and conducted interviews with participants to capture perspectives of those visits. This paper makes two contributions to CSCW. First, we deliver a descriptive account of patient-provider communication through the lens of the values framework. This is valuable because it provides a naturalistic view into patient-provider communication about patient values. Previous work in this area relied primarily on interviews with patients or care team members, leaving a gap of evidence from actual practice [8,40,41]. Second, we characterize the coordination work performed by patients and providers that establishes connections between patients' values and health concerns. This extends prior work in CSCW regarding translation work and operationalization performed by patients [32,36], and perceived communication boundaries between patients and providers [40]. Based on these findings, we offer implications for future research and design to understand and support communication about values between patients with MCC and their healthcare providers.

2 RELATED WORK

2.1 Patient-Provider Communication about Patient Values

A cornerstone of patient-centered care is incorporating patients' values into patient-provider communication and shared decision-making [33]. However, elicitation of patient values is not often part of routine clinical practice [17,37,62]. Scholars in health services have promoted a deliberative model (as opposed to paternalistic or informative models) for patients' and providers' relationships [10,57], and have advocated supporting shared decision-making between patients and health care providers [44]. But, health services research encouraging conversations about values has mostly framed patient values as preferences for discrete options within the context of specific health-related decisions [25]. For example, there has been a large volume of research on values clarification methods (VCMs) to support shared decision-making. VCMs include tools and conversational techniques to help patients clarify preferences with respect to specific decisions, such as listing pros and cons or rating the importance of different factors (e.g., [6,13]). Most values clarification methods may limit discussion to a narrow conception of patient values. For example, Witteman et al. [60] reviewed 98 VCMs and found that most VCMs reviewed were designed for patients to complete independently (59%), provided pre-set options for the patient to consider (61%), and did not encourage an iterative process of values elicitation (91%). Recent work has begun expanding the focus of VCMs to include a broader range of patient values, including "life enjoyment" and "connectedness and legacy" [34,45].

In summary, in health services there is widespread support for incorporating values in patient-provider communication, but prior work in this area has typically adopted a narrow view of patients' values. This view potentially misses the broad range of things patients value in their daily lives.

2.1.1 Utility of a Broader Perspective on Patient Values

Following Friedman et al. [27], we define values as "what a person or group of people consider important in life." We also align with Le Dantec et al. [38] in investigating values as enacted through local contexts, and Houston et al. [31] in recognizing values as produced and reproduced over time. Thus, we treat conversations between patients and providers as specific contexts in which patients may share and withhold values, providers may elicit and consider patient values, and through these interactions, patients' and providers' understanding of patients' values may be reshaped over time.

This definition of values is broader than those adopted in the health services literature reviewed above, and helps understand and support patient-provider communication involving individuals with MCC. A recent stream of research in HCI has shed light on patients' and providers' perspectives toward the function and prevalence of patients' values in patient-provider communication. Patients hold a broad range of values [41], but they often withhold values from providers when they do not perceive them as pertinent to healthcare [40]. One example in that paper described a patient who could not continue working in his woodshop—an activity he had valued for decades—because of fatigue and depression. But, he said when he discussed this with his health care providers, he only mentioned the fatigue and depression, not the woodshop. On the other side, providers say they engage with patients' values for multiple reasons, including querying patients about values to judge the impact of illness on patients' lives, and contextualizing medical concerns in terms of patients' values to motivate patients to acknowledge and address those concerns [8]. However, these previous studies focused mostly on patient and provider self-reports, and lack evidence from clinical conversations to show the extent to which patients and providers discuss the full breadth of patient values. Thus, we posed the following research question: *To what extent does patient-provider communication reflect patients' values in clinical settings*?

2.2 Designing to Support Patient-Provider Communication

Patient-provider communication is a topic of concern in CSCW and related fields [59]. Healthcare technologies are enabling new forms of communication between patients and providers [12]. Patient portals and personal health records have enabled asynchronous communication between patients and care team members [52], and telehealth systems enable synchronous, remote communication [39,53]. There are also technologies geared toward connecting patients' experience of illness in daily life with the medical perspective of providers [1,3,18,46]. There is mixed evidence regarding the potential for technology to support or disrupt in-person communication [15,16,55].

Recent work in CSCW has sought to understand patients' information needs and practices with the purpose of supporting patient-provider communication [14,32,36,47]. Similar work in health services has tested interventions to elicit patients' priorities for specific clinic visits, and revealed that patients wanted these tools to accommodate non-medical priorities and preferences [28,29,42]. This previous work leaves a gap where systems could elicit and promote conversation about patients' values. Some prior work in medical sociology has examined patient-provider communication about topics related to patient values, but approached this communication in relation to specific technologies, like telehealth [49]. In this study, we focused on patient and provider perspectives and conversations about values, instead of investigating practices around specific technologies. This is a strength of our study, as it produced findings and design implications that are general to patients' and providers' perspectives rather than specific to a particular technology.

3 METHODS

We conducted a field study with 16 patients with MCC and their care team members in primary care. We observed patient-provider interactions during one visit for each patient. Some visits included family caregivers. Following each visit, we interviewed patients and care team members. Study procedures were approved by the Institutional Review Board at Kaiser Permanente Washington Health Research Institute. Special considerations were made for working with this patient population, such providing choice in the amount of participation and ensuring voluntary participation without persuasion from providers or caregivers. In addition, researchers were trained in recognition of elder abuse and a protocol for reporting such cases.

3.1 Participant Recruitment

Participants fall into two categories: 1) patients, including optional family caregivers, and 2) clinical care team members. All participants were recruited from an integrated healthcare system in the Pacific Northwest region of the United States. We engaged 16 patient participants (P1-P16) and their care team members, which included nine primary care physicians (PCPs) (PCP1-PCP9) and six medical assistants (MAs) (MA1-MA6). We also allowed each patient participant the option to include one informal family caregiver, who accompanied patients to clinic visits. We included 8 caregivers whose participant numbers correspond to the patient participant numbers (CG3, CG7, CG8, CG9, CG12, CG13, CG15, CG16). Patient demographics are reported in Table 1. We did not collect demographic information from care team members.

We recruited participants through steps designed to ensure voluntary participation from all 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, MAs, registered nurses, clinical pharmacists, diabetes educators, and social workers. We contacted these staff members directly, not through their supervisor, to avoid coercion to participate.

Next, we identified patients whose PCP was enrolled in the study. We initiated the recruitment process by sending a letter to the patient that described the study purpose and procedures. Then we called the patient to invite them to participate in the study. This gave the patient the opportunity to ask questions about the study and determine their level of participation. For example, patients could opt out of the home visit portion of 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 require self-care to achieve optimal health outcomes [5], and care for multiple chronic conditions is often more effectively coordinated than treating each condition in isolation [35]. Additionally, self-care of one condition can conflict with self-care or symptoms associated with another condition. For example, a PCP may encourage a patient to manage diabetes or hypertension by exercising, but a patient who also has osteoarthritis may limit exercise because it is painful. We only enrolled participants who were not receiving help from a professional caregiver at home. From the pool of eligible patients, we purposively sampled to try to match U.S. demographics in terms of sex, education, race and ethnicity.

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.

Table 1. Patient and caregiver demographics

Characteristics	Patient (N=16)	Caregiver (N=8)	All (N=24)
Age			
Mean	69.19	N/A	N/A
Range	50-86		
Gender			
Male	10	3	13
Female	6	5	11
Race and Ethnicity			
White/Caucasian	12	7	19
Black/African American	2	0	2
White and Native American	1	1	2
Hispanic, non-white	1	0	1
Education			
8th grade or less	0	1	1
Some high school	1	0	1
High school graduate or GED	4	0	4
Some college or 2-year degree	5	6	11
4-year college degree	0	1	1
More than 4-year degree	6	0	6

3.2 Procedures

The field study was organized around clinic visits for 16 patients. The visits took place in seven outpatient clinics. Each clinic visit included up to five parts: 1) pre-visit observation of the PCP; 2) pre-visit interview with the patient; 3) observation of the clinic visit; 4) post-visit interview with the patient; and 5) post-visit interview with clinical care team members. Enrolled family caregivers, if applicable, were present at steps 2, 3, and 4. In addition patients and caregivers had the option to take part in a home visit to provide more in-depth detail about their values.

3.2.1 Pre-visit Observation of PCP

When the PCP was available, the observation began when one or two researchers observed the PCP while they prepared for the visit (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.

3.2.2 Pre-visit Interview with Patient and Caregiver

Next, we met the patient (and caregiver, if present) in the waiting area (part 2). We obtained informed consent from the patient and caregiver independently in private conference rooms. As part of this process, we gave participants the opportunity to choose a male or female researcher to observe the visit (part 3), and informed participants they could ask the researcher to suspend the observation for any portion of the visit (e.g., leave the exam room during a physical exam). Patients and caregivers were informed that data collected during the study (e.g., audio recordings, field notes) were considered protected health information, and would be stored anonymously and securely in accordance with the Health Insurance Portability and Accountability Act (HIPAA).

After obtaining informed consent, we conducted pre-visit interviews in a private conference room. These interviews lasted between 5-10 minutes. We asked the patient about the topics they thought were important to discuss during the visit, and how they decided what to discuss.

3.2.3 Observation of Clinic Visit

The observation of the patient-provider encounter began when the patient was called from the waiting room and continued until the patient left the clinic (part 3). One researcher followed the patient through each part of the encounter. This typically involved observing the MA escorting the patient from the waiting area to the exam room, interactions between the patient and MA, and then interactions between the PCP, patient, and caregiver (if applicable). The length of observations ranged from 30 minutes to 2 hours. The researcher took hand-written 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.

3.2.4 Post-visit Interview with Patient and Caregiver

Post-visit interviews with patients (part 4) were conducted by one or two researchers in a private conference room in the clinic after the participant completed the visit. Interviews typically lasted 20-30 minutes and followed a semi-structured interview guide to capture patients' perspectives on the visit (i.e., how well concerns were addressed, whether their agenda differed from the PCP's agenda); and about the values and larger context of daily life for the patient (i.e., how well their providers understand their values, what helps to communicate with providers about values).

3.2.5 Post-visit Interview with Care Team Members

Debrief interviews with care team members (part 5) were conducted in person in a private office in the clinic or remotely by phone, depending on participants' availability. Whenever possible, interviews were conducted in person. Also, depending on availability, interviews were conducted with individual care team members or in a group with the PCP and MA. In practice, interviews never included more than the PCP and MA 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 the patient's values, either during the visit or in general; and communication among care team members.

For interviews with both patients and care team members, interviewers referred 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.

3.2.6 Optional Home Visit with Patient and Caregiver

An optional part of the study for patients was a home visit, which occurred either before or after the clinic visit. The home visits were designed to elicit an understanding of each patient's values in the context of daily life. A detailed account of the procedures for home visits are described in our prior work [7,41]. Each home visit lasted two hours and consisted of a semi-structured interview, aided by photo elicitation, and a home tour. Photo elicitation grounded the interview in events and activities from the patient's everyday life. One to two weeks prior to each home visit, patients received a Polaroid-style camera in the mail with instructions to photograph things that were important or meaningful for their well-being or health. Interviews began with the patient describing each photograph. We used discussion of the photographs to launch discussions about how their values related to their health. The interview guide covered 1) self-care activities, 2) tradeoffs in self-care, and 3) information sharing with caregivers and care team members. Because the home visit was not required to participate in the clinic visits, 11 of the 16 patients also participated in home visits, while 5 opted out (P5, P6, P10, P11, P14). If applicable, a family caregiver was interviewed during the home visit. Audio recordings of interviews were professionally transcribed verbatim.

3.3 Analysis

We adopted a template-based approach [21] to qualitative thematic analysis [11] in which we applied an emerging patient-centered values framework that was developed in prior work [7,41]. This framework offers a preliminary set of six domains that capture a range of patients' values from daily life: activities (e.g., gardening, travel), abilities (e.g., mental sharpness, vision), principles (e.g., religious faith, independence), relationships (e.g., family, community), emotions (e.g., sense of accomplishment, comfort), and possessions (e.g., woodworking tools, photographs). The six domains of the framework are not meant to be mutually exclusive, so patient values might fall across domains. For example, attending church can be interpreted as an activity, but also as the reflection of a principle (religious faith).

We used the value domains as an a priori set of codes (i.e., a template) applied in our thematic analysis. We treated the data corresponding to each patient as a case, which we used as our unit of analysis. Each case included the pre-visit interview, observation notes, post-visit interview with patient, caregiver, and care team members, and transcript from the home visit interviews (when applicable). Analyzing multiple data sources for each case is a form of methods triangulation that boosts the validity and reliability of the findings [19,23,48].

For each case, two authors (AB, CL) developed an understanding of each patient's values by reviewing observation notes and all available interviews with that patient and caregiver. For the 11 cases in which patients participated in the home visit, we used home interviews to supplement the other sources of data (5 patients opted out of the home visit). During this analysis, we used the value domains as a template for identifying the patient's values. This analysis resulted in a set of excerpts for each patient case, with each excerpt labeled with all applicable value domains.

In a secondary analysis, we completed a thematic analysis [30] across the cases to characterize how and under what circumstances patients and care team members discussed or withheld patients' values. This characterization addressed our research question about the extent to which patient-provider communication reflects patients' values in clinical settings. Two authors (AB, CL) participated in coding and analysis of transcripts and field notes. During this process, AB and CL independently conducted open coding over the cases, discussed codes and code definitions, and consolidated and refined codes by consensus. This established a shared codebook. The primary author then re-coded the cases using the established codebook. During this process, the primary author wrote memos to group codes and articulate these as themes. All authors participated in regular meetings to discuss and clarify emerging themes, which included comparing theme definitions with code definitions and excerpts from the data. This approach involved analyst triangulation that helped boost the validity and reliability of the findings [19,23,48].

4 FINDINGS

Below we describe how values from each of the six domains of the patient-centered values framework were discussed during clinic visits (i.e., activities, abilities, principles, relationships, emotions, possessions). Each section corresponds to a single domain, and subsections reflect themes that emerged regarding patient-provider communication about values that fell under that domain. At the end, we report on values that could be categorized under more than one domain of the framework.

4.1 Activities

The values framework defines activities as pursuits, including things people do for work, leisure, or other purposes. In clinic visits, patients and care team members discussed a range of activities, such as volunteering through church (P1), throwing pottery with friends at a local studio (P16), playing pinochle

(P12 and CG12), and cooking (P9). Most discussion we observed centered around valued activities that were impacted or threatened by illness, and activities patients pursued to improve or maintain health.

4.1.1 Valued Activity Affected by Illness

Patients often shared that illness negatively affected activities they valued. One patient, P5, valued his work as a security guard. In one visit between P5, PCP3, and MA3, the discussion centered around how P5's knee pain limited his work as a security guard. The knee pain made it painful to walk, run, and stand for long, and his job required being on his feet for the entire shift. The stated purpose of this visit was a semiannual check-in about diabetes, but most of the visit was devoted to discussing the knee pain. The PCP acknowledged this in the post-visit interview:

> PCP3: "And that's not even an issue that I'm managing, but I think that it's the biggest issue in his life right now, because it's just causing him constant pain and preventing him from doing—from working to his full capacity, doing activities that he wants to be able to do." (post-visit interview)

PCP3 spent time explaining to P5 the notes written by a specialist who had examined P5's knee previously. These notes included the specialist's diagnosis and recommendation to have surgery. PCP3 concurred that P5 should consider having surgery to repair the knee, and as a first step, referred him to have an x-ray to gather more information about the problem.

The challenges of managing MCC were evident in this example. It can take substantial time and effort for providers to understand the breadth of values impacted by illness in patients with MCC. This is not always afforded in the limited time span of typical office visits. The visit between P5 and PCP3 was scheduled for 20 minutes, with the intention of evaluating how well P5 was managing diabetes. But PCP3 and P5 spent most of the visit discussing knee pain disrupting valued activities. A physical therapist was the provider officially in charge of managing the knee pain, but PCP3 chose to address the issue because of the impact on valued activities. Diabetes was covered in the visit, along with a physical exam and care planning related to sleep apnea and chronic obstructive pulmonary disorder. Because of the need to address these multiple issues, the visit lasted more than 40 minutes. Both PCP3 and P5 agreed that they had been able to cover everything they wanted to cover during the visit, suggesting their priorities for the visit were aligned to a sufficient degree, but PCP3 also acknowledged that spending so much time with one patient came at the expense of spending less time with other patients, or caused her to stay late in the office.

In this example from PCP3 and P5, PCP3 was aware of the patient's valued activity and how the patient's ongoing symptoms affected his ability to perform the activity. However, patients did not always share valued activities with their care team. For example, P2 valued spending time with her granddaughter, and there were times when her chronic pain kept her from participating fully in the activities her granddaughter wanted to do (e.g., getting down on the floor to play was difficult). But, P2 did not discuss with PCP6 how chronic pain limited interaction with her granddaughter; she only discussed chronic pain. With another patient, P16, PCP6 recommended that P16 continue gardening to stay active. They did not discuss P16's regular visits to the pottery studio. P16 explained why she discussed some valued activities with providers and not others:

> P16: "Well, because I don't think that's actually part of my health. I mean, I'm here to talk about my problems and my symptoms. And she's busy. I don't like to take too much of her time and I do take a lot of her time, I know." (post-visit interview)

This is one of many instances in which patients mentioned values to us that they did not share with their care team. When patients and providers discussed symptoms such as pain in the context of valued activities, this grounded and focused the discussion. Subsequent care planning could take the valued activity into account, and could be geared toward restoring the patient's ability to engage in that activity without health-related disruptions. In contrast, when they discussed symptoms alone, not in relation to a valued activity, care planning was geared toward eliminating those symptoms in general. We explore the implications of sharing or withholding values in more depth in the discussion section.

4.1.2 Valued Self-Care Activities

Often patients expressed that it was important and meaningful for them to perform activities of self-care. These kinds of activities came up often during discussions with health care providers, and were volunteered by patients as well as elicited by providers. For example, in the home visit and pre-visit interview, P13 expressed that he valued tai chi and chair-based yoga, both of which help him get exercise that is important for managing his health. P13 shared these activities with PCP3 during the clinic visit. PCP3 and P13 were discussing ankle pain P13 was experiencing, and he said he hadn't been able to walk as a form of exercise. CG13 chimed in to encourage P13 to share about tai chi and yoga.

In a similar example, P15 shared that he valued swimming as a form of exercise, since he could no longer run due to foot pain. Through sharing this, P15 found that he and PCP7 both enjoyed swimming. This reveals a potential distinction between activities performed as self-care versus activities performed for their own sake that coincidentally result in self-care. Patients and providers tended not to make this distinction when the patient was engaging in self-care activities of their own volition. This distinction was clearer when a provider wanted to motivate the patient to perform self-care activities that the patient did not already value.

The visit between P9 and PCP2 began with celebration because P9 had managed to walk four times per week every week since the last time she had seen PCP2. They had set this as a goal during the previous visit, and P9 was visibly and audibly proud that she had met the goal. PCP2 celebrated this accomplishment and offered encouragement to continue. PCP2 explained her strategy of setting attainable goals to help the patient feel empowered:

> PCP2: "I think last time she was like, 'No, I'll walk every day.' And I was like, 'Let's come up with a medium that you can for sure make.' So I usually start with, 'I want you to walk, promise me you'll walk out the door for five minutes. That's all you have to do.' You know, because that's a doable goal. Most of the time they go longer because it's like the getting out. And then like four days, not seven. So that they feel successful and come in jumping on top of the world like she was. She was so proud of herself. And I think the more little wins that you can get like that, lets them know that they do have power over what they do and they can make a difference." (post-visit interview)

Later in the visit, P9 mentioned that she had started having pain in her foot. PCP2 examined her foot and found a very painful spot, recommended purchasing walking shoes that provided more support, and raised the possibility of physical therapy if the pain remained. In the post-visit interview, P9 shared that she aspired to go hiking again, and that the pain in her foot had kept her from doing that. She said she hadn't discussed this with PCP2. This resonates with the example at the end of the previous section, and provides further evidence that patients share some valued activities with providers, but withhold others.

4.2 Abilities

The values framework defines abilities as physical or mental capacities or skills. We observed discussion of abilities in many visits, typically in terms of the patient maintaining or losing valued abilities. We also found that patients and providers tended to discuss abilities from different perspectives. Patients often expressed abilities in relation to their identity, but providers did not tend to discuss this aspect of abilities.

4.2.1 Losing Abilities

Many patients looked to the future with concern for abilities they may lose. For example, P12 said:

> "I don't want to lose a leg and I don't really want to lose my eyesight totally. I want to be able to maybe continue to go to [redacted] to travel, which we don't travel very much but the little bit that we do I'm— you know I'd like to be able to continue to do that, and just to be able to go and do things and enjoy life." (post-visit interview)

Eyesight is an ability closely associated with diabetes, and could worsen if blood sugars are not controlled. In contrast, travel is an activity that has a looser connection with a specific illness. For P12, traveling depends on a set of abilities, including eyesight and mobility. She values the activity of traveling, and she also values the abilities on which that activity depends. These abilities could be affected by symptoms and management of multiple chronic conditions. For P12, these included complications of diabetes (retinopathy affecting eyesight), chronic pain in her hips (affecting mobility), and high blood pressure. P12 expressed concern that the beta blocker medication she was prescribed for managing high blood pressure might interfere with her ability to detect low blood sugars. PCP5 was aware that P12 and CG12 enjoy traveling, and he was also attuned to P12's concern about the beta blocker. He checked in with P12 regularly about how she was managing diabetes, and how side effects of medications affected her in her daily life, even when they were away traveling to another state during the summer.

4.2.2 Different Patient and Provider Perspectives on Abilities

In many cases, patients and providers expressed different perspectives on valued abilities. For example, patients often expressed abilities in relation to their identity or self-worth, while providers tended not to make these aspects salient. P7 had her lower leg amputated due to complications of diabetes. Recently, she had changed her eating habits and lost weight, but she had gained the weight back after she started on dialysis for kidney failure. The amputation and weight gain, combined with pain and weakness in her knees, made it very difficult for her to walk. P7 and CG7 discussed her ability to walk as proof of her identity as a self-reliant person:

> P7: It's important to me more as proof to myself that I can do it. I can ride around in this wheelchair for the next 20 years. I don't want to—I want to walk. And I may always have to use a wheelchair for long-distance things but I want there to be that ability to stand up and walk. It's just important. CG7: Yeah. [P7] wants self-reliance. She doesn't want me to do all the things. (post-visit interview)

Most of the visit between P7, CG7, MA1, and PCP1 focused on care planning around helping P7 regain her ability to walk. During post-visit interviews, members of P7's care team acknowledged that her top priority was to be able to walk, but they did not frame this in terms of her desire for self-reliance.

> MA1: "…she's going to get the prosthesis and the shoes and the brace on her knee to help her be more stable so she can start walking…That's what I see as the number one most important thing." (post-visit interview)
> PCP1: "…so mobility is a major challenge. When you have to pee bad or you have diarrhea, the bathroom seems awfully far away. That's the kinda stuff that…affects your quality of life. A lot of times, we're worried about their LDL cholesterols, and they're worried about making the bathroom without peeing their pants. It's a balancing act." (post-visit interview)

MA1 and PCP1 acknowledge that regaining the ability to walk is important to P7, but they did not express this in the same terms P7 and CG7 used. PCP1's statement evinces a generalized perspective on mobility. He references difficulties that might be common to any patient with mobility challenges, but not the particular meaning that mobility has for P7. We report this finding without judgment: it is not necessarily problematic that MA1 and PCP1 adopt this general perspective, particularly since P7 received the medical care she wanted. We explore this further in the discussion.

We observed a similar situation between P8 and PCP7. P8 moved in with her daughter, CG8, after both their husbands passed away. P8 had well-managed diabetes and had recovered from cancer multiple times. However, her back pain made it difficult for her to help her daughter around the house. This challenged her identity as a person who can do most things for herself.

> P8: "It hasn't bothered me for about 4-5 days, and then for some reason today it's really getting me. Some days I can hardly walk. It used to [be] I could vacuum for her. I can't do that anymore. I do that and then I'm on my butt for two or three days." (post-visit interview)
> P8: "Basically, I do everything for myself, like I say, except for the cooking. I can take my own showers. I clothe myself. I wash my clothes. I take care of my bedroom. She [CG8] doesn't have to do any of that for me and I'm thankful for that. I hope I NEVER have to have her, you know, wait on me hand and foot." (home interview)

The first excerpt above comes from the post-visit interview, which occurred several weeks before the home interview. P8 sees herself as independent, but her back pain emerges periodically and limits her ability to vacuum. When this happens, she feels less independent. PCP7 acknowledged that the back pain affects P8's life, and she was aware that CG8 supported P8 by cooking, grocery shopping, and doing other tasks. But, neither PCP7 nor MA4 acknowledged the relationship between P8's back pain, P8's ability to vacuum, and P8's sense of being helpful around the home. Instead, PCP7 prioritized discussing diabetes over the pain because she perceived that the potential long term consequences of diabetes were not salient to P8 in daily life. The following excerpt demonstrates PCP7's reasoning:

> PCP7: "The back pain definitely affects her life, and you can see it when she tells you that, and also with the walker. The diabetes—she does really well with diabetes stuff. She knows she does, too. She's concerned about it but it's probably not...On a day to day basis, she's not seeing the effects of it. So that's probably the more important for me, just in terms of, 'Okay, I'm going to...' We brought her in here for diabetes so that's important for us. For her, it's probably secondary." (post-visit interview)

These examples show that patients and providers discussed patients' valued abilities, but they also show that patients and providers do not always discuss abilities in terms of their meaning for the patient. In post-visit interviews, patients often discussed abilities in terms of their meaning in daily life, while providers usually did not. Still, it is important to note that in these cases, patients' and providers' priorities were aligned to a degree that was sufficient for the patient to receive the health care they sought. It is not necessarily an indication of discordant priorities between patients and providers when they do not discuss the meaning behind valued abilities.

4.3 Principles

The framework defines principles as standards or virtues to live by, including ideals and aspirations. Many visits we observed did not involve discussion of principles. Several participants discussed the value of independence or self-reliance. For example, above we reported how P8 valued being able to do things for herself, like shower and take care of her bedroom. But, when participants like P8 discussed these values, they tended to focus on aspects of those values that would be classified as abilities or activities (e.g., taking care of one's bedroom) rather than principles (e.g., self-reliance).

Other participants shared about values related to faith. P1 said her devotion to God underlies how she thinks through problems and makes decisions, including health-related ones. In the pre-visit interview she said: "I brought all my medicine…And I brought what mind God gave me to answer these questions as best I [can]." In the post-visit interview she said, "I and my Lord thinks about what's important. I tell them what's important to me, and they reinforce what's important to me and what they think that I–that might be important to me that I don't think is important." During the visit, PCP4 referenced P1's faith, and in the post-visit interview PCP4 acknowledged the centrality of faith in P1's life.

Sometimes patients who were frustrated with the care they were receiving expressed or implied principles about how health care should be, but this occurred mostly during post-visit interviews rather than during visits with providers. Furthermore, expressions of frustration about health care do not fit the definition of principles in the framework. For example, one of P6's priorities for her visit with PCP4 was to understand if she needed to continue taking a medication for anxiety. Following the visit, she expressed that health care providers should actively monitor medications and frequently assess whether it was still appropriate to be taking the medication. Patient beliefs like these are relevant to patient-provider communication, but they are not central to our research question about the extent to which in-clinic conversations reflect patient values from everyday life.

4.4 Relationships

The framework defines relationships as connections with others. Most discussions of valued relationships fell into two categories: relationships as sources of support, and relationships as sources of conflict. In some visits, relationships were discussed as a source of conflict. For example, while explaining the importance of knowing the "big picture" of a patient's life, PCP8 revealed two relationships that caused emotional distress for P16.

> PCP8: "[When you know the patient,] you're not flipping back and forth between their problem list and something else that the chart—trying to get the big picture view yourself. You already have the big picture view for the most part…I think when you know patients better you have a better sense of them and what's going on in their life and what their priorities are. And so you're not trying to have that discussion every time. You know that they're stressed because their partner is chronically ill much more so than they are…and that their son is abusing opiate pain medications and living in his car in front of their house. You know that that's going on…" (post-visit interview)

Because care team members recognized relationships as a source of support or distress, they sought to understand when a relationship could undermine a patient's health. In a visit involving PCP3, MA3, P13, and CG13, we observed some conflict between P13 and CG13. For example, when PCP3 and P13 were discussing how he preferred not to walk as a form of exercise because it hurt his ankles, CG13 objected. The following is an excerpt from a field note:

> CG13 stands up and pulls up both of her pant legs to show swollen ankles: "If anyone has swelling of the ankles, it's me, and I never complain. He won't listen. He mentions it every time he comes to the doctor." (observation)

This topic of P13's ankle pain elicited negative reactions from P13 and CG13 at other times during the visit and the post-visit interview. After the visit, PCP3 reflected on their relationship, and the potential implications for P13's health.

> PCP3: "…they're a little bit tricky…I feel like my job is to try and deal with his health, try and keep it healthy and try and kind of bring it back to that. And then I use the mood in the relationship stuff to try and put it in context and say, 'Well, I see this going on. How is that going to impact your management of your diabetes? How is that going to impact your ability to care for yourself when you've got this tremor?' And yet maybe his wife isn't very comfortable with helping him. Maybe eventually he's going to need help with bathing and dressing and…you know what I mean? I think that's when things are really going to get interesting with them is when it requires that level of intimacy and that level of assistance, and then the relationship might not be there." (post-visit interview)

PCP3 told us she had referred the couple to counseling, but they had declined. She had also prescribed medication for P13 that halted angry outbursts he had been having. PCP3 is concerned that the strife in their relationship could cause problems if not addressed, but she also acknowledges her role is limited.

Relationships were also discussed in clinic visits as sources of support for patients with daily needs. While discussing what she knows about P8 in her daily life, PCP7 said, "I know P8 pretty well. P8 lives with her daughter [CG35] who takes very good care of her." Similarly, PCP3 acknowledged the major role that P5's roommate had played in helping him improve his health. PCP3 said when she first started as P5's doctor, P5 was barely willing to carry on a conversation. At the time, P5 suffered from extreme fatigue due to chronic obstructive pulmonary disorder and sleep apnea, which resulted in difficulty staying present in conversations with PCP3. During the visit, P5 and PCP3 explained that their conversations used to be a "tug-of-war." But that changed, and PCP3 attributes the change to support from P5's roommate.

> PCP3: "And I think it was finally his roommate—who is actually his ex-girlfriend but they still live together, and she's very supportive—I think that he finally must have been going home to her and telling her, this doc is bugging me, bugging me, bugging me. And I think she's the one who finally made it happen and got the appointment set up and stuff…And she's really nice, and they have a really funny, interesting relationship together. They're more like siblings." (post-visit interview)

PCP3 recognizes that P5's roommate has been a key source of support over the long term. His roommate played a role in PCP3 and P5 developing a strong partnership that has resulted in improved health for P5.

Relationships were also a common topic during casual conversation between patients and care team members. For example, while D5 was examining a blockage in P4's nose, they discussed vacations they had each taken with family members recently. Similarly, while MA2 was taking P10's blood pressure, she asked, "What are you up to today?" and P10 described his plans to build a bird house with his wife's grandchildren. These casual conversations involved valued relationships, but the purpose of the conversations wasn’t to necessarily to understand how those relationships might affect the patient’s health. Instead, these conversations served to build rapport between patients and providers.

4.5 Emotions

The framework defines emotions as feelings or mood, including states of being that are personal, embodied, and experiential. This definition includes basic emotions such as happiness, and extends to other feelings like serenity, comfort.

We observed several discussions in which patients and providers avoided certain topics because they were emotionally painful for the patient to discuss. These discussions reflected the patient’s valued emotions. One example comes from a visit we observed between P11 and PCP2. In general, P11 avoids discussing her weight because she associates the topic with emotional abuse from a family member during her childhood. In the post-visit interview, P11 told us, “I basically take the stance of, ‘whatever I can do that doesn’t poke those feelings.’” The following excerpt from a field note shows how P11 and PCP2 discussed this topic in the visit:

> PCP2 says, “Now, the one thing I saw” was your “weight jumped up 8 pounds. Can you think of anything that changed?” P11 says no. PCP2 asks, “Do you feel like you’re ready to make any changes?” P11 says her weight has been a “raging battle for 50 years.” P11 tears up and the corners of her mouth droop. She takes a Kleenex from the table next to her and wipes her eyes. P11 says, “I feel like I’m doing well if I’m filling the fridge with salad and not ice cream.” PCP2 says she’s fine with keeping that up for now, “that’s good.” She also says to let her know “in the future, if you want to try something new.” (field note)

Following the visit, P11 reflected on this discussion. Even though the topic came up during the visit, P11 was grateful for how PCP2 handled it:

> P11: “I really respect [PCP2]’s—I hope you saw her technique with that; it's really good…It feels very safe to have things come up when I'm working with her…the empathy is right there. And she remembers that it's an issue from past appointments I've had with her. And she never tries to push…It seems obvious, you do this number one thing, you know, ‘Why can't you just do that?’ She never does that.”(post-visit interview)

These excerpts demonstrate how important it is for P11 to avoid discussing her weight because of the emotional difficulty of the topic. P11 deeply appreciates that PCP2 helps her feel safe when talking about weight. PCP2’s skill in handling the topic creates opportunities to address it while also accommodating P11’s preference to avoid it whenever possible. Acknowledging the value of this relationship with PCP2, P11 said, “When you see somebody over a long period of time, it's good to know you're not a stranger every time. You don’t have to keep filling in the whole story…that’s been important to me.”

Notably, the emotions domain includes cases such as relief from pain, which has a strong physical component. The aspect of relief from physical pain that classifies this as a valued emotion is the way patients with chronic pain yearned for freedom from the pervasive, persistent nature of their pain. In clinic visits, patients and care team members often discussed the values of comfort and relief. For example, P10 had been experiencing discomfort in his abdomen due to constipation, and this was a primary topic of conversation during the visit with PCP2. When P10 talked about this after the visit, he alluded to abdominal comfort, and referenced back pain and discomfort riding in the car. This excerpt shows that P10’s value of comfort is related to other aspects of his life, such as the ability to travel, and his relationship with his wife:

> P10: “Well, comfort—make sure all of your fluids and everything is going…everything flowing and everything's happy and the birds are singing—all that. I don't want to hobble around or, "Oh, my back hurts." I don't want to do that. There's a lot of things I won't do with my wife because I don't want to take time out to do it. I know she gets disappointed but I just don't feel like doing those things...Just different shows that she wants to go to see. Trips she wants to go on that I don't like the discomfort of riding in a car.” (post-visit interview)

There appears to be more to this story than just the desire for comfort, particularly because P10 says he doesn't want to take time out to do some of the things his wife wants to do. Still, there is a strong current throughout that suggests P10 places high importance on feeling comfortable. At one point he put it plainly, "I make life worthwhile as long as I'm comfortable." (post-visit interview)

We witnessed a difference in healthcare priorities between P10 and PCP2 in this visit. PCP2 attempted to focus on diabetes, asking whether P10 had been cutting back on eating sweets as he had promised. PCP2 was in the process of explaining that P10 might need to start injecting insulin daily if he did not change his diet when P10 redirected the conversation from diabetes to constipation. This redirection reflected his priority of addressing physical comfort above addressing his blood sugar levels.

In the home visit, P2 told us a perfect day would be if she could be free from pain. In the visit we observed, P2's discussion with PCP6 focused mostly on her extreme back pain. In the post-visit interview, P2 told us her mobility was limited (ability) because of the pain, and this kept her from doing activities she enjoyed, such as gardening with her granddaughter or going foraging for mushrooms. D6 acknowledged that P2 was experiencing extreme pain, and she acknowledged that pain can affect P2's quality of life. However, PCP6 did not reference specific activities P2 valued.

> PCP6: "I think back pain is probably more important than we give credit to. From my perspective, as her family doctor, I'm more concerned about her weight and blood pressure, cardiac risk, and lots of other things that I worry about being life-shortening or causing serious disability. But I think it's important for me to keep in mind that if she's in pain, that that's really affecting the quality of her life. So, I was really surprised to hear that her pain was 10 out of 10. That's—I mean, that's horrible pain." (post-visit interview)

This suggests that PCP6 was more attuned to P2's desire for relief from pain—a value that would be categorized as an emotion—than activities and abilities that P2 experienced as related to her pain in daily life. This excerpt echoes an earlier point about the degree to which providers consider underlying values patients might hold that give context to their desire to discuss symptoms or functional abilities. We acknowledge that providers are listening to their patients, appreciating patients' priorities for care, and recognize the relationship between symptoms and general well-being—even if in observations or interviews, providers don't mention a specific underlying value.

4.6 Possessions

The framework defines possessions as tangible things kept, owned, or cherished. Participants did not discuss valued possessions in any of the visits we observed. Participants did reference valued possessions during home visits. For example, P12 and P8 both valued their iPads because they liked to play games on them, and P16 valued her computer because it enabled her to go on Etsy and Pinterest to get ideas for gardening, sewing, and pottery projects.

4.7 Values Reflecting Multiple Domains

We used the domains of the values framework as an analytical tool to understand the extent to which patients and care team members discussed patients' values. In the previous six sections, we reported on patterns in the ways values from each of the domains were discussed. However, discussion about a given value often reflected multiple domains of the framework. For example, patients and providers often discussed values that could be classified as both abilities and activities. P5 had lost the ability to run, and this limited his ability to engage in activities he valued, such as working as a security guard. As mentioned in the activities section, P5 and PCP3 discussed the effect that knee pain had on his work as a security guard. In the post-visit interview, P5 discussed the devastating effect diabetes and chronic pain had on abilities and activities he valued:

> P5: "So that's when I went to the doctor and found out I had diabetes. And that killed my whole world, right there. I said, 'I ain't gonna be able to do stuff anymore. Won't be able to play basketball anymore.' So I sleep a lot…this is not me. Me is getting out, having fun…Going out, playing darts, and everything else. I just stopped. And right now, the diabetes ain't doing it no more…right now it's my knees. So it's

> a new joy, you could say, a new chapter in my book. I don't let that get to me. I weather the storm, and I keep going. At work, even though I can't run, I make do..."(post-visit interview)

P5 lamented the effects his illnesses have had on his physical capabilities, and misses the activities he had to give up as a result. Similarly, patients often discussed values that reflected abilities and principles. In the abilities section, we reported on P7's desire to regain the ability to walk. There were plenty of practical reasons for this desire, such as using the bathroom by herself, but one main reason she valued this ability was because she valued the principle of self-reliance.

That values can be placed into multiple domains is not surprising on its own. But, the value domains are useful tools for examining the facets that patients and providers do and do not discuss. For example, in the emotions section we discussed how P2 desired relief from extreme back pain. She discussed the pain with PCP6, but while she associated this pain with the loss of mobility (abilities) and the inability to forage for mushrooms (activities), she did not discuss these aspects with her doctor. Using the domains to examine multiple facets of values can generate insights that have significance for supporting patient-provider communication. We explore this further in the discussion.

5 DISCUSSION

We used the patient-centered values framework as an analytical tool to judge the extent to which patient-provider conversations during clinic visits reflected the breadth of patients' values. We report on the content of these conversations through the lens of each domain, which surfaced patterns in the way values associated with each domain were discussed. We also discussed how patient values can reflect multiple domains of the framework. These findings are a contribution to CSCW because they provide a naturalistic account of the values patients and providers do and do not discuss, as well as the way values from different categories are discussed. Previous work reported on interviews with patients [40] and providers [8] about their perspectives toward discussing values in clinical settings. The present work fills a gap left by this prior work by presenting evidence from actual clinical conversations. In the subsections that follow, we characterize the inherently cooperative work patients and providers engaged in to coordinate their distinct perspectives and establish connections between patients' values and health concerns. We relate this coordination work to prior research in computing, health services, and medical sociology. We also propose directions for future research and design to support patient-provider communication about values.

5.1 Coordinating Perspectives to Connect Values and Health Concerns

One common thread across the findings was the work patients and providers do to coordinate their different perspectives. This coordination work was often geared toward connecting things patients value in daily life with the health concerns raised by the patient or the provider. The following discussion examines this coordination in more depth.

Prior work has demonstrated that patients and providers bring different perspectives to their conversations [2]. For example, from the medical sociology literature, Toombs [54] discussed how the patient's perspective is shaped by the "qualitative immediacy" of illness, whereas the provider's goals are largely shaped by scientific concepts from the biomedical tradition. Patients are enmeshed in the work required to self-manage chronic illness in daily life, as documented by Corbin and Strauss [20], and their values might influence, or be influenced by, their health care concerns. Providers have medical training and can diagnose symptoms, judge medical risk, and prescribe treatment. They see many patients each day as part of a highly-structured system of care.

Our findings extend this prior work by demonstrating conditions under which the breadth of patient's personal values is represented in patient-provider communication. In conversations we observed, patients and providers often coordinated their distinct perspectives in ways that connected patients' values with patients' health issues. In one representative example, at the beginning of the visit between PCP2 and P9, P9 erupted with excitement because she had met her goal to walk four times per week (an activity she said she valued). PCP2 matched P9's energy with congratulations. Later in the visit, P9 shared that her foot had been hurting while walking, and PCP2 suggested wearing shoes with added support. P9 did not share that the foot pain had lasted years, and was keeping her from going hiking (another valued activity). Together, PCP2 and P9 connected the activity of walking with foot pain and the need for new shoes; they did not discuss the connection between foot pain and hiking.

Connections between the patient's health concerns and values can be left incomplete when patients withhold values (e.g., filter values perceived to be impertinent [40]) or when providers don't elicit multiple facets of values (e.g., ability, but not activity). These processes through which patients share or withhold values, and providers elicit or don't elicit values, are contexts in which designers could promote communication that connects values and health concerns.

However, it is a tall task to create technologies that mediate between patients and providers in the exam room without doing more harm than good. Instead, it may be prudent to explore ways to facilitate elicitation of and communication about values outside of clinic visits. To accomplish this, designers may find it useful to draw on Mol's [43] distinction between the "logic of choice" and the "logic of care". In the logic of choice, decisions are made in discrete, bounded episodes in which the provider gives the patient value-free facts, and the patient considers these facts and decides on the best course of action for them based on their values. In the logic of care, decisions are made continuously over time through a process of tinkering and aligning the patient's bodily experience of illness, daily practices, and medical treatments.

In attempts to elicit the full breadth of patient values and to associate these values with patient health concerns, designers may consider how technologies could facilitate the patient's and provider's participation in an ongoing process of understanding patient values, and align these values with the competing demands of MCC. This type of intervention could make use of technologies such as secure messaging in personal health records (PHRs). Prior work by Sun et al. [52] found 11 topics that patients discuss with providers over secure messaging, including medications, appointments, lab tests, and emotional needs. To our knowledge, prior work has not specifically sought to use these technologies to facilitate communication about patient values. For example, PHRs might enable patients to show values from daily life rather than articulate them during clinic visits. This might include patients sharing photos of valued family members or videos of valued activities. Providers could review values shared by patients and prepare to discuss them with patients when they visit the clinic.

5.1.1 Supporting Translation and Operationalization of Patient Values

Examining the facets of values that patients shared or withheld reveals a kind of translation work performed by patients. Previous work in CSCW and related venues has explored translation work performed by patients. For example, Kaziunas et al. [36] described how individuals with chronic illness living in Flint, Michigan reframed recommendations they received from healthcare providers to fit with the local, social contexts in which they carried out chronic illness self-management. Kaziunas et al. framed this as translation work. In the present study, we saw patients performing similar work, but in the opposite direction: translating values from everyday life in ways they perceived as relevant to conversations with their healthcare providers.

The translation work we observed resonates with work reported by Huh et al. [32], in which individuals with diabetes operationalized personal, often tacit knowledge such that it could be shared meaningfully with other individuals who had diabetes. In our study, we witnessed patients operationalizing their values in ways they perceived to be relevant for providers. For example, P16 explained why she shared some valued activities (gardening, water aerobics) but not others (pottery): "I'm here to talk about my problems and my symptoms. And she's busy." P16 wanted to make good use of the time she had with PCP6, so she only shared values as they pertained directly to her health concerns. Previous research reported that in interviews, patients said they filter and withhold values from healthcare providers [40]. Our findings extend this work with evidence from actual clinical conversations.

An implication for design is to support patients in making decisions about what to share and what to withhold. Patients may lack knowledge of what providers want or need to know about their values.

Lacking this knowledge, patients' decisions about what to share may not be well-informed. Future work could explore how to communicate to patients how providers use their values, enabling patients to make better-informed decisions about what to share. Furthermore, systems should not infringe on patients' autonomy to make these decisions. It should remain the patient's prerogative to decide what to share and what to withhold. There is an opportunity to help patients develop a more informed perspective on how sharing values with providers can help them address their health concerns without forcing patients to share values they prefer to keep private.

5.1.2 Supporting Adequate Understanding of Patients' Values

Our findings show that providers understand patients' values to varying degrees. In many cases, providers had rich knowledge of patients as individuals. PCP8 knew that P16's husband (CG16) was chronically ill, and that one of P16's sons was abusing opiate medications and living in a car in front of her house. PCP2 knew that P11 had experienced emotional abuse as a child regarding her weight, and knew to avoid the topic or broach it carefully. PCP4 knew P1 was very religious, and even knew P1's pastor. When providers had developed this level of understanding, this enabled them to make decisions about patients' health care that wouldn't be possible otherwise.

There were also many cases in which providers understood patient values in general terms. For example, PCP1 and MA1 understood P7's value of regaining the ability to walk, and worked with P7 to understand her physical capabilities and agree on the right kind of knee brace to order. However, PCP1 and MA1 spoke in generalities about the challenges of limited mobility, and did not speak explicitly about the association P7 perceived between mobility and self-reliance (valued principle). This general level of understanding isn't necessarily problematic. P7 received the medical care she wanted. But, this raises questions about the degree of understanding required to accomplish shared priorities for health care.

Previous work suggests that when providers do not understand patients' values, this can lead to discordant priorities for health care, and discordant priorities can lead to poorer patient experience and worse health outcomes [51,56,61]. Our findings suggest that deep, intimate understanding of patients' values can improve the patient-provider relationship, but they also reveal a middle ground in which a general understanding of patients' values will suffice. Based on our findings that some values cross domains, and that values expressed by patients can be multi-faceted, future design work might explore how the domains of the values framework could be useful as tools for eliciting values in a richer, more rounded manner. For example, recall that P2 discussed extreme back pain with PCP6, but they did not discuss that P2 wanted to address the pain so she could go mushroom hunting and work in the garden with her granddaughter. A system could help PCP6 identify that back pain might be associated with a valued emotion, recognize that there may be other facets to this value, and ask directed questions based on the domains to understand if the pain affected valued activities.

5.2 Limitations and Future Work

Based on our findings, we saw values functioning in two ways, but our study design might deemphasize one of those functions. First, values were exchanged and referenced to help establish goals for patient care and monitor progress. This was observable in single visits. Second, sharing and acknowledging values appeared to foster and reinforce patient-provider relationships by building trust and rapport. However, observing single visits does not give a good view into how these relationships develop over a long period of time. All our patients had met with their providers in the past and some had developed relationships over multiple decades. Recent work showed that strong patient-provider relationships create contexts in which patients' values continue to emerge over time [8]. Dang et al. [22] recently completed a longitudinal study examining the experiences of newly diagnosed HIV patients as they developed relationships with new health care providers. They reported five actions providers took that helped build patient trust, which included asking patients about treatment goals and preferences. However, there has not been sufficient work to examine the role of patient values in trust and rapport building over time. Future work could take this on.

Our view of 5 patients in this study was limited by their decision not to participate in the home visit (P5, P6, P10, P11, P14). We did observe how their values emerged in clinical conversations, and we probed on their values in post-visit interviews, but being able to interview these patients in home settings would have provided a fuller picture.

6 Conclusion

When patients' decisions about health care priorities conflict with those of their health care providers, patients' health outcomes suffer. We conducted a field study to understand the extent to which communication between patients with MCC discuss their values with health care providers. We analyzed field notes and interview transcripts through the lens of the six domains of a patient-centered values framework, and discussed patterns that emerged within and across domains. These findings reveal the key process by which patients and providers coordinate their distinct perspectives and establish connections between patients' values and health concerns. Based on these findings, we discussed implications for future design and research.

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