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Designing to Account for Patients' Personal Values  
in Collaborative Care for Multiple Chronic Conditions

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**Abstract**

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In this dissertation I reexamine the nature of human values and the relationship between values and design by reporting on the VITAL project—Valuing Important Things in Active Lives. This project aimed to improve health care for people with multiple chronic conditions (MCC) by facilitating shared understanding between patients and their healthcare providers about patients' personal values. Personal values may be anything a person with MCC considers important for their well-being and health: abilities (e.g., mobility, mental sharpness), activities (e.g., gardening, walking the dogs, exercising), emotions (e.g., serenity, joy, relief), possessions (e.g., photographs, a home, a car), principles (e.g., independence, faith, honesty), and relationships with family, friends, co-workers, or others.

To understand opportunities for designers to support shared understanding of patients' personal values, I examined the collaborative practices involved in MCC care. I focused on the

practices of three key actors: 1) people with MCC, 2) informal caregivers (i.e., anyone who helps the patient care for their health, including the patient's spouse, family members, or close friends), and 3) healthcare providers (e.g., primary care physicians, medical assistants, and registered nurses). Through a series of field studies and co-design activities involving these actors, I discovered how patients' personal values shaped collaborative MCC care practices and identified barriers that hindered shared understanding of patients' personal values. This has generated foundational, intermediate-level design knowledge that clarifies how products, services, and systems could be designed to address these barriers.

Reflecting on these findings also provided an opportunity to rework and extend scholarship on the nature of human values and the relationship between values and design. I discuss the utility of the concept of personal values in the VITAL project, introduce the theoretical perspective of designing for moral action, and discuss how this perspective can be useful for guiding future research and design efforts.

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# **DEDICATION**

For Grandma Berry

# Chapter 1. THE NEED TO ACCOUNT FOR VALUES IN MCC CARE

## 1.1 INTRODUCTION

Design is a value-laden activity [87]. Designers may consider values during the design process, and the resulting products may express, embed, or otherwise privilege certain values over others [60,64,101,141]. In scholarship at the intersection of design and computing there has been great interest in accounting for human values deliberately during the design process [64]. Discussion continues regarding the nature of values and the ways in which values can or should be incorporated in design processes (c.f., [64,87,101]). In this dissertation, I will reexamine the relationship between values and design by reporting on a project to improve health care for people with multiple chronic conditions (MCC). The project, Valuing Important Things in Active Lives (VITAL), aimed to promote shared understanding between people with MCC and their healthcare providers about patients' values.

VITAL was motivated by a key problem in MCC care: discordance. Discordance occurs when patients' and providers' priorities for health care do not align [153], and it is associated with worse health outcomes for patients [145]. One factor contributing to discordance is when providers do not understand what patients consider important for their well-being and health (i.e., patients' personal values<sup>1</sup>). In order to better position patients and providers to reach concordance in priorities, there is a need to facilitate shared understanding between patients and providers about patients' personal values.

To better understand barriers and opportunities for facilitating shared understanding of personal values, I examined the collaborative practices involved in MCC care and the extent to which these practices accounted for patients' personal values. I focused on three important actors in MCC care: 1) people with MCC, 2) informal caregivers<sup>2</sup>, and 3) healthcare providers<sup>3</sup>. Through

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<sup>1</sup> Personal values include anything a person considers important or meaningful for their well-being and health [16,106]. The breadth of personal values includes activities, abilities, emotions, principles, possessions, and relationships. This definition was developed through field work with people with MCC and reflects their perspectives. Chapter 2 explains this definition and its origins in more depth.

<sup>2</sup> Following Miller et al. [116], we define an *informal caregiver* (hereafter, caregiver) as any person who helps a patient with some aspect of their care, such as the patient's spouse, child, or close friend. This definition excludes paid professional caregivers.

<sup>3</sup> I'll use the term healthcare providers (hereafter, providers) primarily to mean members of a patient's primary care team, including physicians, medical assistants, and nurses.

a series of field studies engaging patients, caregivers, and providers, I discovered how patients' personal values shaped collaborative MCC care practices and identified important barriers that hinder shared understanding between patients and providers about patients' personal values. These findings have brought new clarity to how products, services, and systems could be designed to facilitate shared understanding of patients' personal values.

Taking a step back, these findings rework and extend scholarship on nature of human values and the relationship between values and design. Across different forms of engagement with patients, caregivers, and providers, my understanding of patients' personal values has shifted, along with my understanding of the opportunities and limitations for designers seeking to engage with values in the design process.

The remainder of this chapter introduces key related research to elaborate the importance of improving MCC care, how MCC care is practiced today, and why discordant priorities pose a problem for MCC care. Later, I outline the research questions and methods I have used to address this problem and preview the contributions of the chapters to come.

## 1.2 DISCORDANT PRIORITIES IN MCC CARE

### 1.2.1 *Importance of improving care for MCC*

Warshaw et al. [159] defined chronic health conditions as “conditions that last a year or more and require ongoing medical attention and/or limit activities of daily living.” I focus on people with diabetes, plus at least two more of the common chronic conditions requiring self-management: hypertension, depression, and osteoarthritis.

Improving care for MCC is important because of the prevalence of MCC in the United States and worldwide, the high cost of MCC care, and the medical complications possible if these chronic conditions are not managed carefully. Currently, spending on MCC care accounts for 65% of all health care spending in the United States [8]. The population of people with MCC is large and growing. In the United States, one in four adults have MCC, including two in three adults over age 65 [8,32,161]. Furthermore, this population continues to grow. People are living longer and the incidence of chronic conditions rises with age [135]. In the United States, a large number of people from the “Baby Boomer” generation are reaching ages at which MCC are more prevalent [19].

And, younger people are experiencing multiple chronic conditions at a higher rate than people from older generations at their age [135].

### 1.2.2 *Living with and managing multiple chronic conditions*

People with chronic conditions can experience medical complications if they are not able to manage their conditions carefully. For example, common complications resulting from diabetes are neuropathy (numbness and pain in the extremities), retinopathy (which can lead to loss of vision), and stroke [55]. Health care for chronic conditions typically focuses on avoiding or delaying complications [19–21], and much of this care falls to patients in the form of self-management activities. Self-management is a core component of care for people with MCC. It can include changing diet and eating habits, exercising, taking medications, and monitoring measures such as blood glucose levels or blood pressure [20,21,42,110]. Self-management support aims to engage and empower individuals to be active problem-solvers, working toward improved health outcomes [21].

Building on previous studies looking at single chronic conditions [31,100,142,160], Bayliss et al. [12] investigated barriers to self-management faced by individuals with multiple conditions. Bayliss et al. [ibid] found three common barriers: 1) symptoms from one condition, or from managing one condition, disrupted management for another condition; 2) taking medications to treat one condition made symptoms of another condition worse; and 3) a single dominant condition can impede care for other conditions. A similar study [88] identified additional challenges, which included other chronic behavioral conditions (e.g., depression, obesity), difficulty with general physical function (i.e., fatigue, pain, ability to exercise), social factors (e.g., communication with physician, family support), and finances. A recent review corroborated these barriers, and highlights that patients' perspectives on self-management don't tend to focus on individual chronic conditions, but on functional challenges across conditions [105].

### 1.2.3 *Collaborative Care model*

Not all care for chronic conditions is carried out by patients individually in the form of self-management activities. The Collaborative Care model establishes a standard for patients and healthcare providers to manage chronic illness together [154]. In this model the patient and their

providers define and target specific health-related problems together, with support from caregivers. As the patient's health and life circumstances change over time, these actors work together to adapt health care accordingly. Since chronic conditions cannot be cured, this work continues for the rest of the patient's life.

In this model, patients bear most of the responsibility for MCC care in daily life. Care for chronic conditions in general requires ongoing self-management<sup>4</sup> to avoid complications [19–21]. Self-management falls into three categories [42,44]: illness work, everyday life work, and biographical work. Illness work involves activities like taking medications, monitoring blood sugar, and exercising; everyday life work involves activities like holding down a job, raising children, spending time with a spouse; and biographical work involves coping with changes in one's life and identity due to illness. Often informal caregivers support this self-management [42,43]. Depending on patients' needs, caregivers might help with activities such as dressing, eating, and finances, and provide emotional support [137].

As part of the Collaborative Care model, patients meet regularly with providers to assess the patient's health and adjust care practices as needed. These meetings typically involve 1) collaborative problem definition, 2) targeting specific problems, and 3) planning care. In collaborative problem definition, patients and providers discuss and define health-related problems. For example, a provider may identify that a patient is not following a previous plan of care, or a patient may raise fears about potential complications of illness looming in the future [154]. If multiple problems are defined, patients and providers select specific problems to target. This can involve focusing on one problem, potentially prioritizing some problems over others. After targeting problems, patients and providers set realistic goals and plan actions for pursuing them. Part of the process of setting goals and planning care involves assessing the patient's readiness to carry out self-management activities associated with the problem(s) selected. The provider is also charged with giving self-management support, cultivating the patient's ability to carry out self-management activities and to address medical and emotional needs in daily life. While patients carry out self-management in daily life, providers actively follow up with the

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<sup>4</sup> I use the term self-management, but I acknowledge there is inconsistency regarding the definition of self-management and related terms (e.g., self-care, c.f., [19,110,133]). Wherever possible, I ground our discussion in the activities themselves instead of referring to self-management or self-care.

patient over time. Part of this follow-up involves identifying emerging complications so they can be addressed and checking on and reinforcing the patient's progress toward goals.

#### 1.2.4 *Competing demands of MCC cause collaborative care to break down*

Despite evidence of its benefits, the Collaborative Care model breaks down for people with MCC. As introduced in section 1.2.2, one of the hallmarks of MCC is the presence of competing demands. People with MCC face competing demands when there are tensions or conflicts among self-management activities, symptoms, and other pursuits of daily life. For example, consider the self-management and symptoms involved for a patient with diabetes and chronic pain. The patient's primary care provider (PCP) may recommend exercise to manage diabetes, but chronic pain makes exercise painful. If the patient wants to attend their grandchild's graduation ceremony, they may choose not to exercise to avoid pain that could prevent their attendance. Alternately, if the patient loves to read and wants to avoid losing their vision—retinopathy is a complication of diabetes—they may choose to exercise even though it is painful.

In the Collaborative Care model, the presence of competing demands can complicate collaborative problem definition, problem targeting, and care planning. Patients and providers may not agree on what constitutes a problem, which problems are most important to address, or how to address them.

There are multiple interrelated reasons for this. Providers typically follow care practice guidelines to identify and prioritize health-related problems and recommend treatment. For example, a clinical practice guideline published in *Annals of Internal Medicine* and endorsed by the American College of Physicians recommends that physicians prescribe metformin, a medication that improves glycemic control, for people with type 2 diabetes [129]. However, care guidelines typically address single chronic conditions in isolation; failing to consider interactions across multiple conditions, these guidelines can sometimes do more harm than good [24].

Some clinical guidelines address multiple chronic conditions directly, calling for providers to elicit and account for patients' preferences for treatment or health outcomes [5]. However, patients think about priorities for treatment, outcomes, or other aspects of care differently than healthcare providers. Patients tend to prioritize symptomatic issues and issues with emotional or social components [91,169], and providers tend to consider severity and prognosis [99]. As a result, people with MCC and providers often disagree on priorities for health care [75,153].

This discordance in priorities for health care is associated with worse patient experiences with their health care and worse health outcomes [144,154]. While Collaborative Care is the standard for care of chronic conditions, this model is not guaranteed to work for people with MCC: it is prone to breaking down when patients and providers cannot reach concordant priorities for care. Collaborative Care requires that patients and providers establish concordant priorities for care, but the competing demands of MCC and different perspectives toward prioritization make it difficult to reach concordant priorities. In order to position patients and providers to reach concordant priorities, providers must understand what patients consider important for their well-being and health. This goes beyond understanding patients' preferences for treatment, outcomes, or other aspects of care; it means understanding patients' personal values.

### 1.3 DESIGNING SUPPORT FOR SHARED UNDERSTANDING OF PATIENTS' PERSONAL VALUES

The VITAL project was conducted in response to this need for shared understanding between patients and providers about patients' personal values. My dissertation focuses on a subset of the VITAL project. In this section I explain how each of my research contributions fit within the broader project of facilitating shared understanding of patients' personal values.

Figure 1 provides a visual summary of the VITAL project. The solid boxes indicate papers that comprise the core contributions of my dissertation. The dashed boxes indicate papers from the VITAL project that provide key background for this dissertation. The figure is divided into three sections: defining personal values, understanding personal values in MCC care practices, and designing support for shared understanding of personal values. The first section of the figure, "Defining personal values," includes two papers that established a definition of personal values for people with MCC. I discuss this work in Chapter 2.

The second section of the figure, "Understanding personal values in MCC care practices," includes four papers. The first paper by Lim et al. [108] is key background for this dissertation. It focused on how patients' think about the pertinence of their values for their healthcare, and how they think about communicating values with healthcare providers. Patients often withhold or filter personal values in conversations with providers when they do not perceive values to be pertinent to their healthcare. Care planning discussions with providers might not fully account for what's important to patients; while patients may be making decisions about their care in accordance with

what's important to them, these decisions may not be visible to the provider, preventing the opportunity for providers to act as partners in collaborative care.

The remaining papers in Figure 1 comprise the core contributions of this dissertation. These focus on collaboration among key actors in MCC care: patients, caregivers, and providers. Below I introduce the motivation, research questions, methods, and findings associated with each of these papers.

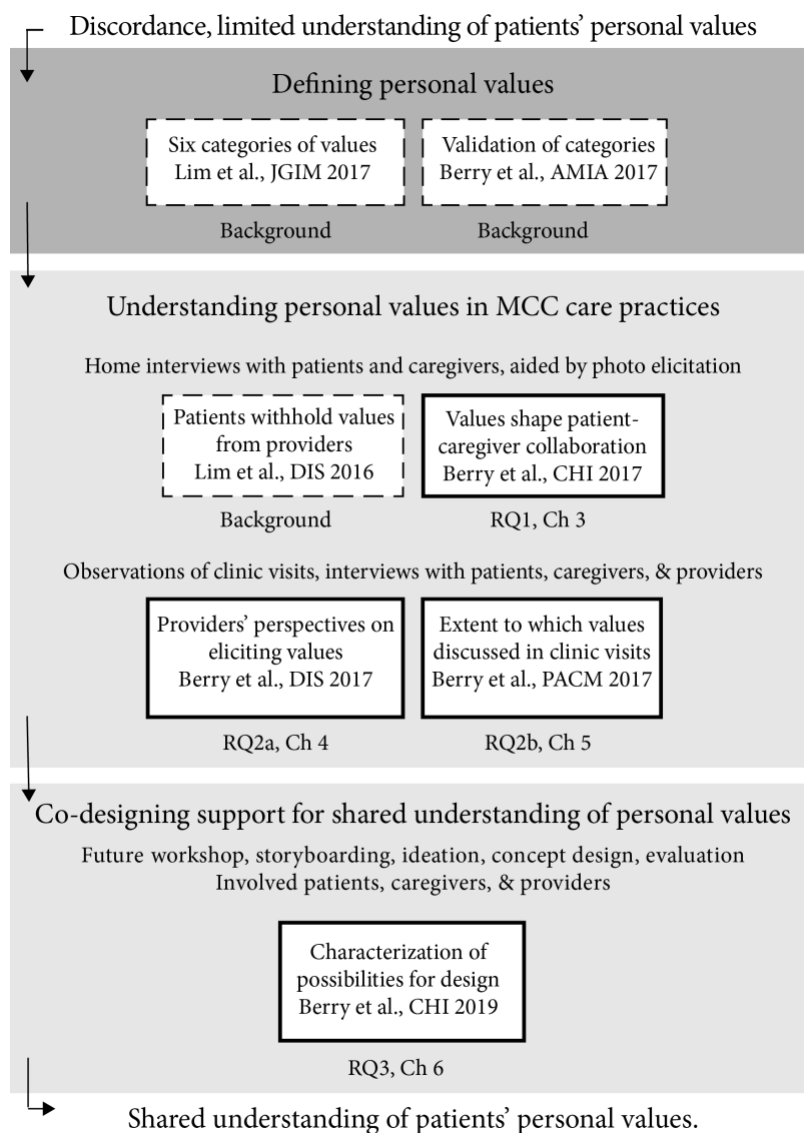


Figure 1. Overview of core contributions

### 1.3.1 *Personal values in patient-caregiver collaboration*

Most of the burden of MCC care falls to patients in daily life. However, patients rarely carry out this work in isolation. It is common for patients to receive support from informal caregivers. For example, depending on the patient's needs, a spousal caregiver may drive the patient to and from clinic visits, take on additional chores around the house, remind the patient to take medications, and even help the patient with basic needs like dressing and bathing. In this dissertation's efforts to align MCC care with patients' personal values, it's important to understand how these values influence the way MCC care is carried out in collaboration with caregivers in daily life. Previous research has described caregiving practices, with a focus on the burden of caregiving (e.g., [36]), but little work has explored the extent to which patients' and caregivers' values influence how they carry out care for MCC. Chapter 3 addresses this evidence gap by addressing the research question:

**RQ1: How does what's important to patients and spousal caregivers shape how they collaborate in the context of daily life?**

To answer this question, I conducted a field study with 12 pairs of patients and spousal caregivers in home visits with photo elicitation, interviews, and home tours. Analysis generated three themes about the role of values in collaboration between patients and spousal caregivers. First, when partners' values coincide, this promotes collaboration and coordination between them. Sometimes this means reinforcing behaviors that align with self-management activities, but other times this means reinforcing behaviors counter to MCC care. Second, when partners' values are asymmetric, this can introduce a tension between partners' ability to coordinate in daily life and patients' autonomy. For example, it may make it difficult for partners to maintain the same diet or to engage in the same exercise activities. Finally, the activities partners performed to carry out MCC care shifted over time, and partners' values played a large role in these shifts. I discuss these findings in relation to recent work in HCI to suggest how systems can better support patients and spousal caregivers. This includes designing systems that facilitate partners' communication about asymmetric values in order to promote smoother coordination between them, and systems that support individual autonomy through social support outside the relationship. Chapter 3 elaborates on this study and its implications for design. A paper resulting from this work was presented at CHI 2017 [17].

### 1.3.2 *Creating conditions for values to emerge in clinical conversations*

Discussion of personal values is not a routine part of clinical practice. To better support patient-provider communication about values, we need to understand the circumstances under which providers elicit and honor patients' values. Chapter 4 explores providers' perspectives on this, pursuing the research question:

**RQ2a: How do providers engage with patients' personal values in the course of clinic visits?**

By using the word “engage” in this research question, I remained 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.). I observed 21 clinic visits and interviewed 16 different care team members following those visits. Analysis showed that providers often sought to build and maintain relationships with patients to create a context in which patients feel comfortable sharing personal values. However, providers often employed their understanding of patients' values in service of their own, medically-informed priorities for care. For example, providers communicated their concerns for the patient's health in terms of patients' values as a way to convince patients to adhere to the provider's recommended treatment. Chapter 4 discusses these findings and their implications for the design of support for shared understanding of patients' values. A paper resulting from this work was presented at DIS 2017 [15].

### 1.3.3 *Extent to which breadth of personal values discussed in clinic visits*

The six categories of persona values presented by Lim et al. and Berry et al. provide useful conceptual grounding for the breadth of patients' personal values. Chapter 5 used these categories as an analytical lens for assessing the content of patient-provider conversations in clinic visits. This chapter pursued the research question:

**RQ2b: To what extent does patient-provider communication reflect what's important to patients in clinical settings?**

Similar to Chapter 4, this chapter is based on observations of clinic visits and interviews with patients (n=16), providers (n=15), and caregivers (n=8) before and after those visits. I analyzed

field notes and transcripts using the categories of personal values from Lim et al. [106] and Berry et al. [16]. I found that different categories were discussed in different ways, and some categories were discussed more often than others. For example, activities and abilities were discussed often, but possessions and principles were discussed little. Additionally, I found that personal values were rarely discussed in isolation; rather, personal values were multi-faceted, spanning multiple categories of the values framework, and discussions in the clinic often involved multiple values and values categories. Finally, I found that discussion of values sometimes established clear relationships between values and health care (e.g., a provider shifting the focus of a visit to focus on a patient's knee pain instead of diabetes because the knee pain was affecting the patient's valued activities, abilities, and relationships). In other cases, discussion of values was incomplete, failing to connect the patient's health care with their values. Establishing these connections between values and care depended on work performed by patients, caregivers, and providers to translate and operationalize patients' personal values in the context of their care. Chapter 5 discusses these findings in detail and their implications for design. These findings were published in the Proceedings of the ACM in HCI in 2017 [14] and were presented at CSCW 2018.

#### 1.3.4 *Co-designing support for shared understanding of values*

The findings reported in Chapters 3, 4, and 5 provided a clearer understanding of how patients' personal values shape MCC care practices across home and clinical settings. Building on this understanding, Chapter 6 presents findings from a series of co-design activities. These activities elicited ideas from patients, caregivers, and providers about how new products, services, and systems could promote shared understanding of patients' values. These co-design activities were guided by the research question:

**RQ3: How do patients, caregivers, and providers envision designing support for patient-provider communication about patients' personal values?**

To address this question, I helped plan and facilitate a series of co-design activities with patients, caregivers, and providers. These activities were conducted in two parts. Part I involved a pair of workshops to enable participants to generate concrete ideas for supporting shared understanding of patients' values. The first workshop was modeled after the Future Workshop and involved critiquing present practices for communication about values, envisioning what ideal communication might look like, and specifying how designers might support it. The second

workshop built on the first, taking key ideas generated in the Future Workshop and concretizing them through the creation of storyboards.

These workshops generated a variety of ideas and did not indicate clear directions for design work to continue. I analyzed this range of ideas and characterized the diversity of participants' ideas in seven design dimensions: explicitness, effort, disclosure, guidance, intimacy, scale, and synchrony. Then, I helped use these dimensions to design concepts to embody key tensions in participants' ideas. I presented these concepts back to participants in focus groups, which clarified future directions for the design of systems to support shared understanding of patients' personal values. These co-design activities and findings are reported in Chapter 6, and were presented at CHI 2019 [18].

### 1.3.5 *Revisiting values and design*

Chapter 7 takes stock of findings from Chapters 3-6 and identifies several key opportunities for design that cut across those chapters. I will discuss a theoretical perspective—moral action—that I find useful as a design ideal to clarify and orient future research and design to account for personal values in MCC care. Finally, I will revisit related work from Chapter 2 to position my use of the concept of personal values relative to prior work on the nature of values in design. I call for designers to remain aware of these different conceptions of values and to explicitly consider how different conceptions of values might serve design processes differently.

## Chapter 2. BACKGROUND

This chapter provides additional related work that helps set the stage for the chapters that follow. My intention for the introduction was to include related work that reveals gaps in research and motivates the research questions. Each chapter after this one will include additional related work specific to the research question and will demonstrate how the findings extend prior work.

Thus, the purpose of this chapter is not to review related work associated with individual research questions. Instead, I will use this chapter to introduce related work that pertains to all of the chapters. This includes sections on how values have been defined and used health care, how they have been defined and used in design, and which existing technologies address communication about values in health care settings.

Overall, this chapter should make clear that there is no single accepted definition of values. Different disciplines have defined values differently, and within some disciplines, usage of values has shifted over time. I do not aim to account for all definitions of values; just to reveal several key ways in which these definitions can vary. Introducing variations in these definitions now will sensitize the reader to ways in which different actors in Chapters 3-6 think about and work with values. It will also set up a conversation in Chapter 7 that revisits the definition of values and the relationship between values and design in light of findings in Chapters 3-6.

### 2.1 DEFINITION OF PERSONAL VALUES FOR PEOPLE WITH MCC

Throughout this dissertation I use the term “personal values” as shorthand for anything a person with multiple chronic conditions (MCC) considers important or meaningful for their well-being and health. This definition was established in the first phase of the VITAL project and has roots in the health sciences literature and Value Sensitive Design (VSD). In VSD, values are defined as “what a person or group of people consider important in life” ([64], p. 70). In health sciences, an influential report from the Institute of Medicine titled, “Crossing the Quality Chasm,” defined patient-centered care as “respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.” ([83], p. 6). The report does not define values explicitly, but implicitly uses it to refer to “individual patient choices and preferences” (ibid, p. 8).

The purpose of the first phase of the VITAL project was to develop an understanding of what people with MCC value, grounded in their own perspectives from daily life [106]. To accomplish this, interviews were conducted with people with MCC in their homes. Each interview was seeded by a photo elicitation exercise, in which participants used a polaroid-style camera to photograph things in their daily life that they considered important or meaningful for their well-being and health. Then, in a semi-structured home interview, participants explained what was important in each photograph they took, grounding the interview in evidence and stories from their daily life. This led to a broader discussion of what the person considered important in life, and how this related to their medical care.

Analysis of these interviews resulted in the definition of personal values introduced above. A paper I co-authored [106] presented this definition along with a set of six categories that describe the breadth of patients' personal values [106]. The six categories—abilities, activities, emotions, possessions, principles, and relationships—are defined in Table 1 below, including examples of each. Subsequently, another paper I co-authored, based on surveys with patients, provided additional evidence that these categories account for the breadth of patients' personal values [16].

Table 1. Personal values of people with MCC

Category	Definition	Examples
Abilities	Physical or mental capacities or skills	Mental sharpness, mobility, vision, hearing
Activities	Pursuits, things that one does	Reading, gardening, working, self-management
Emotions	Feelings or moods one experiences	Comfort, joy, relief, a sense of accomplishment
Possessions	Belongings, personal items	Car, photographs, letters, home
Principles	Beliefs, standards, or virtues by which one lives	Faith, independence, honesty
Relationships	Connections with other people or groups	Family members, companions, religious fellowship

This definition of personal values differs in key ways from the definitions of values typically used in healthcare research and practice. Most importantly, because they pertain to what a person considers important to their *well-being* and health, personal values may or may not be related to

health. It is up to each individual (and the others involved in their health care) to determine how and to what extent the things important to a person relate to their health and their health care. It is possible that a person could value an activity that their doctor considers harmful to their health, as with riding a motorcycle or working in a high-stress environment. It is also possible for a person to value their health or aspects of their health care directly, as when a person values exercising or relief from pain. It is also possible that what a person values may be loosely related or entirely unrelated to what their doctor considers important to their health, as with a person who values keeping a tidy home or talking on the phone with friends. In any case, what a person considers important or meaningful for their well-being and health—their personal values—is up to them.

## 2.2 VALUES IN HEALTH CARE FOR MCC

Health care research and practice has typically adopted narrower perspectives on values compared to my definition of personal values.

### 2.2.1 *Values and preferences*

In many cases, values are considered to be expressed through patients' preferences among options for health care. Scholars of human decision-making have argued that people's values influence how they make decisions and construct preferences. Fischhoff [59] described four steps that show how values influence preference construction: 1) understand the choice, 2) access relevant personal values, 3) interpret values in the context of the decision to construct a preference, and 4) state the preference. Epstein and Peters [57] adopted this framing in their discussion of how patients construct preferences for health care by applying their values.

The perspective of values as preferences is prevalent in health research and practice. For instance, Laiteerapong et al. [99] 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) [61]. Grant et al. [69] 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.

### 2.2.2 *Values and goals*

Other approaches purport to address the patient holistically, which potentially accounts for patients' personal values, albeit implicitly. The Patient-Centered Medical Home model is an example of such an approach. Under a PCMH model, patients and providers establish health-related goals through shared-decision making processes. These goals can take into account a broad set of factors—psychological, emotional, psychological, spiritual—that matter for the patient's well-being.

In a similar approach focused on “patient-important outcomes,” Reuben and Tinetti [132] advocated for goal-oriented patient care that specifically addresses the tradeoffs and decisions that people with MCC face. Reuben and Tinetti presented four main components of this approach:

- Patient-provider discussion centers around outcomes important to the individual patient, not outcomes defined and measured at the population level.
- Patient-provider discussion of health outcomes and potential treatments spans multiple chronic conditions (i.e., does not address single conditions in isolation).
- Patients prompted to explicitly consider tradeoffs in symptoms and treatments among multiple conditions, and to establish relative priorities.
- In accordance with relative priorities, patient and provider agree on health-related goals, treatments, and measures.

In this approach, health care quality and outcomes are measured according to an individual's goals [132]. Patients' personal values may or may not be represented in the patient-provider communication that drives goal-oriented care. People with MCC often do not share personal values with their healthcare providers [108]. Patients cited several factors that influenced whether they discussed values with their providers, including their perceptions of the pertinence of personal values to health care, assumptions about the consequences of sharing values, and their relationship with their providers.

### 2.2.3 *Values and patient-provider relationships*

Finally, a key reference point in the health sciences literature is prior work on the role of patient values in patient-provider relationships. Emanuel and Emanuel [56] described four models of

physician-patient relationships: paternalistic, informative, interpretive, and deliberative. A comparison of the four models from Emanuel and Emanuel [56] is reproduced here in Table 2.

These models are not specific to care for MCC, but they usefully examine the role of patients' values in patient-provider relationships. The definition of patient values varies in different types of relationships. In a paternalistic model, values are considered to be objective and universally shared between patients and providers. In a deliberative model, patients' values are considered as contingent, able to be developed through conversation with their provider.

Each model explores how different modes of engagement between patients and providers engenders different definitions of patient values, different degrees of patient autonomy, and different physician roles and obligations. These models of patient-provider relationships are useful for thinking through different ways of engaging with values in the course of clinical care. Yet, the definitions of patient values focus mostly on the nature of values rather than their content. My definition of personal values adds a focus on content. The six categories of personal values emphasize the breadth of things people with MCC consider important.

My conceptualization of personal values and their role in patient-provider communication aligns most closely with the interpretive and deliberative models. In order to elicit and understand patients' personal values, I envision providers acting as counselors and friends, helping the patient articulate their values and connecting the patient's health care needs and practices with their values. And, I envision patients developing their understanding of their values and exhibiting moral self-development as they consider these connections between their health and their values.

Table 2. Four models of physician-patient relationships.

Model	Physician obligation	Patient values	Physician role	Patient autonomy
Paternalistic	Determine patient's medical condition, identify tests and treatments needed. Present patient with information, encourage patient to consent to intervention physician considers best.	Objective, shared by physician and patient	Guardian	Patient assent to physician determination of what's best
Informative	Provide patient with all relevant information. Patient selects desired medical interventions. Physician executes selected interventions.	Defined, fixed, and known to the patient	Technical expert	Patient control over decision-making

Interpretive	Like informative model, but physician also helps patient articulate values and determine medical interventions to best realize these values.	Inchoate and conflicting, requiring elucidation	Counselor, advisor	Self-understanding
Deliberative	Help patient choose best health-related values that can be realized in the clinical situation.	Open to development through moral discussion	Teacher, friend	Moral self-development

In summary, in terms of the content of values, healthcare research and practice have typically focused on patients' preferences for health care. In terms of processes for engaging with values, healthcare research and practice has explored the nature of the patient-provider relationship, and strategies for shared decision-making and deliberation regarding goals for care. Routine clinical practice does not typically incorporate the breadth of patients' personal values as captured in the six categories [37,98,170]. There is a need to better understand how healthcare practices can better account for the breadth of patients' personal values.

## 2.3 VALUES IN DESIGN

The design literature has a long history of focusing on the nature of human values and the relationship between values and design. In this section I will call attention to three distinctions that are important for this dissertation: 1) designers adopting discursive (and even universal) definitions of values versus designers working with definitions of values that emerge from local design contexts, 2) designers considering values as entities versus designers considering valuation as a process, and 3) designers identifying values and then applying them versus designers working with values dialectically as they advance the design situation. I introduce each of these distinctions to sensitize the reader to different ways in which values have been conceptualized in design research and to set up a retrospective discussion in Chapter 7 of the utility of different conceptualizations of values across Chapters 3-6.

### 2.3.1 *Values defined discursively, or emerging from local contexts*

Value Sensitive Design is a well-established approach to accounting for human values in the design process. This approach was pioneered by Friedman et al. [64], has been applied in a range of contexts—designing for traffic control teams [74], designing robots for health care [166], and

designing safe communication technologies for homeless youth [165], to name a few)—and has continued to develop over time [22] (e.g., multi-lifespan information system design for cross-generational conflict resolution in Rwanda [65,120]).

Adopting a VSD approach means conducting three types of investigations—conceptual, empirical, and technical—in a potentially layered and iterative manner [64]. Conceptual investigations identify key stakeholders in the design process (direct and indirect) and the values relevant to these stakeholders. Conceptual investigations may involve drawing on literature from ethical philosophy to develop definitions of values and may involve reasoning about tradeoffs, tensions, and conflicts between values. Empirical investigations explore human activity pertaining to the design problem, including how people use key technologies of interest in the design problem. Technical investigations explore the extent to which features of technologies account for stakeholders’ values (or fail to account for them). This could involve comparing how different technologies have different consequences for how stakeholders’ values are met or violated, generating ideas for how technologies could be modified to better account for stakeholders’ values, and implementing technologies for use in subsequent empirical investigations.

Le Dantec et al. [101] critiqued VSD for its tendency to prioritize a discursive approach to establishing values of relevance to a design process. Friedman and Kahn [63] suggested a set of 12 values of ethical import from “deontological and consequentialist moral orientations” (p. 1187): human welfare, ownership and property, privacy, freedom from bias, universal usability, trust, autonomy, informed consent, accountability. Friedman and Kahn (*ibid*) were careful not to claim this list as exhaustive or authoritative, and later others clarified that VSD did not intend to make strong claims regarding the universality of these values [22].

Still, Le Dantec et al. [101] rightfully called attention to the tendency of VSD practitioners to begin with a conceptual investigation, identifying and defining values discursively by looking to literature in the philosophy of ethics. And, they called attention to the lack of strong guidance in the VSD literature regarding empirical methods through which design researchers can revise their understanding of values based on conversations with and observations of stakeholders in practice.

As an alternative to defining values discursively, Le Dantec et al. [101] called for designers to seek an understanding of stakeholders’ values as they emerge from particular, local design contexts. They did not argue against conceptual investigations or using discursively-defined values

of ethical import as analytic tools; they argued for giving local understandings of values prominence over discursive definitions.

My approach aligns with Le Dantec et al.'s [101] approach to a great degree. In our efforts to understand the personal values of people with MCC, our approach in the VITAL project has been to privilege the perspectives of people with MCC rather than to start with a list of discursively-defined values and then adjust those retroactively. Additionally, the methods used in the first phase of the VITAL project to develop the definition of personal values [106] align with the photo elicitation methods used by Le Dantec et al. in that they sought to ground values elicitation in people's lived experience. Finally, in later phases of the VITAL project (reported in Chapters 3-6), I have used the definition of personal values, including the six categories that describe the breadth of personal values, as a research tool. As a research tool, this definition and the categories of personal values have enabled me to communicate what I mean by "values" or "what a person considers important for their well-being and health" to different stakeholders in MCC care. Additionally, this definition and the categories have proven useful as analytic tools, sensitizing me to a range of potential values that may emerge during interviews, observations, co-design activities, and subsequent analyses.

### 2.3.2 *Values as fixed entities, or valuation in practice*

More recent work by Houston et al. [81] has raised the distinction between considering values as fixed entities and considering valuation as a practice through which matters of worth and importance are enacted and enacted in action (following theories of practice [122]).

Houston et al. [81] called attention to processes of valuation by studying repair communities. This broke with prior values-oriented design literature, which focused on values in practices of design. Houston et al. focused on repair practices at four sites: two groups of amateur fixers in Seattle and Brooklyn, in the United States, and two mobile phone "repair worlds" in Kampala, Uganda and Dhaka, Bangladesh. Houston et al. [81] call attention to questions of value in these sites: What is valuable to be repaired? To what extent is repair work valued? Focusing on questions like these brought attention to processes of valuation, highlighting the contingent nature of values and ways in which values can be enacted and re-enacted over time. Rather than treating values as entities we think with or act on, Houston et al. [81] argue for attending ways in which people enact valuation: "contingent, ongoing processes through which things are rendered valuable in a wider

social and material context” (p. 1412). One upshot of this perspective is the realization that values are not fixed in the design process; values are continually enacted by people in practice (e.g., through repair, long after the design process has concluded). From this point of view, Houston et al. invite us to reconsider the purpose of design. Rather than seeking to settle matters of value in the design process, we may instead undertake design processes as “ethical provocations and starting points rather than final words” (ibid, p. 1412).

### 2.3.3 *Identifying and applying values, or working with values dialectically*

JafariNaimi et al. [87] characterized the dominant approach in HCI as following an “identify/apply logic.” In this logic, designers first “identify and understand values” relevant to the design situation at hand, after which those values “can be better applied to design practice.” (p. 93) In contrast with the identify/apply logic, JafariNaimi et al. [87] argued that designers may use values like hypotheses in an ongoing, dialectic process of assessing the design situation and making moves to advance the design process. JafariNaimi et al. drew on Dewey’s “question of action” [53] to support this formulation. Figure 2 reproduces the image used by JafariNaimi et al. to show two interrelated questions: “What is the situation that demands action?” and, “What is the action that the situation demands?”



Figure 2. Dewey's question of action, reproduced from JafariNaimi et al. 2015.

JafariNaimi et al. [87] used the question of action to describe how values shape the design process: In straightforward situations in which the designer has a strong grasp on the design situation, the designer’s course of action is clear. In indeterminate situations, the designer may draw on relevant values to make sense of the design situation, which helps the designer determine

appropriate design moves to make. And, as the designer acts to advance the design process, this reshapes the nature of the design situation. In this formulation, design is a dialectic process through which the designer's understanding and actions mutually shape one another, with values providing guidance.

Other researchers, such as Grönvall et al. [70] and Iversen and Leong [84,85,103] have articulated a similar relationship between participatory design and values. For example, Iversen & Leong [85] described values-led participatory design as a dialogical process in which designers and participants cultivate the emergence of values, develop these values, and then ground these values in design products.

#### 2.3.4 *Summary*

The previous sections have identified three key distinctions in the nature of values as they pertain to design: values defined discursively versus values emerging from local contexts, values as entities versus valuation as a process, and identifying and applying values in distinct, linear steps versus working with values as hypotheses. In the empirical chapters to come, it will be useful to remain mindful of these distinctions as setup for the discussion in Chapter 7, which will explore the particular definitions of personal values at play and the relationships between values and design at play in Chapters 3-6.

## 2.4 RELATED TECHNOLOGIES FOR PATIENT-PROVIDER COMMUNICATION

Healthcare technologies are enabling new forms of communication between patients and providers [162,163]. Patient portals and personal health records provide asynchronous, text-based communication between patients and providers [148]. Telehealth systems enable synchronous audio- and video-based communication from a distance [104,149]. During clinic visits, there is evidence that technology in the exam room can support or disrupt face-to-face communication during clinic visits [34,35,152].

Although these existing technologies could support communication about personal values, little work has explored this possibility. Some work has focused on patient-provider communication around specific types of information, such as sharing self-tracking data [38] and social determinants of health [2,52]. In addition, some systems support the capture of qualitative information about patients' experiences in daily life, but these tend to map that information to

symptoms of illness [29]. There remains a specific, unmet need for support of communication about personal values.

In health sciences, efforts to support communication about values have typically conceptualized values narrowly or have sought to elicit values without also supporting discussion of or even communication about values. For example, values clarification methods (VCMs) are techniques to help patients clarify what matters to them in the context of specific health-related decisions, such as decision aids that utilize pros and cons or ratings. Examples include decision aids to help patients choose the best treatment for type 2 diabetes [30] or select lifestyle changes for improving cardiac health [13].

Witteman et al. [164] reviewed 98 VCMs and discussed their limitations. Most (59%) were designed for patients to complete individually rather than with a provider, used closed-ended and pre-set options (61%), and few encouraged patients to reflect on and explore values iteratively (9%). This aligns with related work advocating for designers to consider primary and secondary users of technology (in this case, patients and providers) [4]. For example, in a study in which patients and providers co-designed support for patient-provider communication in the context of breast cancer, participants advocated for supporting shared use of technology by patients and providers together [67].

Furthermore, VCMs tend to generate values about single health conditions, failing to consider multiple conditions. Of the 23 VCMs related to chronic illness, nine focused on cardiovascular health, eight focused on other chronic conditions, and six focused on advance care planning. This suggests a lack of tools for care planning for people with MCC who face competing demands.

This prior research demonstrates that while there has been interest in supporting patient-provider communication, and some work has sought to elicit patients' values and preferences in healthcare contexts, there is a gap in support for patient-provider communication about patients' personal values.

## Chapter 3. PERSONAL VALUES IN PATIENT-CAREGIVER COLLABORATION

### 3.1 INTRODUCTION

People living with multiple chronic conditions (MCC) engage in activities to manage their illnesses amidst the usual demands of daily life. Research in health services and medical sociology have characterized the work patients do to manage chronic illness in terms of three categories: 1) illness work (e.g., changing diet, exercising, taking medications [20,21,42,110]), 2) everyday life work (e.g., spending time with a spouse or holding down a job), and 3) biographical work (e.g., coping with difficult emotions when one's life changes due to illness) [19,44].

Carrying out these three lines of work often involves collaboration between patients and informal caregivers [23,27,123]. Following Miller et al. [116], we define an *informal caregiver* as any person who helps a patient with some aspect of their care, such as the patient's spouse (excluding professional caregivers). Spouses may remind each other to take medications, participate together in discussions with doctors, and establish new divisions of labor in home chores [42,44]. However, most design research has focused on providing individual support for either the patient or the caregiver [123]. There is a need to better understand how systems can support both patients and informal caregivers in the work they do together.

The lives of people with MCC provide a rich context for developing this understanding. Compared to individuals with one chronic condition, individuals with MCC have lower quality of life and are prone to higher rates of physical disability, adverse drug events, and mortality [66,126,146]. For these individuals, activities to manage one condition may conflict with management of others, so patients must prioritize some health outcomes over others. This is in addition to the challenges of incorporating activities to manage MCC into daily life.

To design systems to support individuals facing the competing demands of MCC, it is critical to understand patients' and caregivers' values—the things they consider important in life [64]. Understanding patients' values is key to the provision of high quality patient-centered care [48,96,155,164]. Health services research has traditionally focused on eliciting patients' values during clinic visits with a focus on their decisional preferences among specific options for treatment or evaluation [58,164]. In contrast, little work has been done in the everyday context of

patients' homes to understand what individuals with MCC and their caregivers value, and how this shapes the work they do to manage MCC.

In this chapter, I report on a field study that engaged 12 pairs of people with MCC and their spousal caregivers. As a research assistant on the VITAL research team, I helped plan and conduct these interviews and lead the analysis that produced the findings reported below. When I use the term "we," I am referring to members of the VITAL research team.

The field study involved photo elicitation, home visits, semi-structured interviews, and home tours. Patients had diabetes and at least two other chronic conditions such as hypertension, depression, or osteoarthritis. Patients and caregivers were married and living together. We sought to understand the things participants valued most for their well-being and health, and how they pursued these things while managing competing demands of MCC. We focused mostly on patient-caregiver collaboration that was oriented toward the patient's health and well-being, but this did not preclude participants from discussing activities geared toward the caregiver's well-being.

Analysis of data yielded three themes about the role of values in collaboration between patients and spousal caregivers: 1) coinciding values, 2) asymmetric values, and 3) values and shifting responsibilities. These findings extend previous research by articulating how the values of patients and spousal caregivers shape how they collaborate in daily life to manage illness and pursue well-being. We discuss these findings in relation to recent work in HCI to suggest how systems can better support patients and spousal caregivers. This includes designing systems that facilitate partners' communication about asymmetric values in order to promote smoother coordination between them, and systems that support individual autonomy through social support outside the relationship.

## 3.2 BACKGROUND AND RELATED WORK

### 3.2.1 *Support for individuals managing chronic illness*

Most studies in health services and HCI have aimed to design technologies that enhance how individuals (as opposed to dyads) manage chronic illness [124]. This work falls into three categories: direct support for patients, indirect support for patients via support for caregivers, and direct support for caregivers to reduce caregiving burden. Direct support for patients includes tools

for self-monitoring blood pressure [71,147] or blood glucose [134,147], or facilitating reflection [113] and awareness of symptoms [10]. Indirect support for patients through support for informal caregivers has included supporting information sharing among caregivers of infants [109], facilitating communication between caregivers, friends, and family of persons with dementia [46], and a monitoring system to help caregivers protect elderly patients from wandering or social exploitation [54]. Finally, research focused on caregiver burden [36] has studied how caregivers balance demands of caregiving with other demands of everyday life. For example, researchers have examined the burden on people who care for family members with mental health challenges such as depression or Alzheimer's disease [137,150,167].

### 3.2.2 *Support for collaboration between patients and caregivers*

Recent research has emphasized the collaborative nature of daily care activities performed by patients and informal caregivers. Informal caregivers for patients with chronic conditions might help with dressing, eating, or finances, and provide emotional support [137].

Of particular relevance to this chapter is the need to treat the patient-caregiver pair as the unit of analysis [123]. This is especially true for the population we are studying: married couples who live together. According to the United States census, 57% of adults over the age of 65 are married [172]. This sizeable population warrants attention because spousal caregivers tend to be more vulnerable than family caregivers who are not spouses [131]. For example, spousal caregivers are more likely to face financial strain [102].

Nunes and Fitzpatrick [123] highlighted that collaboration between patient and caregiver changes as illnesses progress and other life circumstances change. They also emphasized that partners' collaboration is flexible and changes over time, and that mutual commitment to managing illness is likely to be a feature of many patient-caregiver relationships [123].

However, less is known about how patients' values influence this dynamic collaboration. It is possible that patients' and caregivers' values may differ, particularly with regard to health care and other aspects of daily life. In this chapter, I attend to the range of ways in which patients' and caregivers' values influence collaboration, even if that means a disruption of collaboration. This view of collaboration is consistent with previous work in computer-supported cooperative work that debated the meaning of "cooperative." For example, Kling [97] highlighted the existence of non-convivial relationships in collective work.

Furthermore, there is a need to understand how technology can support collaboration between patients and caregivers [123]. Abowd et al. [1] surveyed collaborative technologies for chronic care and generated challenges and opportunities for future work. Many design efforts in this space have sought to support collaboration between members of a patient's care network [41], which includes informal caregivers, professional caregivers, and health care providers such as doctors and pharmacists. One example is CareCoor, a calendar tool that supports articulation and coordination of care work between informal family caregivers and professional caregivers [23]. In another example, digital family portraits supported family members' awareness and peace of mind regarding seniors' daily activities [119]. However, there has been little research on technologies for collaboration between patients and spousal caregivers.

### 3.2.3 *Research question*

Supporting individuals with MCC requires understanding their values, but previous studies with this patient population have focused on values from a clinical perspective. An early paper from the VITAL project [108] showed that individuals with MCC often do not disclose their values to healthcare providers, which highlights the importance of understanding how values shape self-management in the home. Furthermore, managing chronic illness involves collaboration between patients and informal caregivers, but previous research has focused on either the patient or the caregiver, neglecting to treat the patient-caregiver dyad as the unit of analysis. We know little regarding the role that values play in collaboration between patients and spousal caregivers. This gap motivated us to investigate the following research question:

*RQ1: How do the values of patients and spousal caregivers shape how they collaborate to manage illness and pursue well-being in the context of daily life?*

## 3.3 METHODS

This section outlines a field study conducted with participants in their homes. This study began with a photo elicitation exercise and continued with semi-structured interviews and home tours. Study procedures received institutional review board approval at Group Health Research Institute.

### 3.3.1 *Participants*

This study engaged 12 patient-caregiver dyads (P1 and CG1 through P12 and GC12). All of these dyads were married and living together. Participants were recruited from an integrated healthcare system in Washington State. To be eligible for participation, patient participants had to have diabetes and at least two of the following common chronic conditions: depression, osteoarthritis, and coronary artery disease. These conditions are more likely to require self-management than other conditions, and self-management for these different conditions can often conflict. Patients receiving help from a professional caregiver were not eligible for participation.

Informal caregivers were invited by asking each patient participant if there was anyone they lived with who helped manage their health care. During recruitment we did not require the caregiver to be a spouse, but it turned out that every patient-caregiver pair in our sample was married. Table 3 shows demographics of the sample.

Table 3. Participant demographics.

Characteristics	Patient (N=12)	Caregiver (N=12)	All (N=24)
<i>Age</i>			
Mean	65.75	N/A	N/A
Range	25-87		
<i>Gender</i>			
Female	6	6	12
Male	6	6	12
<i>Employment</i>			
Full-time	2	2	4
Part-time	1	2	3
Retired	7	5	12
Unemployed	1	1	2
Disabled	1	2	3
<i>Education</i>			
8th grade or less	0	1	1
Some high school	1	0	1
High school graduate or GED	4	4	8
Some college or 2-year degree	4	5	9
4-year college degree	0	0	0
More than 4-year degree	3	2	5

Participants were mostly older adults, had a range of educational backgrounds, and mostly reported having the same race. Of all patients, 1 reported they were American Indian or Alaska

Native, 1 reported they were Black, and 10 reported they were White; of caregivers, 1 reported they were Black and 11 reported they were White. Caregiver age is missing from the table because we did not collect this information.

### 3.3.2 *Home visits*

The field study consisted of home visits with each patient-caregiver dyad, including photo elicitation [101], a semi-structured interview, and a tour of the home. From beginning to end, home visits lasted roughly two hours. Before each visit, we sent participants a Fujifilm Instax Mini camera that produced instant 62 mm x 46 mm photos. We asked participants to take up to 10 photos of things that were important to the patient's health or well-being. We invited the caregiver to take photos but specified that the photos should show things important to the patient. When we visited participants' homes, we interviewed the patient alone first, then the caregiver alone, and concluded by interviewing both together. This format gave each participant the opportunity to speak freely in private and also showed how participants answered while together.

We began each individual patient or caregiver interview with a review of photographs from the photo elicitation exercise. We asked the patient or caregiver to tell us what was important in each photo. We used the discussion of the photos to lead into the semi-structured interview. This flow grounded each interview in the context of what participants valued in their daily lives. The interview guide (patient, caregiver, and combined) covered four issues: values (e.g., "What is most important or meaningful to you in your life?"), daily activities (e.g., "What do you do in a typical day?"), self-management (e.g., "What do you do to manage your health?" or "What do you do to manage your partner's health?"), and tradeoffs (e.g., "Tell us about a time when you found it difficult to balance the things that are important to you."). The topics covered in individual versus combined interviews were similar; the combined interview gave us the opportunity to clarify topics from the individual interviews and dig deeper into aspects of their daily lives that they shared. After concluding the interviews, participants gave us a tour of their home and pointed out things that were important to their health and well-being. This further connected the interview discussion with participants' daily lives. We took photos with a digital camera during the home tour.

### 3.4 ANALYSIS

Interviews were professionally transcribed verbatim. Analysis was guided by grounded theory methods [33]. We began analysis after the first interview and continued after the last was completed. We iterated across open coding, focused coding, writing code memos to define and clarify codes, grouping codes into themes, and writing memos to elaborate and clarify themes. With one other member of the VITAL research team, we independently conducted open coding of transcripts using talk turns as the unit of analysis and wrote code memos to define and clarify codes. Wherever possible the two coders named codes to honor the language participants used. The coders met weekly to discuss code definitions and split or merge codes, then conducted focused coding to test and further refine codes and code definitions. As codes stabilized, the coders wrote memos to identify themes that emerged across codes. Throughout the process, all VITAL team members participated in meetings to discuss, clarify, and elaborate codes and emergent themes.

### 3.5 FINDINGS

This section reports on the main themes and subthemes generated through analysis of interview transcripts. Partners' values shaped how they worked together to manage well-being and health in daily life. Their collaboration involved supporting each other's health and helping each other pursue their values. The first theme, *coinciding values*, captures ways that empathy for each other's values motivated partners to support each other. The second theme, *asymmetric values*, reflects tradeoffs patients and caregivers faced when their values did not align. Often these tradeoffs involved a tension between maintaining collaboration and pursuing individual autonomy. The third theme, *values and shifting responsibilities*, discusses how patients and caregivers shifted responsibilities to manage chronic conditions and their complications, and how values interfered with these shifts.

#### 3.5.1 *Coinciding values*

In many cases the caregiver and patient both valued the same thing, such as the shared enjoyment of spending time with grandchildren. This is covered in the *shared values* subsection. In other

cases, a caregiver valued something by virtue of its importance to a patient. This is covered in the *empathy drives support* subsection. Overall, when partners' values coincided, this facilitated collaboration between them. Often this collaboration was in service of health, although there were exceptions to this rule.

#### 3.5.1.1 Shared values

Patients and caregivers often described activities, relationships, and other aspects of daily life that they both valued. For example, many partners placed importance on following a healthy diet or exercising regularly in tandem. When partners shared values like these, this facilitated coordination between them.

The following excerpt from P2 and CG2 demonstrates how shared values can boost partners' resilience when working toward health-related goals. In the past P2 contemplated suicide because her back pain was so extreme. She inquired with her doctor about having bariatric surgery, a procedure to reduce the size of the stomach to promote weight loss. CG2 and P2 described the decision to go ahead with the surgery as a "*couples' decision*." At the time we interviewed them, P2 and CG2 had lost 100 pounds and 25 pounds, respectively, since the surgery. Both valued eating healthily and wanted to continue losing weight. The following excerpt shows how they support each other when one of them falters:

"We lost our daughter in October...and I lost my mom in February, so two losses in the last eight months...[P2 has] been extremely encouraging to get me to not stuff [binge eat]...she knows and I know what I'm doing, and she'll say, 'You don't wanna go back where we were. We don't wanna go back where we were...let's not do that,'...and encourage me to make sure I continue to eat right...we're on track, and we're both trying to keep each other on track." (CG2)

P2's and CG2's close proximity in daily life means one notices when the other is tempted to eat unhealthily and can provide encouragement immediately. Furthermore, their past discussions and shared decision-making about their diet created the common ground on which this daily support rests. Individuals with caregivers who do not live with them do not have the advantage of such timely and highly personalized support.

In contrast with P2 and CG2, some participants described values that were shared between patient and caregiver that they did not perceive to be healthy. For P4 and CG4, the most important things were faith and family. CG4 said pursuing these things kept them very busy. CG4 said the following when we asked what she did to manage her health:

“...we have 11 grandchildren. We go to their sports functions...we're never home...The neighbor next door just said to us, ‘You are the most people on the go that I've ever seen.’ So, we just do a lot with our church and with our kids. When you have four and five kids, there's a lot to do—and 11 grandkids. Keeps me busy...we probably need to take more time for—to take care of our body in a sense of exercising, yes...but on the other hand, if we weren't on the go, we might just be sitting here and doing nothing.” (CG4)

This excerpt shows a case in which shared values between patients and caregivers can mean they eschew self-care activities. In this case there were indirect health benefits to being on the go with family, but under other circumstances partners’ shared values could just as easily undermine health. Resonating with the previous example from P2 and CG2, in which their shared values promoted resilience in the face of temptation to break from their diet, partners’ shared values can reinforce an unhealthy status quo, potentially preventing partners from changing their behavior in ways they perceive as healthier.

Together the examples in this subsection show that shared values can facilitate collaboration between patient and caregiver, although this does not necessarily mean collaboration toward self-care.

#### 3.5.1.2 Empathy drives support

Many caregivers demonstrated that they understood what was important to patients. Often when something was important to the patient, this was all it took for the caregiver to consider it important to them, also. In these cases, the caregiver’s values coincided with the patient’s. When the caregiver observed that the patient faced challenges related to something they valued, the caregiver empathized with the patient. This empathy motivated the caregiver to collaborate with the patient to overcome challenges of illness and pursue the patient’s values. As context for the first example below, P5 showed us photographs of his grandchildren that hung in his kitchen to demonstrate the importance he placed on family. He told stories about how he and CG5 regularly hosted their children and grandchildren for family meals. However, P5 had a heart attack that limited his strength and endurance and threatened his ability to enjoy time with family:

“I [have been] trying to keep him interested and have enough energy to do the family things that we can do. He didn’t want to go to our grandson’s graduation...It’s in the football field arena...and he was afraid he wouldn’t be able to make it. But we did. And I’m sure he wouldn’t have gone if I hadn’t

just encouraged him. So, I guess maybe that's what my role is, is [to] be a cheerleader, sort of."

(CG5)

CG5 knew how important it would be to P5 to attend the graduation, and she believed he was physically capable. Her "*cheerleading*" helped him make it. This active encouragement contrasts with passive encouragement CG3 provided for P3, demonstrated in the next excerpt below. Along with diabetes and chronic pain, P3 struggled with anxiety and depression related to post-traumatic stress disorder. She developed these symptoms after she was robbed at gunpoint. Afterward, P3 spent much of her time at home, withdrawn from others. When P3 started volunteering in a women's group from her church, CG3 recognized this was good for P3's well-being. However, CG3 wished P3 would socialize more with him, too:

"I do get a little jealous at times, and a little agitated...because the [women's] group goes out and does work in the community...having seen her here, isolating and quiet, and sheltering, and pushing away a lot of public contact...To see her on the move, and doing so much, I usually don't say nothing. It's not my way to, I guess the word is hinder...Because it helps her tremendously...and at the same time, it's odd that my wish for her to be outgoing, and full of life is coming true, except it's more of outside the house, away from the home." (CG3)

CG3 recognized that the best way to support P3 was passively, by not interfering with her volunteering. CG3 sacrificed his desire to be social with P3, putting P3's values ahead of his own. This shows that even when partners' values coincide, the risk of caregiver burden remains. Furthermore, the burden CG3 experienced was invisible to P3. CG3 avoided expressing that he wanted to participate in social activities with P3 because he feared hampering P3's progress.

Together these examples showed that caregivers' understanding of what is important to patients motivated them to support patients, but they also illuminate how this motivation can have darker side effects.

### 3.5.2 *Asymmetric values*

Patients and caregivers often did not share the same values, or they valued the same things to different degrees. We refer to such mismatches as asymmetric values. Two common forms of asymmetry were 1) when the caregiver wanted the patient to take care of their health, but the patient's behaviors or preferences conflicted with this desire, and 2) when the patient attempted to behave in ways they perceived to be healthy but the caregiver did not support this or even

undermined it. When there was asymmetry in values, patients and caregivers often faced a tension between individual autonomy and coordination.

### 3.5.2.1 Patient's health, caregiver's prerogative?

Spousal caregivers are likely to care deeply about their partner's health, but they cannot necessarily expect the patient to share this concern. In the following excerpt CG7 recounted when he encouraged P7 to see a doctor when he thought she was having a heart attack. CG7 feared that P7's health was in jeopardy, but the patient saw no such urgency.

CG7: I married a tough wife...Like she had a heart attack, and she was sick a lot. And I told her to go to the doctor, and she kept staying home. And then, finally, when she did go, she got a stent put in and stuff like that. So, I've got to watch her pretty close because she never tells me.

P7: I wouldn't have gone if he hadn't been so pushy.

CG7: The word is persistent.

P7: Oh, all right. He was very persistent.

When she had symptoms of a heart attack, P7 initially managed her health in the way she wanted, by being tough and not seeing the doctor. P7 did see a doctor in the end, but she had to be persuaded by CG7. The outcome was positive for P7's health because she received critical treatment for a heart attack, but the outcome also infringed on P7's autonomy to a degree because she wasn't able to handle the situation in the way she had wanted. This example shows the tension some partners face between exercising autonomy and coordinating with each other.

Not all patients acquiesced like P7, and repeated resistance by the patient can wear down the caregiver's resolve. CG12 gave up reminding P12 to avoid sugar in his diet because P12 repeatedly reacted negatively when CG12 raised the issue. P12 and CG12 agreed that lowering P12's blood sugars was important because this would enable P12 to have surgery to repair his painful ankle. Despite this, P12 resisted when CG12 urged him not to put sugar on his cereal.

CG12: He thinks I don't see him putting sugar on his cereal. He goes downstairs ahead of me. And he mixes it in with the cereal...but I know.

Interviewer: But you don't say anything?

CG12: I do sometimes. But it doesn't do any good, so I don't—not anymore.

Over time, P12's autonomy won out over CG12's desire to persuade him to change his diet. Because CG12 wanted to maintain harmony in their relationship, it wasn't worth it to CG12 to stir up acrimony with her husband when she didn't believe it would result in P12 changing his

behavior. She judged the matter of P12's sugar intake to be less important than enjoying harmony with her husband during breakfast each morning. Thus, they stopped discussing this disagreement and their asymmetric values became entrenched.

Caregivers demonstrated sensitivity to the potential negative side effects of pushing patients too hard. Caregivers relied on this sensitivity when deciding how best to intercede in a patient's behavior. The next excerpt from P3 demonstrates how CG3 balanced interceding with stepping back:

“Sometimes, he'll let me be, and sometimes he'll try to make me engage into conversation. [...] Like today, he wanted to take me out, just to drive around, and I know that's because...the last three days, I've been going through some of that mess. [...] I actually apologized to him yesterday. I said, “I'm sorry that I'm in this funk.” And he said, “I know.” He said, “I know you've been in there for a few days.” He said since Monday, but I didn't—I don't know. And he said, “I know you've been going through it since Monday, and it's all right.”” (P3)

CG3 knew that P3 tended to become withdrawn when in a “funk.” He handled this carefully by sometimes encouraging her to interact and sometimes leaving her alone. CG3 noticed P3 was in a “funk” even before she did, and he waited several days to broach this with her. From elsewhere in the interview we know CG3 misses interacting with P3, and we also know that P3 can become agitated if she has to interact with others beyond her comfort zone. CG3 had developed sensitivity to the boundaries of this comfort zone. Part CG3's caregiving work is to balance his desire to interact with P3 with respect for P3's autonomy. CG3 helps P3 manage anxiety and depression while allowing her to progress at a rate that is comfortable for her.

### 3.5.2.2 Patients enacting autonomy

Some patients thought that caregivers' attitudes or behaviors disrupted their ability to pursue healthy behaviors. This is another form of asymmetric values. Diet was a common point of contention. In some cases, the patient deemed it important to change their diet and their partner's, but the caregiver resisted attempts to make changes. In the following example, CG3 resisted P3's attempts to introduce healthier foods into their diet and eliminate unhealthy foods.

P3: ...when I try to change our diet—he's a meat and potato man. And I just started throwing kale, trying to make him eat—I think I'm trying to make him eat more healthier than I'm doing myself. But again, he's—that's the hardheadedness, with him...he don't wanna eat salads—he'll eat salads, but if I was to make salad, say two three, maybe three times a week, he'll probably eat it once...

CG3: Well, honey, man wasn't made to eat salad. Ever since he's been bouncing around the cave, he had meat.

In this partnership P3 cooks dinner often, so changes to her diet affect CG3's diet. However, diet is not as important to CG3 as it is to P3, leading to discord. In the context of their relationship, CG3's resistance to changing diet limits P3's autonomy to eat healthier meals. Hypothetically, in order for P3 to eat what she wants to eat, she would have to make corresponding sacrifices. She would either have to cook two separate meals for herself and for CG3, requiring extra work, or she would have to ask CG3 to cook his own meals, which could introduce conflict. In other words, coordinating her diet with CG3's limits P3's autonomy, but changing her diet could disrupt coordination with CG3.

Paying attention to asymmetric values between partners reveals a complex relationship between individual autonomy and collaboration. Pursuing one's values can express and enact one's own autonomy, but this may disrupt coordination with one's partner. Deferring to the values held by one's partner may preserve coordination but can come with tradeoffs for health.

### 3.5.3 *Values and shifting responsibilities*

The activities partners performed to support each other's health and well-being shifted over time, and partners' values played a large role in these shifts. Participants supported each other when they perceived that help was needed, and they adjusted this support over time as their partner's values and health changed. First, I discuss how patients often performed caregiving work, resulting in mutual support. Then I discuss challenges participants faced when they shifted responsibilities, with special attention to the function of values in these challenges.

#### 3.5.3.1 Mutual support

An important finding was that many caregiver participants in our sample were also living with chronic conditions. Many participants we recruited as patients reported performing caregiving duties to support their partner (the person we recruit as the caregiver). This underscores the relevance of the partners' relationship when considering how values shape collaboration between patients and caregivers. When both partners have caregiving needs, both partners act as caregivers.

For example, P6 actively managed diabetes and chronic pain, and CG6 attended medical appointments for his own illnesses two to three days per week. When CG6 got into a car accident and became nervous about driving, P6 said she began driving him to his appointments:

“I did that [weaving] on hook latch. I do this when I'm at [the] hospital this year...My husband goes to [clinic name]. I'll sit there for hours while he's in his mental health classes...Like on Tuesdays, we're there from 9:00 to 2:00. And on Thursdays, we're there from 10:00 to 2:00...I just take him because he doesn't drive much anymore. He got into an accident here and is real nervous about driving. His driving isn't the best anymore. So, I do most of the driving now.” (P6)

P6 sacrificed hours of her time several days per week in service of CG6's health and well-being. This is despite P6 managing her own health conditions. Echoing a finding in Nunes and Fitzpatrick [123], many of our interviews revealed that “caregiver” and “patient” are not necessarily stable roles, and this excerpt demonstrates a clear case in which the “patient” supported the “caregiver.” In the case of mutual support, both partners could be called the “patient” or the “caregiver” depending on the context. In this population, in which the patient has multiple chronic conditions and the spouse is also likely to have chronic conditions, it is more useful to speak in terms of what partners do to support each other than in terms of “patient” and “caregiver” roles. This is particularly true when partners think of themselves as sharing a health condition, rather than associating the illness only with the patient.

### 3.5.3.2 Giving up valued activities

When the patient can no longer perform an activity, the caregiver may take on responsibility for that activity, alleviating the patient's responsibility. However, if the patient values an activity, giving it up can generate difficult emotions. In the following example, CG8 described completing a task that used to be P8's responsibility:

“I went and hosed off our deck because that hasn't been hosed off for a while...He [P8] feels bad he can't do that himself anymore. It's just too hard for him, you know? ...he's worked hard all of his life so it's hard for him. He wants to do stuff but he's just not able to.” (CG8)

Working hard is something P8 values, and it has long been part of his identity. He often experiences extreme fatigue, so performing chores such as hosing off the deck is no longer possible. Giving up this chore and similar ones means P8 no longer perceives himself as a hard worker, and this is emotionally difficult for him. CG8 recognizes this difficulty. She told of how she tries to help P8 overcome the sadness he feels by reminding him of things he does well that she cannot do, such as working with the computer. Together they established new chores P8 is able to perform, such as bringing in the mail each day.

This example shows that when the patient has to give up something they value, the caregiver's expertise regarding the patient's values is very useful. The caregiver is likely to understand the history behind a patient's values. CG8 understood that P8's hard-working identity began when he started working at his father's gas station when he was 12 years old. Someone less familiar with P8's sense of identity might see giving up the chore of hosing off the deck as trivial, but CG8 understands the connection between this chore and P8's well-being. This underscores how the long-standing relationship between partners contributes in subtle ways to either partner's ability to overcome challenges due to health.

### 3.5.3.3 Resuming responsibilities following recovery

Over time, each partner's health may worsen or improve. When a patient's health does improve, they may want to resume responsibilities they passed to the caregiver. Eight months before we interviewed her, P2 had bariatric surgery to help her lose weight. She struggled with chronic back pain and weakness in her legs. Some days she came home from work feeling extremely fatigued. When this occurred, CG2 would 'fill in' for P2:

“[If] I'm having a lot of pain, I'll just say, “Do you mind if I don't do this or that? If I can just not because I don't think I can stand long enough to do that.” He's like, “Yeah, sure.” And he'll ask me if I'm up for walking the dogs yet. And I've actually been able to start doing that, a little bit...Actually, he's been so protective of me that he doesn't let me walk the dogs, and actually, I think I'm ready to start doing that.” (P2)

CG2 helped P2 manage pain and fatigue by walking the dogs for her. P2 loved her dogs, whom she referred to affectionately as “my girls.” At the time of the interview, P2 was ready to walk the dogs again. The last sentence of the excerpt signals that it may be difficult for CG2 to agree to shift the task of walking the dogs back to P2. There is a tension between CG2's protectiveness of P2 and P2's feeling that she has recovered.

Shifting responsibilities is a way for patients and caregivers to overcome limitations of illness together. However, these shifts are consequential. They become part of partners' routines, making it difficult to return to previous arrangements. Furthermore, while well intentioned, one partner's values can reinforce partners' daily arrangements in a way that infringes on the other partner's values. One can imagine a situation complementary to P2's in which the patient recovers. The caregiver may perceive that the patient is no longer suffering and may suggest returning duties back to the patient. The patient may have grown accustomed to freedom from particular duties and

resist taking them back. This resonates with previous findings showing that differences in values can become entrenched.

### 3.6 DISCUSSION

The background and related work section addressed how systems intended to support individuals with chronic illness have focused on the patient (e.g., [10,113]) or the caregiver (e.g., [150]). Recent work has emphasized that patients and caregivers collaborate in daily care activities [123], and thus there is a need to consider how systems can support partners as dyads. Our findings extend this prior work with deep and novel descriptions of values within patient-caregiver dyads. Coinciding and asymmetric values help explain how partners carry out the lines of self-management work articulated by Corbin and Strauss [42]. Caregivers' empathy motivated them to support patients through coinciding values. But, when partners' values were asymmetric, this introduced tensions between individual autonomy and collaboration. Also, values influenced the way patients and caregivers shifted responsibilities to support each other. This support was mutual and both partners acted as caregivers when they both had chronic conditions. Together, these findings illustrate the need for systems to support patient-caregiver dyads rather than supporting one or the other. In the following subsections we emphasize the importance of accounting for partners' values in this design context and discuss implications for the design of systems that support patient-caregiver dyads.

#### 3.6.1 *Designing to account for partners' values*

These findings contribute a new perspective on collaboration in patient-caregiver dyads: how partners' values shape the collaborative work of managing chronic illness. Previous work has explored phenomena such as the division of labor between patients and caregivers [23,123] and the burden of caregiving activities [36,137]. This chapter's findings show how partners' values explain and give context to those phenomena. For example, shifting responsibilities between partners can be particularly difficult emotionally when those responsibilities are tied to the patient's values. As discussed below, there is a need to support partners in recognizing, acknowledging, and coping with values being impacted by the trajectory of chronic illness. This may be particularly important for shared values, where the partnership as well as the individuals are affected.

Among our participants it was common for partners to trade responsibilities over time, especially when both partners managed health conditions. Because of this, the roles of “patient” and “caregiver” depended on the context and shifted over time. This echoes findings in previous studies [123].

These findings suggest that systems should not enforce strict patient and caregiver user roles. Systems should instead enable both partners to perform activities traditionally associated with “patient” and “caregiver” roles. Furthermore, individuals should not be limited to a fixed set of tasks. The system should be adaptable to changes in health, caregiver support, and values.

Partners’ daily activities were intertwined, and partners were deeply familiar with each other’s values and health. This interrelatedness and expertise of partners is a resource for designers. As a point of comparison, MONARCA is a persuasive self-monitoring system developed for individuals with bipolar disorder. It collects data from self-assessments and sensors and uses those data to give users timely, personalized feedback [10,11,114]. Our findings suggest caregivers could be a valuable source of qualitative data to complement patient self-assessments and sensor data. Furthermore, systems like these can leverage partners’ close proximity. It may be more effective for a system to prompt a caregiver to suggest behavior changes to the patient instead of delivering persuasive feedback directly from system to patient.

Our findings support the call in [123] for research involving patients with chronic conditions to consider the patient-caregiver relationship as context for design. In this study we explored marriage as one such context. There are other types of caregiving relationships that deserve scrutiny as well: a parent caring for a child, an adult caring for a sibling, an adult caring for a parent. Recent research has investigated how to support caregiving relationships like these (e.g., parents and teens with complex chronic illnesses [78], parents and children undergoing bone marrow transplants [94,95], blind and sighted companions [26]). Researchers who work with patients and caregivers of any kind should attend to the role of values in the relationship. Patients and caregivers face tradeoffs between protecting and empowering each other [128]. Our findings suggest that focusing on the values of participants in these caregiving relationships can illuminate how they collaborate.

### 3.6.2 *Supporting partners with asymmetric values*

Asymmetric values can disrupt collaboration between partners. There is an opportunity for systems to help partners work through disagreements. Previous work (e.g., [23,123,137]) has not explored how technology can be designed specifically to support this values-related relationship work. This chapter's findings showed that asymmetric values can become entrenched, particularly when communication between partners breaks down, leading to behaviors that one or both partners perceive as unhealthy (e.g., CG12 gave up on urging P12 to stop mixing sugar with his cereal). This chapter also showed that careful handling of asymmetric values can lead to progress (e.g., CG3 pushed P3 to overcome symptoms of PTSD while allowing her to progress at a rate that was comfortable for her).

There is an opportunity for systems to help partners overcome asymmetric values and pursue health and well-being in coordination with each other. An example is *A Diary Built for Two* (aDBFT), a journaling system for cohabitating partners. In that system, each partner shares snippets of journal entries, fostering reflection and communication [25]. The system was designed based on interviews with marriage and family therapists, who prescribe activities for couples such as “re-patterning” (i.e., exploring new ways of interacting in daily life) or “reconnecting” (i.e., sharing experiences and emotions to reestablish common ground and empathy) [25].

Systems like aDBFT could help partners communicate about asymmetric values. Such a system could help partners co-develop new self-care behaviors or reestablish empathy for each other's health needs. However, more work is needed to understand how to adapt systems like aDBFT for this design context. For example, it's not straightforward how such a system would balance private aspects (e.g., reflection on one's own values) with public aspects (e.g., highlighting where partners' values do not align).

### 3.6.3 *Supporting individual autonomy*

In some cases, the patient or caregiver may perceive compromising with their partner to be counterproductive for their health. It was important to P3 to eat more vegetables but CG3 complained when she made salads too often, so P3 didn't eat as healthily as she wanted. While systems like aDBFT could help partners overcome asymmetric values together, it is crucial to also

provide support for individuals like P3 if they choose to manage their health independently of their partner.

This raises questions about the degree to which it is possible to support individual autonomy when partners' lives are closely intertwined. One avenue could be to connect individuals with social support outside their relationship. Through interactions with others who share the same values, an individual may find encouragement and strategies for accomplishing those goals. Some avenues for this could be online health communities or in-person group meetings. For example, CaringBridge ([www.caringbridge.org](http://www.caringbridge.org)) is a website on which patients can share updates with family and friends, receive encouragement, and coordinate caregiving support. Similar work by Skeels et al. [143] investigated the design of systems for individuals to get help from members of their social network to address break downs in caregiving support. Our findings suggest that users of tools like CaringBridge might find it useful to interact with people outside their social network when the issues they want to discuss might be too sensitive to discuss with close family or friends acting as caregivers.

#### 3.6.4 *Limitations and future work*

This chapter's focus on patients and spousal caregivers may not be representative of the way patients receive care from other close family and friends. Prior work suggests that many people, including those with MCC, rely on networks of care that may include multiple informal caregivers, each of whom have their own values and priorities [41,76]. Future work should consider how values are shared and negotiated across such networks. The relationship between values and collaborative self-management is dynamic, and it is possible that the methods used in this chapter only captured participants' lives at one point in time, failing to account for dynamics over time. Future studies could examine these long-term dynamics. The patient sample in this chapter is likely to differ from other patient populations in terms of access to care. All patients in this study had health insurance and had access to a primary care provider and a range of other providers. Not all individuals with MCC have access to these resources, so their health care and self-management could look very different. For example, Senteio and Veinot [139] described the invisible work individuals in low-resource areas performed as part of their self-management work. Another limitation is that the findings have been influenced by the healthcare policy context: Washington state is unique in the United States because legislators have mandated that the perspectives of

patients and family members must be included in treatment decisions [140]. Conducting this study in other locations with different policies may have produced different results. Finally, the way families and patients view illness differs across cultures [173], and spousal relationships differ across cultures as well. Because of this, the relationship between values and collaboration in American culture is likely to be different from other cultures.

### 3.7 CONCLUSION

This chapter demonstrates ways in which patients' and spousal caregivers' values shape how they collaborated to manage MCC in daily life. In many cases, both partners provided care for each other's illnesses, blurring the boundary between "patient" and "caregiver" roles. In general, when partners' values coincided, this facilitated collaboration, although not necessarily always in ways that supported health. Asymmetric values introduced tensions between collaboration and individual autonomy. Patients and caregivers shifted responsibilities over time as their values and health needs changed, but these shifts were challenging when they implicated partners' values. These findings call for future research on patients with MCC to take patient-caregiver relationships into account, and to consider the importance of patients' and caregivers' values for how they collaborate in daily life. Given this rich design context of spousal relationships for managing MCC, this chapter offers suggestions for designers to support partners in overcoming asymmetric values while supporting autonomy for individuals who choose to pursue their values alone.

## Chapter 4. PROVIDERS' PERSPECTIVES ON COMMUNICATION ABOUT PERSONAL VALUES

### 4.1 INTRODUCTION

There is widespread agreement among scholars and policy-makers that high quality patient-centered care involves health care providers understanding and honoring patient values [83]. Understanding values is especially important in care for people with MCC such as diabetes, coronary artery disease, osteoarthritis, and depression. These people face challenges when the symptoms or treatment of one condition has an adverse impact on the self-care of another condition [12]. Making matters worse, people with MCC often disagree with members of their health care team on priorities for self-care and health outcomes [75,153,169], which leads to lower patient satisfaction and poorer health outcomes [145].

For patients with MCC and their providers to reach shared priorities for health care, they must communicate about what patients consider important for their well-being and health (i.e., their personal values). Following previous chapters, this chapter defines personal values as what a person considers important for their well-being and health, including abilities, activities, emotions, possessions, principles, and relationships.

Values elicitation is not a routine part of clinical practice [37,98,170]. As discussed in Chapter 2, previous health sciences research on the incorporation of values in clinical practice has adopted narrower definitions of values than “personal values.” For example, literature on eliciting patients’ values has examined tradeoffs patients perceive between potential health outcomes [61]. This leaves out other aspects of patients’ personal values that may give important context to patients’ health care priorities. There is an opportunity for designers to support new forms of patient-provider communication to help patients and providers reach shared understanding of patients’ personal values. 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, designers need to understand the circumstances under which providers engage with patients’ personal values. To address this evidence gap, this chapter reports on a field study involving 16 providers who cared for people with MCC. The field study included observations of clinic visits and follow-up interviews with

providers to explore how they understand patients' values and incorporate them into care assessment and planning. The study showed that care team members sought to understand the extent to which patients' health issues affected the things they valued. It also found that care team members attempted to persuade patients to change behaviors by communicating how health risks threaten their values. Finally, the study revealed how providers created contexts in which patients felt comfortable sharing their values, and ways providers negotiated localized practices within care teams for eliciting and communicating about patients' values. These findings have implications for the design of interactive systems to support shared understanding between patients and providers about patients' personal values.

## 4.2 RELATED WORK

### 4.2.1 *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 [62]. One proposed solution is to move away from disease-specific guidelines and toward patient-important outcomes [121]. 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 [156,157]. Care teams often include a primary care physician (PCP), plus one or more medical assistants, nurses, pharmacists, social workers, and specialists. This means it is important for design researchers to attend to potential differences in communication between patients and providers in different roles. It also highlights the importance of not only focusing on patient-provider communication but understanding communication among providers as well.

### 4.2.2 *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., [162,163]). 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 [148]. Other studies have assessed the effects of technology on the quality of face-to-face interactions between patients and providers [34,35], and have explored design interventions to improve these interactions, such as providing shared access to health information during conversations [143]. 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.

Prior work in the VITAL project explored MCC patients' perspectives on communicating with providers about values [108]. This chapter extends that work by adding providers' perspectives. To enable better care for patients with MCC, there is a need to understand the circumstances under which care team members engage with patients' personal values. This understanding can provide insight for the design of interventions to encourage care team members to routinely elicit patients' values and incorporate them in Collaborative Care processes.

To address this evidence gap, this chapter pursues the following research question:

*RQ2a: 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, I 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.)

### 4.3 METHODS

As a member of the VITAL project team, I helped plan and conduct a field study with clinical care team members who care for people with MCC. Throughout this chapter, when I use the term “we,” I refer to VITAL project team members. 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.

#### 4.3.1 *Participants and recruitment*

Participants fall into two categories: clinical care team members and patients. Care team members are healthcare providers in different roles, including nine PCPs (D1-D9), six medical assistants (MA1-MA6), and one otolaryngology specialist (S1). There were 16 patient participants (P1-P16). Participants 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 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, patients, and caregivers. 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, we asked patient participants if they with anyone who helped manage their health care, and who attended their visits to the clinic.

#### 4.3.2 *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 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.

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.

#### 4.3.3 *Analysis*

Interview transcripts and field notes were analyzed in Dedoose [171]. Along with one other member of the VITAL team, I analyzed the interview transcripts using thematic analysis [73]. This included open coding, focused coding, and writing themes that emerged in the process of coding. During open coding, we read through transcripts and field notes, generated and applied provisional codes, and met regularly to refine the codebook. During focused coding, we 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 VITAL team members participated in analysis meetings to discuss emerging codes and themes.

### 4.4 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. In the following sections I describe four themes generated by the analysis.

#### 4.4.1 *Judging impact of health concerns on patient values*

In every visit we observed, PCPs listened to patient concerns and made 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. She had been waking up to use the restroom several times at night. D4 sought to understand the extent to which this was affecting P1's life. D4 did this by asking P1 if she had to get up to use the restroom during church. Also, while 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 parents-in-law. 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 that care team members judged the extent to which patients’ health concerns affected things they valued.

#### 4.4.2 *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 their patients did. Sometimes, when PCPs feared long-term and life-threatening consequences of illness, PCP’s thought 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 PCPs used was to communicate their medical concern in terms of patients’ values. By referencing patients’ 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 concerns to the 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. In some cases, providers thought that communicating the severity of health risks, such as the potential for a heart attack, was enough to convince patients to better manage self-care. However, providers felt it was more persuasive to explain how health risks might threaten a patient's ability to pursue their values.

This was especially relevant to patients with asymptomatic health conditions. 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 patients' values was to motivate patients to change their attitudes and behaviors toward self-care. For providers, referring to patient values facilitated more persuasive communication about the seriousness of certain health risks that patients might not perceive as concerning.

#### 4.4.3 *Encouraging patients to share values*

Care team members used strategies to encourage patients to share personal values. 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 that 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 preferences 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 his values, and this understanding shaped her approach to caring for him. 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 the therapeutic relationship with the 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 therapeutic relationships with patients over the long term instead of pushing for patients to adhere to medical objectives in the short term.

#### 4.4.4 *Local practices for values communication within care teams*

The way care teams communicated with each other about patients' values played an important role in how patients' values became incorporated into patient-provider communication, and ultimately influenced the degree to which the patient's health care aligned with their personal values. In this section I describe how care team members engaged with patient values in the context of a collaborative, team-based environment.

Within each care team, different team members engaged with patients in different ways. 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, there was no 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 a care team member's role is a factor in shaping communication about values with patients, but role alone does 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 or communicating risk, as discussed earlier). 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 between care team members were not always clear to providers.

## 4.5 DISCUSSION

These 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 provides a grounded, naturalistic view of an area of concern to designers of interactive systems (e.g., [162,163]): patient-provider communication. The following discussion makes additional contributions by relating the findings to prior work in interactive systems design and suggesting new avenues for future design.

### 4.5.1 *Encouraging communication about patients' values*

In the first two themes we identified two ways in which providers applied knowledge of patients' values to personalize patient care: providers judged the extent to which patients' health concerns affected their values (theme 1), and providers communicated their concerns for the patient's health in terms of their values, making those concerns salient for the patient (theme 2). Research and policy work in health services has called for providers to elicit patients' values and incorporate those into patient care [83]. This chapter shows that providers do this to some extent. However, it also suggests that providers' views on patients' values may be limited, focusing on the utility of patients' values for providers' medically-oriented goals. This may leave out values that providers do not perceive to be directly related to health care concerns. A prior paper from the VITAL project [108] 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.

#### 4.5.1.1 Support focused on 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 [68], so adding additional discussion during visits may take away from other aspects of the patient's care.

Prior work has focused on eliciting patients' health care priorities before visits with health care providers so patients are primed and prepared to discuss these things during the visit. Lyles et al. [112] 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.

The findings reported in this chapter suggest the need to extend tools like this in two ways. First, tools could elicit patients' values instead of just patients' concerns for the visit. The definition of patients' personal values [16,106] offers some guidance for the range of values such a tool could elicit, including principles (e.g., religious faith), relationships (e.g., family), emotions (e.g., sense of accomplishment), activities (e.g., gardening), abilities (e.g., mobility, mental sharpness) and possessions (e.g., woodworking tools). More work is needed to understand whether including these categories in elicitation tools would help care team members understand patients' values. Chapter 6 explores this in more depth.

Second, designers could explore how and when such instruments should be deployed. For example, this chapter's findings showed that care team members specialize in how they engage with patients' 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.

#### 4.5.1.2 Support focused on patients

Many providers may want to know about patients' values, but patients choose not share their values with providers when they do not perceive values to be pertinent to their health care [108]. 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. [111] 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. Education for patients could include reasons why care team members want to know about patients' values.

#### 4.5.2 *Balancing trust with open communication among team members*

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 patients' privacy concerns and patients' 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 [3]. Typically, storage and portability of patients' health data is viewed positively because it enables coordination of patient care among healthcare providers working in different 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 for follow-up care. However, 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. Chapters 6 and 7 explore this in more depth.

#### 4.5.3 *Supporting concordance despite different priorities*

In this section I bring this chapter's findings into conversation with recent work by Bagalkot et al. [9] and Grönvall et al. [72]. They have called for concordance as a design ideal in HCI. Drawing on a report by Horne et al. [80], 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) [80]. Concordance emerged in response to health care practices focused on compliance or adherence. In those practices, 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.

I agree that concordance is a worthy design ideal for supporting patient-provider relationships. There is resonance between my findings regarding patient-provider communication about values and Bagalkot et al.'s [9] and Grönvall et al.'s [72] prior work on concordance. Providers I observed and interviewed 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.

#### 4.5.4 *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. I 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.

I also cannot rule out that patients withheld values during this study in the same ways they reported by Lim et al. [108] in an earlier VITAL paper. It is possible that this biased our view of patient-provider communication about patients' values. Future work could explore this further by analyzing differences in the types of values patients share at home [108] 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). This could potentially inform the design of new roles, or new practices within existing roles, to improve patient-provider communication about values.

I 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.

#### 4.6 CONCLUSION

This chapter contributes 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 (i.e., categories of personal values), and educating patients about ways in which 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 research community regarding concordance as a design ideal by pointing to some challenges we face in supporting concordance in practice.

## Chapter 5. EXTENT OF VALUES COMMUNICATION IN CLINIC VISITS

### 5.1 INTRODUCTION

In the context of health care for multiple chronic conditions (MCC), patients and providers face challenges due to the competing demands of health care. Since clinical care guidelines are typically oriented toward single chronic conditions, health care providers face difficulties when guidelines for different conditions conflict [62]. People with MCC (patients) face challenges when self-care for one condition conflicts with self-care or symptoms associated with another condition [12]. Furthermore, patients potentially face conflicts between symptoms of illness, self-care, and the demands of daily life [136]. Thus, for both patients and providers, health care for MCC can involve making difficult decisions among competing demands. This can mean prioritizing care for one condition over others or prioritizing other aspects of life over caring for chronic conditions.

Unfortunately, it is common for patients and providers to prioritize differently. Zulman et al. [169] 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. When patients' and providers' decisions about healthcare priorities do not align, patient experience and health outcomes are worse [144,153,169]. For example, Staiger et al. [144] 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.

Patients' personal values—what they consider important or meaningful in everyday life [106]—shape decisions they make about their health care priorities [57]. Thus, it is important to support patient-centered communication between patients and providers that incorporates patients' values [83]. Early work from the VITAL project by Lim et al. [108] described perspectives on incorporating personal values in care, and Chapter 4 described providers' perspectives [15]. This previous work has 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. This chapter addresses this evidence gap by pursuing the research question:

RQ2b: To what extent does patient-provider communication reflect what's important to patients in clinical settings?

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 [61]. This potentially neglects the range of things patients value in their daily lives. Early work in the VITAL project described the breadth of patients' personal values by developing a patient-centered values framework [16,106]. This work provided 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) [16,106]. In this chapter, I 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.

This chapter will report on a field study conducted with people with MCC and members of their health care team. As a member of the VITAL team, I helped observe clinic visits and conduct interviews with patients, caregivers, and providers to capture their perspectives of those visits. This chapter makes two contributions to computer-supported cooperative work (CSCW). First, it delivers 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 patients' values. Previous work in this area relied primarily on interviews with patients or care team members, leaving a gap of evidence from actual practice [14,106,108]. Second, this chapter characterizes 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 [82,93], and perceived communication boundaries between patients and providers [108]. Based on these findings, I discuss implications for future research and design to understand and support communication about values between patients with MCC and their healthcare providers.

## 5.2 METHODS

As in previous chapters, when I use the term "we" in this chapter I am referring to the VITAL project team. 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.

### 5.2.1 *Participants*

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 and caregiver demographics are reported in Table 4. Unfortunately, we did not collect demographic information from care team members. Thus, no table is included with this information.

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. 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. To reduce the burden of participating, we allowed patients to 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 [12], and care for multiple chronic conditions is often more effectively coordinated than treating each condition in isolation [92]. Additionally, self-care for 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 4. Patient and caregiver demographics

Characteristics	Patient (N=16)	Caregiver (N=8)	All (N=24)
<i>Age</i>			
Mean	69.19	N/A	N/A
Range	50-86		
<i>Gender</i>			
Male	10	3	13
Female	6	5	11
<i>Race and Ethnicity</i>			
White/Caucasian	12	7	19
Black/African American	2	0	2
White and Native American	1	1	2
Hispanic, non-white	1	0	1
<i>Education</i>			
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

## 5.2.2 *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.

### 5.2.2.1 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.

### 5.2.2.2 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.

### 5.2.2.3 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.

#### 5.2.2.4 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).

#### 5.2.2.5 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.

#### 5.2.2.6 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 [106]. 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.

### 5.2.3 *Analysis*

We adopted a template-based approach [45] to qualitative thematic analysis [28] in which we applied the categories of the patient-centered values framework developed in prior work [16,106]. This framework offers a preliminary set of six domains that capture a range of patients' personal 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 [40,51,127].

For each case, another VITAL project team member and I 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 [73] 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. Along with the other VITAL team member, I coded and analyzed transcripts and field notes. During this process, we independently conducted open coding over the cases, discussed codes and code definitions, and consolidated and refined codes by consensus. This established a shared codebook. I then re-coded the cases using the established codebook. During this process, I wrote memos to group codes and articulate these as themes. All VITAL team members 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 [40,51,127].

### 5.3 FINDINGS

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

#### 5.3.1 *Activities*

Activities are 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.

#### 5.3.1.1 Valued activities affected by illness

Patients often shared that their 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, in other cases patients did not 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 in interviews with me 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. I explore the implications of sharing or withholding values in more depth in the discussion section.

#### 5.3.1.2 Valued self-care activities

Often patients expressed that it was important and meaningful for them to perform activities of self-care. The valued activity itself was health-related. 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 from P16 about not disclosing her pottery hobby, and provides further evidence that patients share some valued activities with providers but withhold others.

### 5.3.2 *Abilities*

The values framework defines abilities as physical or mental capacities or skills. We observed discussion of abilities in many visits. Typically, patients and providers addressed abilities in terms of 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.

### 5.3.2.1 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. Eyesight can worsen if blood sugars are not kept low. 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.

### 5.3.2.2 Different perspectives on abilities

In many cases, patients and providers expressed different perspectives on valued abilities. Patients often expressed abilities in relation to their identity or self-worth, while providers tended not to make these aspects salient.

In one example, 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 acknowledged 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 referenced 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 [my daughter, CG8]. 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 saw herself as independent, but her back pain emerged periodically and limited her ability to vacuum. When this happened, she felt 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 and being self-reliant. Instead of focusing on P8's back pain, PCP7 prioritized discussing diabetes because she perceived that the potential long-term consequences of diabetes were not salient enough to P8 in her 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.

### 5.3.3 *Principles*

Principles are 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 in the clinic, 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 discussed 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. Patients’ beliefs like these are relevant to patient-provider communication, but they are not central to the research question about the extent to which in-clinic conversations reflect patient values from everyday life.

#### 5.3.4 *Relationships*

Relationships are connections with others, such as family members, friends, or co-workers. 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, PCP3 and P13 were discussing how he preferred not to walk as a form of exercise because it hurt his ankles. CG13 interjected. The following excerpt from a field note captures the moment:

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 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 that 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.

### 5.3.5 *Emotions*

The values framework defines emotions as feelings or moods, 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 or 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.

### 5.3.6 *Possessions*

The values 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.

### 5.3.7 *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 domains of values 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.

## 5.4 DISCUSSION

In this chapter, I 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. I 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. I 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 [106] and Chapter 4 reported on interviews with providers [15]; this prior work gave patients' and providers' perspectives toward discussing values in clinical settings. This chapter fills a gap left by this prior work by presenting evidence from actual clinical conversations.

In the subsections that follow, I characterize the inherently cooperative work patients and providers engaged in to coordinate their distinct perspectives and establish connections between patients' values and health concerns. I relate this coordination work to prior research in computing, health services, and medical sociology. I also propose directions for future research and design to support patient-provider communication about values.

#### 5.4.1 *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 [7]. For example, from the medical sociology literature, Toombs [151] 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 [44], 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.

This chapter's findings extend this prior work by demonstrating different conditions under which different aspects of patient's personal values are 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 [108]) or when providers don't elicit multiple facets of values (e.g., discuss an ability, but not an associated 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 to 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 [117] 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 patients' values, and accounting for these values when addressing 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. [148] found 11 topics that patients discuss with providers over secure messaging, including medications, appointments, lab tests, and emotional needs. Prior work has not used secure messaging to facilitate communication about patients' values. For example, PHRs might enable patients to describe values from daily life or even provide photographs of them, rather than share them verbally during time-bounded 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.

#### 5.4.1.1 Supporting translation and operationalization of patients' 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. [93] 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. This chapter describes 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. [82], in which individuals with diabetes operationalized personal, often tacit knowledge so they could share it meaningfully with other people with 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 (i.e., values that could be easily operationalized within what she understood to be the boundaries of her care). Previous research reported that in interviews, patients said they filtered and withheld values from healthcare providers [108]. This chapter extends this work with evidence of this filtering and withholding occurring in 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.

#### 5.4.1.2 Supporting adequate understanding of patients’ values

This chapter has shown 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 as a child had experienced emotional abuse regarding her weight, and PCP2 knew to avoid the topic or broach it carefully. Similarly, PCP4 knew P1 was very religious, and even knew P1’s pastor personally. When providers had developed this level of understanding, this enabled them to make decisions about patients’ health care that

wouldn't be possible otherwise. This resonates with findings in Chapter 4 about providers striving to understand the “big picture” of the patient's life, including factors outside their health care.

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. They worked with P7 to understand her physical capabilities and agree on the right kind of knee brace to order. In interviews, 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 (a 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 [144,153,169]. The findings in this chapter suggest that deep, intimate understanding of patients' values can improve the patient-provider relationship. This chapter also reveals a middle ground in which a provider's general understanding of patients' values will suffice.

Based on 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.

#### 5.4.2 *Limitations and future work*

This chapter's findings have shown patients' personal values functioning in two ways, but the methods used 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 of 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 shift over time [15]. Dang et al. [47] 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.

Also, the view of 5 patients in this chapter was limited by their decision not to participate in the home visit (P5, P6, P10, P11, P14). We did observe how their values were discussed 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.

## 5.5 CONCLUSION

When patients' decisions about health care priorities conflict with those of their health care providers, patients' health outcomes suffer. This chapter reports on a field study conducted to understand the extent to which 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 the patient-centered values framework [16,106], and discussed patterns that emerged within and across these 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.

## Chapter 6. CO-DESIGNING SUPPORT FOR COMMUNICATION ABOUT PERSONAL VALUES

### 6.1 INTRODUCTION

One reason people with MCC experience poorer health outcomes is discordance in health care priorities between patients and healthcare providers [68,153,169]. Standard approaches to care for chronic conditions like the Collaborative Care model [154] rely on patients and providers to make decisions about health care together, but this approach breaks down for people with MCC. In order to reach concordant priorities for MCC care, there is a need to support better communication between people with MCC and their healthcare providers about patients' personal values.

In this chapter I use the same definition of personal values from previous chapters: what people with MCC consider important for their well-being and health [16,106]. This definition includes six categories that describe the breadth of patients' personal values: activities (e.g., reading, exercising), abilities (e.g., mobility, vision), emotions (e.g., serenity, joy), possessions (e.g., photographs, car), principles (e.g., independence, honesty), and relationships [106].

Several barriers prevent patients and providers from discussing personal values. In an earlier paper from the VITAL project, Lim et al. [108] showed that patients often do not perceive what's important in their daily lives as pertinent to their healthcare, so they withhold or filter this information from providers. In Chapter 4, I showed that providers often strive to understand what's important to patients, but they tend to deploy this understanding in service of their own priorities, potentially overshadowing patients' priorities [15]. As a result, patient-provider communication about patients' personal values remains limited [14]. Using evidence from observations of clinic visits, Chapter 5 elaborated on the extent to which values are discussed.

While Chapters 3-5 used the qualitative empirical methods of interviews and observations, this chapter uses co-design activities with patients, caregivers, and providers to envision and give form to possible systems to improve shared patient-provider understanding of patients' personal values.

In Part I, a series of co-design activities with patients, caregivers, and providers generated seven design dimensions, each of which characterizes a different way in which co-design participants' ideas varied. In Part II, VITAL project members and I used these design dimensions

to generate three design concepts and presented these concepts in focus groups to scrutinize tensions within and across the design dimensions.

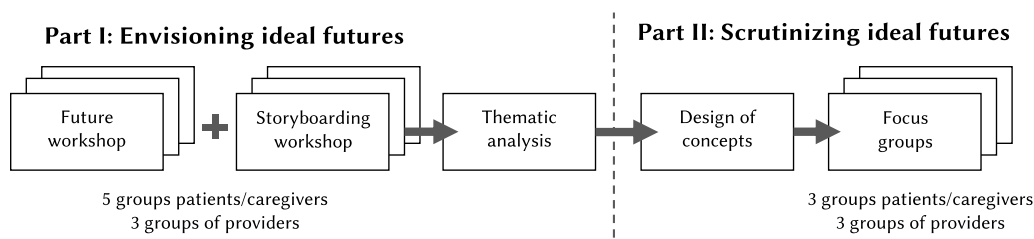
This chapter makes two principal contributions to human-computer interaction (HCI). First, I present the design dimensions as “intermediate-level [design] knowledge” [79]. These dimensions clarify the space of possibilities for supporting patient-provider communication about values. I define and illustrate these dimensions with concrete examples from co-design activities. Second, by discussing these findings in relation to active streams of research in HCI, I suggest future directions for supporting patient-provider communication, including contexts beyond personal values and MCC care.

## 6.2 STUDY OVERVIEW

This chapter describes a two-part co-design study to envision and scrutinize ideal support for patient-provider communication about personal values. This chapter pursues the following research question:

*RQ3: How do patients, caregivers, and providers envision designing support for patient-provider communication about patients’ personal values?*

Figure 3 shows an overview of the methods used. The purpose of Part I (Section 6.3) was to generate ideas for products, services, and systems to help incorporate patients’ values in patient-provider communication in an ideal future. The purpose of Part II (Section 6.4) was to scrutinize the ideas generated in Part I to understand and clarify the most promising future directions for



**Figure 3. Overview of methods.**

design. All activities were approved by the institutional review board at Kaiser Permanente Washington Health Research Institute. As with previous chapters, I conducted this research as a member of the VITAL project team. When I use the term “we,” I’m referring to VITAL team members.

### 6.3 PART I: ENVISIONING IDEAL FUTURES

Part I involved co-design activities with three groups of providers (n=19) and five groups of patients and caregivers (n=32). Each group completed two workshop sessions in consecutive weeks. In the first week, workshop procedures were modeled after the Future Workshop [90,118] to generate ideas (Section 6.3.1), and in the second week, participants created storyboards to explore potential implementations of those ideas (Section 6.3.2).

Patient and caregiver participants were recruited from three outpatient clinics in an integrated healthcare delivery system in the United States. To be eligible, patients had to have type 2 diabetes and at least two of the following: depression, osteoarthritis, or coronary artery disease. Caregivers were recruited by asking patients if they knew or lived with someone who helped them with their health care. Providers were recruited from outpatient clinics in the same healthcare system as patients, and included primary care physicians (PCPs), physician assistants (PAs), registered nurses (RNs), and medical assistants (MAs). To be eligible as a PCP, the provider had to care for people with MCC. To be eligible as a non-physician, the provider had to be a member of a care team lead by an eligible PCP.

Table 5 lists workshop sites and participants. Groups of patients and caregivers have the prefix PCG- and provider groups have the prefix PR-. We chose to keep patient and caregiver sessions separate from provider sessions for three reasons. First, we wanted to engage patients and caregivers for longer (90 min) than healthcare providers' schedules allowed (45 min). Second, we anticipated that power differences between patients and providers might dampen participation from patients. Last, we anticipated that these stakeholder groups would focus on different aspects of patient-provider communication; conducting workshops separately freed facilitators to explore their distinct perspectives.

Workshops were conducted in a private room in clinics from which participants were recruited. Video and audio were recorded for each workshop. Along with another member of the VITAL team, I co-facilitated the workshops, with assistance from another team member for setup, the consent process, distribution of incentives, and cleanup. When I use the term "facilitators," I am referring to myself and my teammate. Lunch was provided to all participants and each received \$100 upon completion.

Table 5. Participants in Part I, future and storyboarding workshops.

Group	Site	Participants
PCG1	1	P1, P2, P3, P4, P5, P6, P7
PCG2	1	CG1, CG2, CG3
PCG3	2	P8, P9, P10, P11, P12, P13, P14, CG4, CG5, CG6
PR1	1	PCP1, PCP2, PCP3, RN1, MA1, MA2
PCG4	3	P15, P17, P18, P19, P20, P21
PR2	4	PCP4, RN2, MA3, MA4, MA5, MA6
PCG5	3	P22, P23, P24, P25, CG7, CG8
PR3	5	PCP5, PCP6, PCP7, RN3, MA6, MA7, MA8

### 6.3.1 *Future Workshop session*

These workshops followed a Future Workshop [90] format, including an introduction to the problem, critiquing the present, and envisioning ideal futures.

#### 6.3.1.1 *Setting the stage*

Informed consent was obtained from all participants. We began by defining “personal values” as “what a patient identifies as most important for well-being and health,” and by giving the rationale for encouraging patient-provider communication about personal values.

For PCGs, participants individually filled out a worksheet with two prompts. The first prompt was, “What is most important to your well-being and health?”, accompanied by the six categories of personal values established in prior work (abilities, activities, emotions, possessions, principles, relationships) [14,16,106]. Examples further illustrated the kinds of personal values participants might consider. The second prompt was, “Who do you count on most for your well-being and health?” and included examples (e.g., PCP, spouse). Participants were asked to reflect on the people with whom they discuss the personal values they listed.

In PRs, facilitators defined the six categories of patients’ personal values [106] and gave examples from prior research [14] to explain when and why patients might share or withhold this information with providers. Facilitators prompted providers to reflect on their experiences interacting with people with MCC in clinical settings.

### 6.3.1.2 Critique the present

Next, facilitators lead participants in an exercise to critique current patient-provider communication practices, with a focus on personal values. Facilitators provided each participant with a printed storyboard and read it aloud. The storyboard centered on a fictional person with MCC (“Gary”) and his spouse (“Sharon”). The scenario reflected findings from previous research involving people with MCC and their healthcare providers [14,15,108]. In the scenario, Gary feared he would no longer be able to bake cookies with his grandchildren (an activity he valued) because of symptoms related to chronic pain and depression. When Gary visited his doctor, they discussed his symptoms and lab results but did not discuss how his symptoms affected his ability to bake with his grandchildren. Additionally, Sharon told the doctor about Gary eating cookies, reflecting her concern that this raised his blood sugar. Later, Gary’s grandchildren called to bake cookies together, but Gary was unable to participate due to fatigue and pain.

Facilitators invited participants to critique the scenario. As participants spoke (e.g., “Doctor is not open to suggestions,” “Gary didn’t speak up”), a facilitator recorded participants’ critiques on a flip chart. At the end, a facilitator read the list of items and invited participants to amend it. The outcome was shared understanding among participants about problems with current patient-provider communication about values.

### 6.3.1.3 Envision ideal futures

Facilitators lead an ideation session in which participants responded to the prompt: “In an ideal future, how might we improve communication between patients and providers so they both understand what is most important to the well-being and health of patients?” Facilitators encouraged participants to reflect on their experiences and on the critique from Section 6.3.1.2. Facilitators established ground rules for ideation: one voice at a time, every idea is a good idea, no judging, encourage wild ideas, quantity over quality, and have fun (inspired by [174]).

Participants wrote ideas on post-it notes, and facilitators placed them on the wall. Facilitators grouped similar ideas and participants were invited to suggest alternate groupings. After participants finished generating ideas, facilitators read the ideas out loud and prompted participants to add or clarify ideas. Next, facilitators asked participants to label the groups of ideas (e.g., “Appeal to human side,” or “Preparation for visit”), and compiled the labels on a flip chart. These

comprised a set of themes that summarized the ideas participants generated. Finally, facilitators asked each participant to write down and submit three themes that were most important to them.

#### 6.3.1.4 Preparation between workshops

Facilitators reviewed the themes to determine which to focus on during the storyboarding workshop session the following week. Facilitators prepared a half page summary of the three themes rated most important by participants and which aligned with the design problem. Each summary included a title, short description, and a list of relevant ideas generated during the Future Workshop.

#### 6.3.2 *Storyboarding Workshop session*

The purpose of this session was to elaborate ideas generated in the future workshop and show how they could be implemented. Participants worked in small groups of two to four. Facilitators began the session by reviewing themes from the future workshop and soliciting additions or clarifications. This served as a member-checking activity and re-oriented participants to the ideas they had generated. Then, each group was assigned a theme (e.g., “Preparation for visit”) and was asked to show on storyboards an ideal first visit between a patient and a new primary care team, with special focus on products, services, and systems that would help accomplish the theme. The purpose of focusing on a first visit was to encourage participants not to take issues of trust and relationship-building for granted when considering how to support communication about values.

Afterward, each group was asked to create a “sequel storyboard” to show how the patient and providers would interact at a future visit (at least six months later) after something in the patient’s life had changed (e.g., a change in health or a change in personal values). In contrast with the first prompt, the sequel prompt encouraged participants to show how a patient and their providers might interact after having established a relationship.

Finally, a member from each small group presented their storyboards to the larger group. Following each presentation, facilitators lead discussion about the features of the storyboards that stood out (e.g., “scribe takes notes,” “doctor listens actively”) and wrote these on a flip chart. The artifacts resulting from the storyboarding workshop were a pair of storyboards from each small group (2-3 small groups per workshop session) and an associated list of key features.

### 6.3.3 *Analysis*

Analysis of the future and storyboarding workshops began as soon as the first workshop sessions concluded and continued until all workshop sessions were completed. It became clear early that participants were generating a variety of divergent ideas. Our team decided to focus analysis on characterizing the diversity of ideas through a template-based, thematic analysis [73].

Workshop facilitators produced a written summary for each of the PCGs and PRs (8 total groups, 16 total workshop sessions). These summaries followed a template to extract key information and organize it for subsequent analysis. The template included themes from critiquing the present, themes representing ideal futures, and ideas generated in storyboards. These summaries were produced through review of artifacts produced in the workshops (e.g., lists of problems and themes, post-it notes, storyboards) and review of video and audio recordings. In the months during which the workshops occurred, workshop facilitators shared these workshop summaries, artifacts, and other findings in research team meetings. This cultivated a shared understanding among team members about the discussions and artifacts produced in the workshops.

Next, excerpts from workshop summaries were grouped according to emerging themes. Provisional themes were named, and short definitions written, and these were distributed and discussed among all authors. Through comparison of excerpts to excerpts, excerpts to themes, and themes to themes, researchers continually revised theme definitions and combined and split themes as needed. This process was repeated to refine the themes until they became stable.

### 6.3.4 *Part I findings: Design dimensions*

The final set of themes includes seven dimensions that characterize the diversity of participants' ideas for supporting patient-provider communication about values: Explicitness, Scale, Synchrony, Intimacy, Guidance, Effort, and Disclosure. Each dimension expresses a spectrum along which some quality of participants' ideas varied. We included these dimensions because they emerged empirically in analysis of participants' ideas for design. Several factors may have influenced which dimensions were expressed (e.g., the worksheet from Section **Error! Reference source not found.** or facilitators' interactions with participants) and which were not.

*Explicitness*: the degree to which patient-provider communication is a deliberate effort to elicit personal values versus an indirect process in which values emerge spontaneously. A storyboard by P11, P12, and CG5 represented the most explicit end of this dimension. In this storyboard, the “patient would be emailed or mailed a questionnaire.” The questionnaire would ask the patient about what’s important to them, the patient would write their responses, and the provider would review the responses before the patient’s next clinic visit. In the storyboard the provider said to the patient, “I feel I know you already.”

A storyboard from CG3 illustrates the implicit end of the explicitness dimension. Figure 4 shows the first panel (personally-identifying information is redacted). In this example, the patient’s values are not elicited directly. An in-home monitoring technology called a “digital angel” would “see how [the patient and caregiver] spend their day” and “see how they’re doing.” The digital angel would relay this information to the patient’s healthcare providers. This information would support a later conversation involving the patient, caregiver, and care team to “learn about the family.” The storyboard implies that the digital angel and the home visit would help the care team learn about what’s important to the patient and caregiver, but the storyboard does not include explicit elicitation of this information.

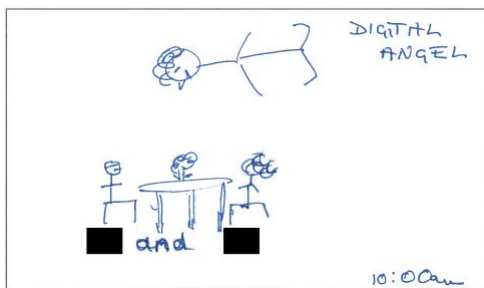


Figure 4. Storyboard panel with Digital Angel.

These examples raise questions about the consequences of designing technologies that fall at different points along the Explicitness dimension. Relying on patients’ values to emerge implicitly might leave room for the doctor to misinterpret what’s important to the patient. On the other hand, it may feel unnatural to the patient to explicitly share values without first establishing rapport through more general conversation with their provider. This resonates with findings from Chapter 4 in which providers worked at forming and maintaining relationships with patients so patients would feel comfortable sharing personal values.

*Scale*: the number and type of people engaged in the conversation. On the smallest scale, the patient meets with one provider (e.g., PCP). At larger scales, additional people from the patient’s

life (e.g., caregiver) and additional providers (e.g., MA, RN) may become involved. The storyboard by P11, P12, and CG5 provided an example of small-scale communication (one-on-one). Later panels of the storyboard by CG3 above illustrated larger-scale communication (patient and family member meeting with a group of providers). As an example of the largest scale communication, PCP1 and RN1 depicted a bus transporting the PCP, RN, MA, social worker, pharmacist, and scribe to the patient's home for a visit.

Some storyboards represented varying Scale at different points in the care process. For example, the "bus" storyboard by PCP1 and RN1 included a later step in which an MA followed up with the patient by phone or email to review and confirm the scribe's record of the large group discussion. Some storyboards showed conversations among providers without the patient (e.g., the PCP and MA meet to refresh their memory of a patient's values).

The Scale dimension sheds light on different kinds of roles needed to elicit and understand patients' values. For example, multiple PR groups included a scribe to create a written record of patient-provider conversations so providers could focus on the patient. One group from PR3 included a health coach to educate the patient about interacting with providers effectively. A group from PCG4 included a medical coordinator to "help the patient understand how health challenges are connected to other aspects [of life]," such as social activities and emotional well-being.

*Synchrony*: the degree to which discussion about personal values happens in real time (synchronously) or not (asynchronously). Multiple groups suggested freeing more time during clinic visits for synchronous discussion of patients' values. One method for this was to use asynchronous communication prior to visits to address routine medical topics. A group from PR2 suggested that an MA should message the patient through the electronic health record before a visit to ask for current health issues, medications, and family medical history. This would free time during the visit to focus on the patient's values.

Participants also suggested eliciting what's important to patients asynchronously. Participants thought this approach could be beneficial for the patient, giving them time to reflect on and share what's important to them at their own pace, outside the pressures of a time-constrained clinic visit.

*Intimacy*: the degree to which patients' values are shared and heard in a personal, caring context, as opposed to an impersonal one. Several storyboards created by PCG groups highlighted aspects of patient-provider communication that make it feel more intimate. In separate storyboards, P1/P2 and P3/P4 showed how a provider's body language can signal interest and understanding of

patients' values. Other examples include touching the patient's arm to "establish a personal bond" (P1/P2), listening attentively and clarifying to make sure they understand the patient, and showing compassion (P22, P23, CG7). While some of these methods (e.g., touch) would require in-person engagement, some participants suggested that body language and eye contact could be achieved through other media, such as phone or video (P11, P14, CG6).

These examples show how moment-to-moment dynamics of patient-provider communication influence intimacy, but other examples show that longer-term dynamics also play a role. For example, P3/P4 showed a provider reviewing a patient's medical record to recall what's important to the patient. Based on this review, the provider asked the patient, "Have you been on any good hikes lately?" This question enables the patient to discuss how neuropathy (pain resulting from diabetes) does not allow them to hike. In this case, the patient feels that the conversation is personal because the provider asked the patient about something important to them that they had discussed in a previous visit. This intimacy is supported by recording what's important to the patient in the medical record and revisiting this information over time.

*Guidance:* the level of support and direction given to a patient to indicate or influence what they should share. This includes communicating to the patient a range of personal values they might share, why values are pertinent to their healthcare, and why providers are interested in understanding values. Some storyboards illustrated how providers could phrase questions about patients' values. Some prompts elicited specific information, such as, "What do you enjoy in life?" (P1/P2), and "What activities, hobbies, interests are you involved in?" At the other end of this dimension, many storyboards did not include content-related guidance, but instead used open-ended questions (e.g., D6/MA8). Several storyboards had people other than the provider provide guidance to patients. For example, P5/P6/P7 suggested the patient should have a "sidekick" (friend or family member) attend the visit to help fill in details about the patient's values.

*Effort:* the degree of burden patients or providers associate with how the patient's values are shared, collected, or reviewed. The "digital angel" example above illustrates very low effort required of the patient, since the in-home monitoring device does not require the patient or caregiver to perform any activities that are out of the ordinary. Other examples, such as mailing the patient a questionnaire, represent higher effort, since the patient must spend time thinking about what is important, respond to the questions in writing, and mail the responses. How a questionnaire

is implemented would entail different levels of effort, since a paper questionnaire requires returning the responses by mail, whereas an electronic questionnaire would not require this effort.

Several storyboards distributed effort across provider roles. For example, as mentioned above, some storyboards enrolled a scribe to record the content of patient-provider conversations to free providers from this effort. In other examples mentioned above, an MA would expend effort before the visit to understand the patient's concerns for an upcoming visit so the provider would be freed from this effort during the visit.

*Disclosure:* the degree to which the patient controls what information is collected or shared, and with whom it is shared. For example, the “digital angel” provides very little control over what information is recorded and shared with the provider. The device indiscriminately records audio and video of patient and caregiver activities. A patient might be willing to expose themselves to this monitoring if they believed it would help the provider understand their values. In contrast, another patient might reject such a tool because they prefer to retain control over what is disclosed. Other storyboards allowed patients to retain more control over what they disclose, and to whom. For example, on a questionnaire or in a face-to-face conversation with a provider, the patient can choose what to share and what to withhold.

## 6.4 PART II: SCRUTINIZING IDEAL FUTURES

The seven dimensions described in section 4.2 characterize patterns across participants' ideas for supporting patient-provider communication about patients' personal values. Upon completing Part I our team faced the challenge of moving the design process forward. This was challenging because the volume and diversity of participants' ideas suggested many potential avenues.

In Part II we aimed to explore some future directions systematically. We created design concepts to probe these directions in focus group discussions with patients, caregivers, and providers. Rather than create concepts to test every possible future direction, we focused on variations along the Explicitness dimension. We chose this dimension for two primary reasons. First, we expected there to be a range in patients' abilities for articulating personal values (e.g., some may not be willing or able to respond in writing). Creating design concepts that vary in Explicitness enabled us to explore perspectives on these abilities. Second, in participants' storyboards, variations in Explicitness placed constraints on how other dimensions could be expressed. Thus, representing varying degrees of Explicitness would enable us to foster

conversations about tensions across the seven design dimensions. For example, choosing explicit elicitation through a questionnaire would provide an entry point for conversations about Guidance (e.g., How narrowly should the questions be framed?), Effort (e.g., How long would it take patients to fill out, or providers to review?), and Intimacy (e.g., If the questionnaire were submitted electronically, could the patient judge whether providers considered their responses thoughtfully?), among others.

## 6.4.1 *Design Concepts*

### 6.4.1.1 Design Process

We used an iterative approach to create three design concepts in the form of storyboards. Each storyboard demonstrated how a new product, service, or system could facilitate elicitation of patients' personal values. The storyboard format enabled us to show how new practices could unfold in action, and how those practices could be supported.

We started by reflecting on participants' storyboards and the design dimensions generated in Part I. Team members sketched ideas, some inspired directly by participants' Part I storyboards (e.g., survey, monitoring device). We reflected on how clearly the sketches expressed the dimensions, how they revealed tensions across dimensions, and the discussions we expected them to generate among participants. The outcomes of this process were three design concepts (storyboards): Survey, Camera, and Clip.

*Survey:* We intended for the Survey to represent the most Explicit approach to values elicitation. With the Survey, patients are asked deliberately and directly to write responses in a structured format. In the storyboard, a provider sends the patient a survey to elicit the patient's values. The storyboard depicts a survey delivered through a touchscreen tablet, but the captions indicate that the patient could receive the survey in any form they preferred (e.g., paper).

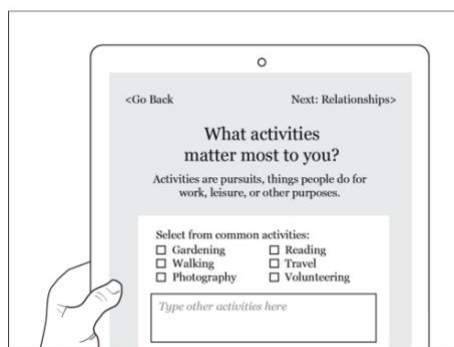


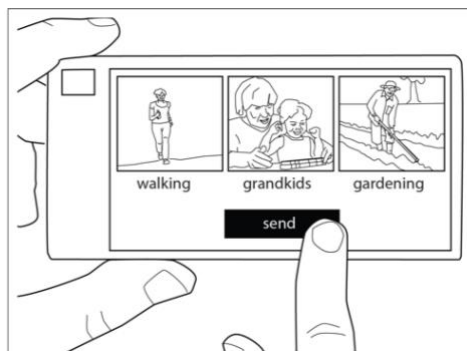
Figure 5. Panel from the Survey storyboard.

The survey is structured around the six categories of personal values from prior work [16,106]: activities, abilities, emotions, possessions, principles, and relationships. The patient answers a question for each domain, e.g., “What activities matter most to you?” Beneath each question, a list of suggested answers (e.g., gardening, photography) are provided for selection, and the patient can also give free-text responses. The patient submits survey responses to their primary care team. All members of the care team can view the responses and the primary care provider (PCP) reviews the responses before the patient’s next visit to the clinic. During that visit, the patient and PCP refer to the patient’s responses while making decisions about the patient’s care. Figure 5 shows one panel from the storyboard.

The Survey represents points along other dimensions in addition to Explicitness. Responding to a survey requires a moderate degree of time and concentration (Effort). The survey is structured around the six categories of personal values and enables the patient to select predefined options for each category (Guidance).

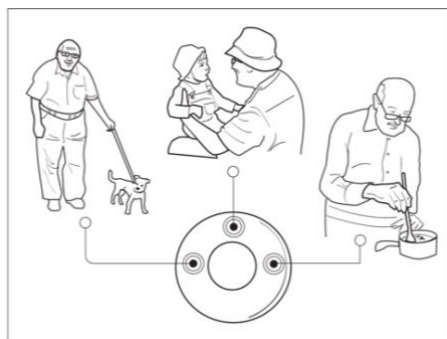
*Camera:* The Camera design concept demonstrates elicitation that is less Explicit than the Survey. Like the Survey, the Camera prompts the patient to reflect on and share what matters to them, but the patient is able to share this visually, without writing. In the Camera storyboard, the PCP gives the patient a camera and asks them to photograph personal values. The patient carries the camera with them and takes photographs during daily life. If desired, the patient can label photographs with a short caption. The patient sends the photographs to their providers. The PCP reviews the photographs before the patient’s next visit, and the patient and PCP discuss the photographs during the visit. Figure 6 shows one panel from the storyboard in which the patient submits photographs of three values.

The Camera design concept represents points along other dimensions in addition to Explicitness. Unlike the Survey, the Camera does not provide the six categories of personal values, and there are no predefined choices suggested for selection (less Guidance). The Camera also raises questions about Effort and Disclosure. For example, patients may find it easier to take photographs than to write responses (less Effort), but they may perceive sharing photographs as an invasion of privacy (less control over Disclosure). Providers might find it takes less Effort to review photographs than to review written survey responses.



**Figure 6. Panel from the Camera storyboard.**

*Clip:* We created the Clip design concept to represent the least Explicit form of elicitation. Unlike the Survey and Camera, the patient is not asked directly to reflect on and share what matters to them. In the Clip storyboard, the patient wears a device that collects video, audio, and biometrics from the patient's behaviors and conversations. From these data, an algorithm automatically infers what matters to the patient. Figure 7 shows one panel from the Clip storyboard. This panel shows the clip capturing data about the patient walking his dog, spending time with his grandson, and cooking.



**Figure 7. Panel from the Clip storyboard.**

The Clip involves other dimensions in addition to Explicitness. The Clip represents the lowest Effort on the part of the patient. Depending on the format in which the algorithm presents values to the provider, the Clip may also represent low Effort for providers. Like the Camera, the Clip raises questions about patients' willingness to give up control over sharing personal information (Disclosure).

#### 6.4.2 *Focus Groups*

We conducted focus groups to understand participants' reactions to the three design concepts, with attention to utility, desirability, and ease of use. We intended for the design concepts to focus

participants' attention on variations in the Explicitness dimension, and for these variations to raise questions about other dimensions.

Three focus groups included patients and caregivers (n=21) and three included providers (n=19). Table 6 shows group composition. PCG8 and PR5 included new participants who had not participated in Part I co-design activities; the other groups included participants who had participated in Part I. Participants were recruited from three of the five clinics from Part I, and eligibility criteria remained the same. Participants received \$100 upon completing the focus group.

**Table 6. Participants for Part II focus groups.**

Group	Site	Participants
PCG6	1	P3, P26, P27, P28, CG1, CG2
PCG7	2	P10, P29, P30, P31, CG8, CG9, CG10, CG11
PR4	5	PCP5, PCP6, RN3, MA6, MA7, MA8
PR5	5	PCP8, PCP9, PCP10, MA9, MA10
PCG8	5	P32, P33, P34, P35, CG12, CG13, CG14
PR6	1	PCP1, PCP2, PCP3, PCP11, RN1, MA1, MA2, MA11

#### 6.4.2.1 Procedures

Focus groups occurred in conference rooms in clinics within the same integrated healthcare system as Part I. Each lasted 90 minutes for patients and caregivers, and 45 minutes for providers (time differences for same reasons discussed above). Focus groups were recorded in video and audio.

Facilitators provided participants with paper copies of each storyboard (Survey, Camera, Clip). For each storyboard, one facilitator read the captions for each panel and gave participants time to look over each image. After reading the storyboard, facilitators posed questions to participants according to a semi-structured guide. The guide included questions about the utility, desirability, and ease of use associated with the systems depicted in the storyboard. The guide also included questions about the Scale dimension, such as how participants envisioned different types of providers or informal caregivers playing a role in the storyboard.

#### 6.4.2.2 Analysis

After each focus group, facilitators wrote a field note capturing key session content and events. Facilitators conducted thematic analysis of the field notes. This analysis extended the analysis completed in Part I. The analysis refined the design dimensions and extended our understanding of a key tension between effort and disclosure, as discussed below.

### 6.4.3 *Part II findings*

#### 6.4.3.1 Resistance to added effort

Participants expressed more resistance to the effort required by the Camera than the Survey or Clip. Participants explained this resistance in terms of the extra effort required to plan and take photographs. This was expressed as a psychological or emotional burden as opposed to a physical burden. Patients and caregivers did not want to have to think about when and where they would be doing or experiencing things they valued and did not want to have to remember to carry the camera with them to capture those moments. Providers agreed, predicting that the Camera would be “anxiety-inducing” (PR5), and that patients might worry about producing photographs that “look good” (PR5).

Resistance to the effort required by the Camera could be explained by the burden patients and caregivers already experience due to the demands of managing MCC. P1 and P3 explained this using the example of tracking what they eat, a self-management activity for managing diabetes. They thought that photographing personal values would be “a hassle” and “one more thing they would have to do” (P1, P3). In addition to adding more work to managing health, the Camera might taint the time spent enjoying activities. CG1 thought the camera might “involve a little stress,” and said she would rather do something she enjoys without working to document it.

There was an exception to the perceived effort associated with the Camera. Some providers thought they could review photographs more efficiently than responses collected through a Survey or data collected by the Clip. A group of providers from PR5 thought three to five photographs in the patient’s electronic medical record could serve as a “trigger” to “ring a bell” about what is important to a given patient. Providers thought this would enable quick review of a patient’s values. This resonates with findings in Chapters 4 and 5, in which providers sought the “big picture” about a patient and used this big picture to evaluate and make sense of the smaller-scale issues in the patient’s life. Having a small number of photographs in a patient’s record could help providers quickly reinstate the “big picture” view of a patient.

#### 6.4.3.2 Retaining control of disclosure

Participants preferred that patients retain control over the information disclosed, even if this meant patients, caregivers, or providers spending more effort to express or elicit what matters to patients. Thus, there was some tension between effort and disclosure.

Despite the Clip's lower effort, loss of control over information disclosed to the care team was not worth the benefits in ease of use. PCG and PR participants expressed the desire to turn the Clip off during sensitive activities, such as using the bathroom or going to bed. Other participants were concerned about disclosing their location and the people with whom they talked (e.g., CG14). Similarly, patients, caregivers, and providers all worried about issues of consent and privacy if the Clip recorded activities and conversations with other people. For example, P28 worried that the Clip would pick up conversations with friends or family members who would expect what they say to remain private. This would be especially problematic if it negatively affected the patient's valued relationships. Similarly, P33 wondered if his spouse, who regularly goes walking with friends, would have to ask permission to wear the Clip while walking.

Participants perceived the Survey as a compromise in this tension between effort and disclosure. Compared to the Camera, participants thought the Survey would be less burdensome. The Survey was not expected to take a significant amount of time and could be completed in one sitting. One explanation of this perception could be that the Survey would not add to the burden of self-management or taint valued activities, while the Camera would. Another explanation could be that the Survey provides guidance about the type of information to share, since it was structured around the six categories of personal values and includes examples for each category.

Overall, the disclosure dimension featured much more prominently in discussions of the design concepts in Part II than in the future and storyboarding workshops in Part I. This may be because the co-design activities in Part I were framed as efforts to design an ideal future. Participants did not represent fears or concerns about disclosure in these ideal futures. Additionally, in Part I few participants expressed reservations about sharing with their doctor what matters to them, but during discussion of the design concepts, several participants (e.g., P30 and spouse) expressed that sharing this information would constitute an invasion of privacy.

## 6.5 DISCUSSION

Co-design participants (n=51) generated diverse ideas for supporting patient-provider communication about patients' personal values. Seven dimensions characterize ways in which participants' ideas varied: Explicitness, Scale, Synchrony, Intimacy, Guidance, Effort, and Disclosure. Focusing on variations along the Explicitness dimension, we created three design concepts and presented them in focus groups with patients, caregivers, and providers (n=40).

Discussions in focus groups deepened our understanding of the dimensions, particularly the tension between Effort and Disclosure.

The outcome of this process is not a product or service to implement. This chapter's principal contributions are the design dimensions and the explication of tensions across them. The dimensions are not normative, wherein one end of the spectrum is inherently desirable, nor do the dimensions represent requirements or criteria. Instead, each represents a spectrum along which participants' ideas for supporting patient-provider communication varied.

Following Höök and Löwgren [79], we consider the dimensions to be “intermediate-level [design] knowledge” between specific design instances and generalized theory. As intermediate knowledge, these dimensions can be used as resources in future design research. The dimensions render patterns in the diversity of participants' ideas explicit and enable systematic inspection of design possibilities.

The design concepts in Part II explored a subset of the design space described by the seven dimensions. Future research can continue exploring this space. The methods in Part II provide a blueprint for how this could be carried out systematically. By varying Explicitness, we raised questions about other dimensions and revealed a tension between Effort and Disclosure. Grounding design concepts along one dimension invited participants to discuss the space of design possibilities in more nuanced ways, as illustrated by the increased discussion of Disclosure during focus groups. This resulted in clarification and extension of our understanding of the design space.

We acknowledge that previous work has identified similar dimensions. For example, similar to the Synchrony dimension, Miller et al. [116] used Johansen's [89] time-space matrix to inform design considerations for supporting caregivers in hospital settings. Similar to the Effort dimension, Ancker et al. [6] showed that people with MCC experience self-tracking as overtly effortful. However, this previous work has focused mostly on individual dimensions in isolation. The novelty of this chapter's contribution stems not from any one dimension alone but from the set of dimensions that coherently characterizes participants' diverse ideas. This coherence is evident in relationships identified across dimensions. Below I discuss how these findings relate to scholarship in HCI and related fields.

### 6.5.1 *Designing for effort and disclosure*

Responding to the Camera concept, participants said planning ahead to photograph personal values would be burdensome and could mute their enjoyment of valued activities and relationships. Self-management is already burdensome for people with MCC, and this burden disrupts a patient's active participation in collaborative care [115]. Any intervention to support patient-provider communication about values should not introduce undue burden. However, not all low-effort interventions will work. Despite the low effort of wearing the Clip, participants resisted the device if it meant surrendering control over what was disclosed to providers. This was particularly true when information about family or friends could be shared inadvertently.

Scholars have sought to understand how patient-generated data influences patient-provider communication. Chung et al. [39] found that patients and providers had trouble establishing shared expectations for self-tracking for irritable bowel syndrome (IBS). Schroeder et al. [138] found that when patients and providers collaboratively reviewed visualizations of food intake and IBS symptoms, comprehension and mutual trust improved. This chapter's findings raise new questions about sharing patient-generated data with providers.

To what extent is a patient's willingness to disclose information to providers shaped by the type of information shared? Do patients prefer to retain more control over disclosure of personal values versus disclosure of biometrics, self-management activities, or other information? And, considering participants' concerns for disclosing information about family and friends, to what extent do patients' relationships influence their preferences for disclosure (c.f., [17,168])? Future research could explore the role of self-tracking technologies in supporting patient-provider communication about personal values, particularly in terms of effort and disclosure. More generally, research could explore dependencies between the type of information shared (e.g., values from different categories [106]) and the design dimensions.

### 6.5.2 *Designing for guidance*

An early paper from the VITAL project showed that people with MCC withhold personal values from providers when they do not perceive values as pertinent to their health care [108]. The Guidance dimension can involve communicating to patients the pertinence of their personal values to their health care. Some research has explored how to provide this type of guidance. For example,

Berry et al. [16] found that introducing people to the six categories of personal values expands the breadth of values they subsequently share. In this paper, the Survey concept included two types of guidance: signaling the breadth of personal values that may be pertinent to share (i.e., six values categories) and the level of detail that may be helpful to share (i.e., specific examples of values). Beyond breadth and level of detail, there is an opportunity explore what other kinds of Guidance are useful. In one example, Hong et al. [77] created a visual library to support teens in communicating subjective experiences of illness with family caregivers. There is an opportunity for future work to continue exploring how new forms of guidance, like visual libraries, can facilitate communication about values.

Additionally, the Guidance dimension could have relevance for supporting patient-provider communication beyond MCC care. Jacobs et al. [86] showed that oncologists and surgeons want to understand the emotional health of people with breast cancer, but these patients hesitated to share this information. Similarly, Park et al. [125] found that patients in the emergency department (ED) struggled to share certain types of information that ED providers found useful because patients didn't understand how this information fit into ED practice. Thus, there is a need to explore how to design guidance for patient-provider communication beyond the context of MCC care.

### 6.5.3 *Limitations*

I included the seven dimensions because they emerged empirically from analysis of participants' ideas for design. It is possible that other dimensions are relevant (e.g., clarity, persistence). For example, Park et al. [125] suggested that in an emergency department, information that remains unclear to a patient or caregiver could persist on an electronic whiteboard to give them more time to process it. It is not my position that dimensions like persistence or clarity are not relevant, just that the seven dimensions characterized our participants' ideas coherently.

The co-design activities reported in this chapter encouraged divergent thinking. Our team developed the dimensions to characterize the diversity of participants' ideas (Section 6.3.4). Our analysis did not evaluate the relative prominence of dimensions, although our findings suggest that this may be influenced by the methods we chose. For example, participants' discussion of design concepts in Part II addressed disclosure more prominently than in Part I (Section 6.4.3). Our interpretation is that the "ideal world" ideation of Part I did not compel participants to explore negative aspects of possible futures. Had we used different methods, other dimensions may have

been prominent. There is also potential for future research to scrutinize differences in patients', caregivers', and providers' perspectives, similar to the approach by Rajabiyazdi et al. [130].

Finally, it is possible that particular demographics might prefer particular points along particular design dimensions. For example, it could be that older patients can tolerate more effort, or younger providers are more concerned about disclosure, and so on. I was not able to complete this analysis as part of this study. Thus, there is an opportunity for future work to examine interactions between the demographics of key actors in MCC care and their preferences along the design dimensions.

#### 6.5.4 *Conclusion*

People with MCC often disagree with healthcare providers about priorities for health care, contributing to worse health outcomes. As a step toward aligning priorities between patients and providers, this paper explored how products, services, and systems could support patient-provider communication about what patients consider most important for their well-being and health. An iterative co-design process generated seven dimensions that characterize how MCC stakeholders envision designing this support: explicitness, effort, disclosure, guidance, intimacy, scale, and synchrony. I discussed tensions across these dimensions (e.g., effort and disclosure). These findings advance understanding of how to design support for patient-provider communication about patient's personal values.

## Chapter 7. REVISITING AND REFRAMING DESIGN OPPORTUNITIES

The purpose of the VITAL project was to enable shared understanding between patients and providers regarding patients' personal values. I have focused on how patients' personal values shape the collaborative practices involved in MCC care, and how designers might create products, services, and systems to better facilitate shared understanding of personal values. These collaborative practices involve three key actors: people with MCC, informal caregivers, and healthcare providers. The findings I reported in Chapters 3-6 have brought clarity to the role of values in patient-caregiver coordination in daily life, the role of values in interactions between patients and healthcare providers, and how patients, caregivers, and providers envision supporting better communication about values.

In this chapter I will discuss a theoretical perspective—moral action—that I find useful for clarifying the key opportunities for design. I will close by returning to related work from health sciences and design research on the nature of values and the relationship between values and design. I will emphasize the notions of values and approaches to values in design that I have found most useful as a design researcher in my efforts to inform improvements to MCC care.

### 7.1 MORAL ACTION AS A DESIGN IDEAL FOR IMPROVING MCC CARE

#### 7.1.1 *Background: my introduction to moral action*

I was first introduced to the notion of “moral action” by a paper by JafariNaimi et al. [87]. The purpose of that paper was to articulate a relationship between values and design that differed from previous work (i.e., Value Sensitive Design) that followed an “identify/apply” logic. When following an identify/apply logic, designers first identify and define values relevant to the design situation at hand. Then in a separate step, designers apply those values. What it means to apply values can vary, but it typically includes embedding values in a design artifact or creating an artifact to express or align with particular values.

JafariNaimi et al. articulated an alternative in which designers work with values continuously and dialectically throughout the design process. In this approach, designers work with values as hypotheses, deciding which values are relevant, assessing how they reframe the design situation,

and assessing how this clarifies how to move forward with the design process. This approach emphasizes working with values in a processual manner, acknowledging that the relevance and applicability of values may shift as the design process progresses. This contrasts with design approaches that consider values as discrete and stable entities.

JafariNaimi et al. drew on Dewey's [53] notion of the "question of action" [53] to illustrate their perspective on values in design. Figure 8 reproduces the image used by JafariNaimi et al. to introduce the "question of action." It is composed of two interrelated sub-questions: "What is the situation that demands action?" and, "What is the action that the situation demands?" When a designer apprehends a design situation, asking these two questions in a dialectic process brings clarity to the situation and ultimately leads to a solution to the design situation.



Figure 8. Dewey's question of action, reproduced from JafariNaimi et al.

Having established Dewey's question of action, JafariNaimi et al. described the role that values play in advancing and resolving the question of action. They distinguish between straightforward situations and indeterminate situations. In straightforward situations, the designer has a strong grasp on the factors and considerations relevant to the design problem. They can assess the situation and the action required and move forward without delay. The designer's course of action is clear.

In indeterminate situations, it is not clear to the designer how to proceed. There may be multiple conflicting factors that are difficult to resolve. Or, there may be so many factors that it's difficult to assess which ones are relevant. In these situations, designers can consider values as tools in their efforts to advance the question of action. Designers use values as hypotheses, bringing them to bear on the design situation and assessing which aspects of the situation or which potential actions come to the fore. As the designer tries out different values, this can help clarify the situation

at hand or make clear which design moves to make. In this formulation, design is a dialectic process through which the designer's understanding and actions mutually shape one another. In this process, values provide guidance and clarity to indeterminate situations.

### 7.1.2 *Definition of moral action*

In accounting for the roots of the question of action, JafariNaimi et al. point back to Dewey's [53] 1891 paper exploring the relationship between moral theory and practice. Dewey argued that moral theories can range from very general (i.e., social and cultural values of moral and ethical import, such as autonomy, democracy, or informed consent) to very specific (e.g., an individual's judgment of what they consider good and right for a particular situation). Dewey argued that there is only a difference in degree between specific and general moral theories, not a difference in kind. More general theories may be more portable (i.e., they can be applied to a wider range of situations of practice), but portability is not a necessary condition of a moral theory.

Then, Dewey distinguished between moral action and other types of action. Dewey introduced the question of action and argued that for an action to be considered moral action, a person must have raised and answered the two questions: What is the situation that demands action? and What is the action the situation demands? This definition is straightforward and is quite permissive in that it includes a wide range of actions a layperson might not consider having a moral character. According to Dewey's perspective, any time an actor assesses a situation, reasons about what course of action would be appropriate, and acts in accordance with this assessment, this is moral action.

Dewey acknowledges that an actor is not likely to approach each situation as a blank slate. Actors possess "certain working tools" (ibid, p. 194) they can draw on in their analysis of the situation. One such tool is a moral rule (or a value). Dewey wrote, "I cannot resolve this practical situation which faces me by merely looking at it. I must attack it with such instruments of analysis as I have at hand. What we call moral rules are precisely such tools of analysis" (ibid, p. 194). But again, it matters not how broad and lofty or specific and personal those values may be. This means that for a person with MCC, deciding that they ought to take medication to address chronic pain could be considered moral action under certain circumstances. If that person assessed their situation (e.g., do nothing, take medication, or complete physical therapy) and decided to take medication because it would enable the person to spend more time with their grandchildren (a

personal value), this would be considered moral action. The same could be said if the person considered a more general value, such as deciding to take medication in order to pursue autonomy. And, the same could be said if the person considered “relief from pain” to be one of their personal values. Following Dewey, I do not aim to adjudicate what counts or does not count as a value. I look to people with MCC to define for themselves what they consider important or meaningful to their well-being and health. As long as people with MCC assess the situation of action and act in accordance with their personal values, this can be considered moral action.

### 7.1.3 *Collaborative MCC care as a site for moral action*

I find it useful to conceptualize collaborative care for MCC as a site for moral action. MCC care is characterized by its indeterminate situations. A hallmark of living with MCC is facing competing demands for health care. If a person has diabetes and chronic pain, their doctor is likely to suggest exercising to manage diabetes, but if they exercise, pain symptoms are likely to worsen. What should the patient do?

In MCC care, the situation of action is often indeterminate, comprised of multiple competing demands stemming from the three lines of self-management work performed by patients. These include illness work, such as taking medications or exercising; everyday life work, such as spending time with a spouse or holding down a job; and biographical work, which involves coping with difficult emotions as one’s life and identity changes due to illness [44]. The situation of action may also include the patient’s lived experience of illness, such as the degree of pain they experience or their functional status. The situation of action may also include health status indicators, such as their A1C value (a measure of blood glucose levels over time used to assess diabetes) or their blood pressure (used to assess hypertension). Finally, the situation of action may include a range of concerns stemming from other actors’ perspectives.

In a collaborative care model, these indeterminate care situations are rarely addressed by the patient alone. An informal caregiver, such as a family member or close friend, may help the patient talk through their care needs and provide support as the patient manages their conditions in daily life. A primary care provider may seek to understand the patient’s daily experience with illness in order to deliver recommendations for care, or they may check in with the patient to determine if they are carrying out a previously defined care plan. Thus, the work of clarifying the situation of

action in indeterminate MCC care situations is rarely personal. The moral action associated with MCC care is often carried out in collectives.

And, these indeterminate care situations are not one-off, finite matters. Part of the challenge of MCC care is that many relevant factors are in flux. Patients' bodies change continuously; since they have chronic conditions, these changes tend to be for the worse, creating new limitations in daily life. What patients consider important to their well-being and health also changes over time, partly in response to changing health. The availability and willingness of informal caregivers may wax and wane over time. The team of healthcare providers with whom the patient interacts may change. Epidemiological knowledge (e.g., which levels of blood sugar and blood pressure are considered healthy) clinical best practices (e.g., recommended medications and self-management tasks associated with diabetes), and organizational incentives (e.g., billing amounts for health care services provided) may all shift over time and influence how MCC care is carried out.

Continuing the hypothetical example above, one might approach the care situation as a site for moral action and ask, "What is the situation that demands action, and what action does the situation demand?" Since the situation is indeterminate, a person might search for factors to help clarify the situation or the action needed. These factors may include the doctor's assessment of the medical risks to this patient if they do not keep their blood sugar in check through exercise, or the caregiver's assessment of the patient's ability to withstand pain symptoms following exercise, or the patient's assessment of the extent to which pain symptoms might affect other aspects of their daily life. Or, a person may draw on their personal values.

Current collaborative MCC care practices may address these indeterminate situations to some degree, but my findings reveal several important opportunities for designers to create space for more careful consideration of patients' personal values, how those values might clarify indeterminate care situations, and help patients, caregivers, and healthcare providers plan and carry out health care in ways that better account for patients' personal values.

Going forward, I believe moral action will be a useful design ideal to guide future work in this space. How might we design technologies to insert opportunities for moral action among the other collaborative MCC care practices?

## 7.2 DESIGNING FOR MORAL ACTION IN MCC CARE

Patients' personal values are of critical importance for bringing clarity to the indeterminate care situations associated with MCC. My findings from Chapters 3-6 have explored the extent to which patients' personal values are accounted for in collaborative MCC care practices. In the subsections below I discuss four themes that cut across the findings from individual chapters. Each theme represents a set of opportunities for designers to promote moral action among patients, caregivers, and providers.

### 7.2.1 *Facilitating shared awareness of the situation of action*

For moral action to occur in MCC care, patients, providers, and caregivers must be able to develop a shared understanding of the situation of action. There is an opportunity for designers to support this shared awareness.

Designing for shared awareness of the situation of action in MCC care would need to account for the three lines of self-management work performed by the patient and/or caregiver (illness work, everyday life work, biographical work) [44], the patients' personal values, the caregiver's perspective on the patient's daily life and values, and the provider's medical expertise and knowledge of this patient's health care needs. Additionally, under a Collaborative Care model, shared awareness would also need to account for problem definition, problem targeting, and planning care [154].

There is an opportunity for future design and research to explore what kinds of technologies might support shared awareness of the situation of action. There are some clues in my findings. For example, some participants in the co-design activities reported in Chapter 6 expressed preferences for remote communication channels between patients and providers that could give the provider visibility into the patient's daily life. Video-based communication is one such channel. Communication via video can give the provider contextual information the patient may not think to share, or that the provider may not think to ask about. For example, in a video-based conversation with a patient in their home, the provider could observe the resources available to the patient to exercise or cook for themselves at home. Similarly, video communication could enable patients to show providers personal values in their context. One category of personal values is possessions, and patients use video communication to show providers photographs of family

members or a favorite comfortable chair. (As discussed in Chapter 6, Chung et al. [38] and Schroeder et al. [138] explored similar ideas with a food tracking application for people managing irritable bowel syndrome (IBS). Christina Chung's ongoing work is examining the role of contextual information from image-based food tracking in shaping patient-provider communication about IBS symptoms and treatment.)

Also, technologies currently in use in MCC care could be adjusted to better facilitate shared awareness of the situation of action. My observations in Chapter 4 and Chapter 5 demonstrated that electronic health records (EHRs) give providers the ability to piece together information about the patient, such as results from lab tests, notes from previous clinic visits, current diagnoses, and so on. Some EHRs provide a "snapshot" page that displays much of this information on one screen. However, such screens do not typically include dedicated spaces for recording information about patients' personal values, or details from the patients' daily life. Similarly, patients typically do not have access to the "snapshot" page. There is an opportunity to reimagine "snapshot" screens as places to foster shared awareness among patients, providers, and caregivers regarding the situation of action, including awareness of patients' personal values and the extent to which the patient's health care accounts for those values. More work is needed to understand what information these actors would prefer to include on a "situation of action" screen, who should be able to access it, and so on.

Another existing tool is the personal health record (PHR), or the "patient portal" to the EHR. Mirroring the limitations of the "snapshot" screen in the EHR, the PHR may support the patient's awareness of the situation of action to some extent, but the information displayed is limited, and it does not support awareness for both the patient and their providers. The information displayed in a PHR is similar to what providers see in the EHR, including lab values, doctor's notes, diagnoses, medications, and so on. However, unlike the provider's ability to add and edit information in the EHR, the patient rarely has the ability to edit information in the PHR. It is a view of data stored in the EHR, not a place for the patient to participate directly in achieving shared awareness of the situation of action. This is a major opportunity for future research and design. To what degree should patients be able to curate the information about them stored in the EHR, including patients' personal values?

Designing for shared awareness of the situation of action combines two trends in personal health information management. First, providers are giving patients more access to their health

records. For example, health systems are increasingly giving patients access to the notes doctors write after each patient encounter (e.g., [49,50,158]). Second, patients are collecting more data about themselves and bringing this information to clinic visits (e.g., [6,39]). Similar to these trends, my findings suggest the need to explore how to give patients more control over the information stored in their medical record. Perhaps patients should be able to populate and maintain a section of their health record with personal values. Additionally, if this information were stored in the health record, perhaps patients should be able to create linkages in their health record between illness-focused information (e.g., diagnoses, symptoms, medications) and their personal values. This is an exciting frontier at the intersection of personal health informatics and clinical informatics. The need to incorporate personal values into MCC care is a valuable use case for exploring possibilities for giving patients more control over information stored in EHRs.

### 7.2.2 *Moral action in navigating patient-caregiver relationships*

Looking back on Chapter 3 it is clear that a patient's relationship with a spousal caregiver has significance for the extent to which the patient's health care accounts for their personal values. In imagining how to create opportunities for moral action in MCC care, these relationships are a key consideration.

Within patient-caregiver relationships, routines of daily life become entrenched and habitual. Dewey argued that when action is habitual—when a person does not take stock of the situation of action—moral action is not occurring. For cases in which partners' routine daily practices do not reflect the patients' personal values, these present an opportunity for designers to facilitate moral action that could lead to partners adopting routines that better align with patients' personal values.

Chapter 3 showed that when a person's values do not align with those of their spouse, this can introduce a tension between the person's ability to coordinate with their spouse and the person's ability to pursue their personal values. Sometimes individuals chose to maintain harmony in their relationship with their partner, foregoing personal values as a result (e.g., CG12, who chose to stop urging P12 not to sprinkle sugar on his cereal because this introduced strife in their relationship). In other cases, individuals chose to pursue a personal value despite the disruption to coordination with their partner (e.g., P3, who continued cooking meals with more vegetables despite CG3's strong preference for meat and potatoes).

Chapter 3 also showed that when a person's values align with their partner's values, this reinforces coordination between them. A caregiver, knowing their partner values serenity and relief from pain, may be motivated to take on extra work around the house, such as walking the dogs or cleaning. However, these shared values between partners may or may not align with the medical priorities of their healthcare provider. For example, one patient-caregiver pair described how they both used to enjoy spending hours at a casino buffet, and how their shared enjoyment of this activity contributed to weight gain.

Regardless of alignment or misalignment between partners' values, the desire to maintain harmony in their relationship played a major role. In the case of alignment or misalignment between partners' values, designers could facilitate occasions for moral action in which partners surface values and discuss how to adjust practices to better align with those values. For example, technologies like "A Diary Built for Two" help partners reconsider and work through disagreements [25].

### 7.2.3 *Overcoming mutually reinforced boundaries in patient-provider communication*

Chapters 4 and 5 clarified and extended our understanding of communication boundaries reported by patients in an earlier phase of the VITAL project [108]. Lim et al. [108] reported that patients often withhold or filter personal values from providers, particularly when patients do not perceive personal values to be pertinent to their health.

Chapter 5 confirmed similar boundaries, but also showed how patients and providers worked to coordinate their perspectives and establish the pertinence of patients' values to their health care. Some types of values, such as activities affected by illness or abilities lost due to illness, were discussed often. Possessions, principles, and emotions were discussed little. For values to be discussed in clinic, patients often translated values to establish pertinence to care. To support this translation, there is a need to enable patients to make informed decisions about what to share.

This is one avenue for designers to support moral action: creating opportunities for people with MCC to become more aware of their personal values, to guide them in understanding how their values may be related to their health, and ultimately to enable them to enact health care practices that align with their personal values. I am a member of a new project to design and evaluate interactive technologies for self-reflection on personal values, and reflection on their pertinence to MCC care. Early findings from home visits with people with MCC showed that

people appreciated the opportunity to “stop and think” about what’s important to them, and how this relates to their care [107]. Future work will evaluate a variety of prototypes for supporting this reflection and ultimately deploy an interactive self-reflection technology for evaluation in the wild.

Chapter 4 also illustrated that providers had good intentions to elicit and understand patients’ personal values, but that providers often employed this understanding to serve their own medical priorities. This reinforces the communication boundaries perceived by patients by focusing conversations on values that providers perceived as pertinent to health care.

This presents is an opportunity to support providers in rounding out their understanding of what patients share, rather than closing off conversations in service of medical priorities. From a moral action perspective, this could mean prompting providers to evaluate decisions about patients’ care with a broader definition of patients’ personal values in mind. Observations in Chapter 5 demonstrated that many providers quickly reviewed the patient’s record in advance of a clinic visit. This review included opening the patient’s record in the EHR, reading notes they (or other providers) had written to document previous clinic visits, reviewing the patient’s problem list (a list of diagnoses in the EHR for which the patient is actively receiving care), and sometimes even discussing the patient’s personal values with other members of the care team. This pre-visit review could more explicitly involve considering the extent to which the patient’s problem list and current plan of care aligns with what’s important to the patient. One way to accomplish this could be to store the patient’s values in the EHR and prompt the provider to explicitly link the patient’s values to items on their problem list. However, there are many avenues to promoting moral action on the part of providers while preparing for clinic visits, and more research is needed to understand and explore these possibilities.

#### 7.2.4 *Accommodating a range of preferences for accounting for values*

Patients, caregivers, and providers expressed widely diverse visions for improving communication about values. My analysis in Chapter 6 characterized this diversity using seven dimensions: explicitness, effort, disclosure, guidance, intimacy, scale, and synchrony. These dimensions rendered patterns in the stakeholders’ ideas explicit and enabled systematic inspection of design possibilities. In focus groups we presented three design concepts for eliciting personal values. These concepts varied along the explicitness dimension. The most prominent finding was a tension between effort and disclosure.

The findings from these co-design activities demonstrate that no single solution will meet the expectations of all stakeholders in MCC care. We're looking at a future in which particular groups of patients, caregivers, and providers may choose from a range of possible approaches and supporting technologies. This implies the need to also support processes through which patients, caregivers, and providers discuss the possible approaches to incorporating values, and the possible technologies for supporting those approaches.

Designers should account for this plurality of technologies and approaches. The imperative is not just to introduce new tools into collaborative MCC care practices, but also to support processes through which patients, providers, and caregivers can determine (and revisit) the approaches that work best for them. Providers should not assume they can adopt the same approach with each patient, and health care systems should not enforce policies or processes that assume a uniform approach. Part of collaborative care should be making different approaches possible and deciding together on the best approach.

### 7.3 REVISITING VALUES AND DESIGN

Chapter 2 reviewed how scholars in health sciences and design research have described the nature of human values. In health sciences, values have typically been defined as preferences (e.g., a patient's choice from among a predefined set of options for treating a particular health condition) or goals (e.g., one or more health outcomes toward which a patient would like their treatments and self-management to operate). In design research, understanding of the nature of values continues to develop. Early work in Value Sensitive Design (VSD) [63,64] dealt with values of moral and ethical import, but subsequent work by Le Dantec et al. [101] critiqued this approach as privileging values that can be defined discursively. Le Dantec et al. [101] called for designers to seek an understanding of values as they emerge from local design contexts (a more bottom-up approach compared to VSD's top-down approach). Later work by JafariNaimi et al. [87] distinguished between approaches that use an identify/apply logic and approaches that work with values as hypotheses in a dialectic process. And, work by Houston et al. [81] called attention to the distinction between values as entities (i.e., values as fixed, discrete, objectified) and processes of valuation (i.e., practices through which things are rendered valuable). This perspective emphasizes the contingent nature of values and focuses on values as enacted and re-enacted in practice.

My research has not necessarily operated from a fixed definition of the nature of values. In the home visits from Chapter 3, participants expressed values through a photo elicitation exercise. In this exercise, I expressed few constraints to participants when inviting them to share what they considered important (i.e., I did not impose the categories of personal values). In Chapter 5, I also did not impose the categories up front in interviews with participants, but sometimes I used the categories opportunistically to push participants to consider a greater breadth of potential values. And, I explicitly used the values categories as a priori codes in my analysis of those interview transcripts and field notes. In Chapter 6, I explicitly used the term personal values and the six categories of values when introducing the design problem to co-design participants.

Operating with slightly different understandings of values—and particularly, providing participants with slightly different definitions of values at different points in the research process—reflected my developing understanding of the design problem and the role of values therein. Looking back, it is likely that different definitions of values served the research and design process differently. There is an opportunity for future work to explore this in more depth. Currently, my inclination is not to argue that a particular definition of values most accurately reflects reality in all cases, or that a particular definition of values is most useful to designers in all design situations. Rather, I am optimistic that considering ways in which different definitions of values serve design processes differently could open up new possibilities for design, new understandings of human values, and new understandings of the relationships between values and design.

### 7.3.1 *Characterizing the concept of “personal values” and its utility*

The definition of personal values in this thesis is based on interviews with people who have multiple chronic conditions. The categories of personal values reflect the breadth of things interview participants expressed as important for their well-being or health. Utilizing this definition of personal values aligns with Le Dantec et al.’s [101] call for designers to understand values as emerging from the local design contexts (bottom-up). This is in opposition to starting with discursively-defined values (top-down).

Using this definition has been particularly useful in working with providers. The definition has the authority of patients behind it. It truthfully reflects what people with MCC consider important, and it reflects their perspectives as whole persons, not just as patients from a medical standpoint. This definition has been useful in interviews with patients because it helps break

through any availability bias they may be operating from. For example, patients may have particular values on their mind because of recent events in their life, but using the categories of personal values to probe for additional values can open their thinking to other things they consider important in general, but aren't primed to report at any given moment. Finally, this definition has been useful when working with patients, providers, and caregivers as co-design participants. When imagining new technologies to support shared understanding of patients' values, describing the breadth of personal values is useful to help co-design participants think beyond their own personal values to consider what others see as important, and how to design to support communication about values for others beyond themselves.

My findings align with Houston et al.'s [81] perspective that in reality, people's values are not fixed. My findings have shown that people express different personal values in different contexts (e.g., at home versus in the clinic), that people give up some personal values due to health concerns, and that some people attend to new personal values as they grow older, as they health changes, and as their perspectives evolve.

My findings also resonate with JafariNaimi et al.'s [87] argument that designers tend to work with values in a flexible, ongoing process of making sense of the design situation. In my research, operating with the definition of personal values has tended to treat values as entities separable from action. This goes against the realities of values in practice as described by Houston et al. and JafariNaimi et al. However, I think it would be very challenging to express to the average patient, caregiver, or healthcare provider the idea of values as enacted, or values as hypotheses. At the very least, there is more work to be done to understand how to communicate these different notions of values to key actors in MCC care.

In my research, the definition of personal values (with the six categories) has been useful for making the concept of values intelligible for actors in MCC care. Thus, this concept is useful for understanding ways in which MCC care practices account for values currently, and how these practices might better account for values in the future. This does not mean that scholars concerned with values in design are wrong to focus on valuation over values as entities, or to argue for the need to focus on certain discursively-defined values. Nor does it mean that designers should not strive to create products, services, and systems that align with these particular definitions of values. But, for the purposes of this dissertation, I have found utility in adopting a pluralistic approach to defining values. Different definitions of values foreground different aspects of the design situation.

Over the long term, I will continue reflecting on the definition(s) of values at play in design situations, and to consciously consider how particular definitions of values might serve the design problem best by accounting for the context, methods, and participants involved.

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## VITA

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