

Supporting Communication About Values Between People with Multiple Chronic Conditions and their Providers

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ABSTRACT

People with multiple chronic conditions (MCC) often disagree with healthcare providers on priorities for care, leading to worse health outcomes. To align priorities, there is a need to support patient-provider communication about what patients consider important for their well-being and health (i.e., their personal values). To address barriers to communication about values, we conducted a two-part study with key stakeholders in MCC care: patients, informal caregivers, and providers. In Part I, co-design activities generated seven dimensions that characterize stakeholders' diverse ideas for supporting communication about values: explicitness, effort, disclosure, guidance, intimacy, scale, and synchrony. In Part II, we used the dimensions to generate three design concepts and presented them in focus groups to further scrutinize findings from Part I. Based on these findings we outline directions for research and design to improve patient-provider communication about patients' personal values.

CCS CONCEPTS

• **Human-centered computing** → **Computer supported cooperative work** • **Human-centered computing** → **Empirical studies in collaborative and social computing**

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KEYWORDS

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1 INTRODUCTION

Health care for people living with multiple chronic health conditions (MCC) is a major public health concern worldwide [22]. One in three adults have MCC, including three in four adults in developed countries [35]. Compared to people with single chronic conditions, people with MCC experience poorer quality of life, higher incidences of physical disabilities and adverse drug events, and higher mortality [46]. Additionally, out of pocket medical expenses increase with the number of chronic conditions, affecting the elderly and low-income groups [42].

One reason people with MCC experience poorer health outcomes is discordance in health care priorities between patients and healthcare providers [20,47,53]. Standard approaches to care for chronic conditions like the Collaborative Care model [48] 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 paper we use the definition of personal values from our previous work: what people with MCC consider important for their well-being and health [8,33]. Our work also identified 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 [33].

Several barriers prevent patients and providers from discussing personal values. Lim et al. [34] 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. Berry et al. [7] 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 [7]. As a result, patient-provider communication about patients' personal values remains limited [6].

This paper picks up where this prior work left off to envision products, services, and systems to facilitate patient-provider communication about 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 participants' ideas for design varied. In Part II, we used these design dimensions to generate three design concepts and presented these in focus groups to scrutinize tensions within and across the design dimensions.

This paper makes two principal contributions to CHI. First, we present the design dimensions as "intermediate-level [design] knowledge" [24]. These clarify the space of possibilities for supporting patient-provider communication about values. We 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 CHI, we suggest future directions for supporting patient-provider communication, including contexts beyond personal values and MCC care.

2 RELATED WORK

Recent work in CHI and related fields has aimed to improve patient-provider communication, but there has been little work to directly engage stakeholders in MCC care to envision how to support patient-provider communication about personal values. Section 2.1 establishes the relevance of personal values to the problem of discordant priorities in collaborative care for MCC. Section 2.2 reviews recent work in CHI and related fields aimed at supporting patient-

provider communication and reveals a gap in support for communication about values.

2.1 Collaborative Care for MCC

The model of Collaborative Care for Chronic Illness sets a standard for chronic illness care [48], and involves ongoing communication between patients and providers who work as partners in the patient's health care. During clinic visits, patients and providers (and sometimes caregivers) discuss and define health-related problems. For example, a provider may recognize that a patient is not consistently measuring their blood sugar or following a special diet; or a patient may raise fears about complications due to illness [48]. Having defined a set of health-related problems, patients and providers choose specific problems to target, discuss realistic goals for addressing the problem, and make an action plan. This usually involves focusing on one problem (potentially prioritizing some problems over others) and assessing patient readiness to carry out self-management activities associated with that problem. The provider offers self-management support, including fostering behavioral skills to address medical and emotional needs. As the patient carries out self-management in daily life, providers actively follow up with the patient over time, identify potential complications, and check and reinforce the patient's progress toward goals they set.

2.1.1 Competing demands and the problem of discordance. People with MCC face competing demands for their health care and this can complicate Collaborative Care, particularly when patients and providers do not agree on which problems are most important to address, or how to address them. Bayliss et al. [4] found that people with MCC face three types of competing demands: 1) symptoms from one condition, or from managing one condition, disrupt management for another condition; 2) taking medications to treat one condition makes symptoms of another condition worse; and 3) a single dominant condition impedes care for other conditions. Other work [17,28] has identified additional competing demands, including mental health challenges (e.g., depression, mental exhaustion), limits to physical function (i.e., fatigue, pain, ability to exercise), social factors (e.g., family support, limitations to social activity), and finances.

Because of these competing demands, people with MCC often must prioritize some health care demands over others. For example, consider a person living with diabetes and chronic pain. This person's doctor may encourage them to exercise to manage diabetes, but exercise may be painful. If the person strongly values relationships with her grandchildren and wants to attend her granddaughter's

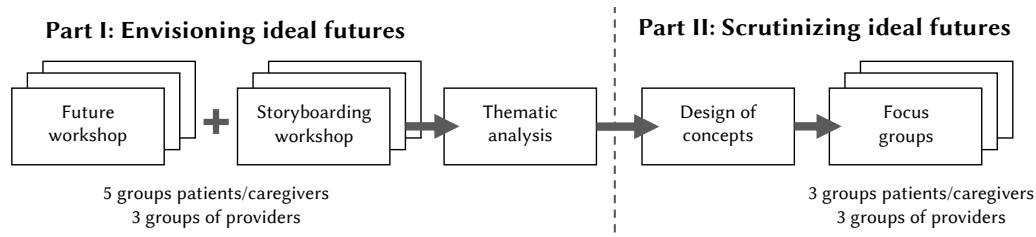


Figure 1. Overview of methods.

high school graduation ceremony, she may choose not to exercise to avoid pain that would prevent her attendance. Alternately, if the person strongly values reading, she may choose to exercise despite the pain because she wants to avoid losing her vision as a complication of diabetes. This example highlights the importance of understanding what's important to patients in addressing the competing demands of MCC.

2.1.2 Patient-provider communication about personal values. Scholars in CHI have discussed the definition of values, and the relationship between values and design (c.f., [18,25,27,31]). As mentioned in the introduction, in this study we adopted Lim et al.'s [33] definition of personal values because it emerged from research with people with MCC. This definition aligns with Le Dantec et al.'s [31] call for designers to consider values as emerging from local design contexts. In the introduction we also referenced recent research involving people with MCC. This represents the point of departure for this study. This prior work has shown that people with MCC often withhold values from providers when they do not perceive that information to be pertinent to their healthcare [34], and that while providers often seek to understand patients' values, they employ this understanding to serve their own medically-oriented priorities [7]. When patients and providers discuss values in clinic visits, this discussion covers some types of values (e.g., abilities, activities) more frequently than others (e.g., principles, emotions) [6]. This paper builds on Lim et al.'s [33] definition of values, and the research just mentioned, but this paper is distinct in objective and methods. Moving beyond understanding current practices for communicating about values, this paper examines how to design systems to improve communication about values, with a focus on patients', providers', and caregivers' perspectives as co-designers.

2.2 Supporting Patient-Provider Communication

Healthcare technologies are enabling new forms of communication between patients and providers [49,50]. Patient portals and personal health records provide asynchronous, text-based communication between patients and providers [43], and telehealth systems enable

synchronous audio- and video-based communication from a distance [32,44]. During clinic visits, there is evidence that technology in the exam room can support or disrupt face-to-face communication during clinic visits [12,13,45].

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 [14] and social determinants of health [1,16]. 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 [10]. There remains a specific, unmet need for support of communication about personal values.

Outside of CHI, efforts to support communication about values typically conceptualize values more narrowly or elicit values without fully supporting communication practices. 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 [11] or select lifestyle changes for improving cardiac health [5]. Witteman et al. [51] 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) [2]. 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 [19]. 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.

Related work demonstrates that while there is interest among scholars 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.

3 STUDY OVERVIEW

To address this gap, we conducted a two-part co-design study to envision and scrutinize ideal support for patient-provider communication about personal values. Figure 1 shows an overview of the methods used. The purpose of Part I (section 4 of this paper) 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 5) was to scrutinize the ideas generated in Part I in order to understand and clarify the most promising future directions for design. All activities were approved by the institutional review board at Kaiser Permanente Washington Health Research Institute.

4 PART I: ENVISIONING IDEAL FUTURES

4.1 Methods

We conducted 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 [30,38] to generate ideas (section 4.1.1), and in the second week, participants created storyboards to explore potential implementations of those ideas (section 4.1.2).

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 1 lists workshop sites and participants. Groups of patients and caregivers have the prefix PCG- and provider groups have the prefix PR-. We kept patient and caregiver sessions separate from providers 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. Two authors [redacted] facilitated the workshops, with assistance from [redacted] for setup, the consent process, distribution of incentives, and cleanup. Lunch was provided to all participants and each received \$100 upon completion.

Table 1. Participants in Part I 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

4.1.1 Future Workshop session. These workshops followed a Future Workshop [30] format, including an introduction to the problem, critiquing the present, and envisioning ideal futures.

4.1.1.1 Introduction. 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) [6,8,33]. 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 [33] and gave examples from prior research [6] 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.

4.1.1.2 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 [6,7,34]. 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.

4.1.1.3 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 4.1.1.2. 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 [54]).

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.

4.1.1.4 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.

4.1.2 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.

4.1.3 Analysis. Analysis of the future and storyboarding workshops began as soon as the first workshops concluded and continued until all workshops were completed. It became clear early that participants generated a variety of divergent ideas. Our team decided to focus analysis on characterizing the diversity of ideas through a template-based, thematic analysis [21].

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.

4.2 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 4.1.1.1 or facilitators' interactions with participants) and which were not.

4.2.1 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 2 shows the first panel (personal information 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.

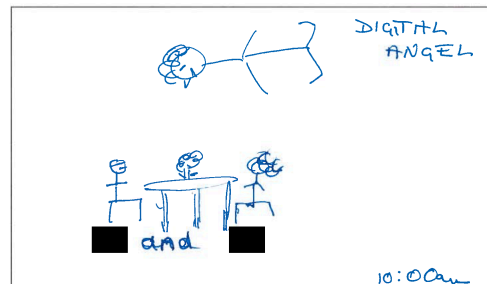


Figure 2. Storyboard panel with Digital Angel.

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.

4.2.2 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.

4.2.3 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.

4.2.4 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.

4.2.5 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.

4.2.6 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.

4.2.7 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.

5 PART II: SCRUTINIZING IDEAL FUTURES

5.1 Part II Methods

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.

5.1.1 Design Concepts

5.1.1.1 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.

5.1.1.2 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).

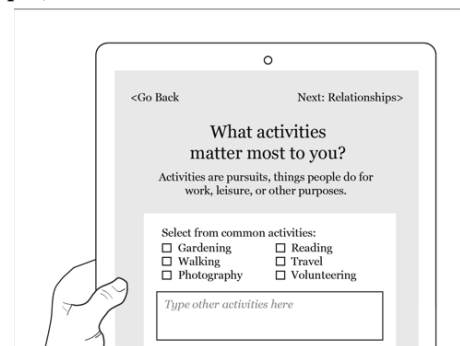


Figure 3. Panel from the Survey storyboard.

The survey is structured around the six categories of personal values from prior work [8,33]: 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 3 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).

5.1.1.3 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 4 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.

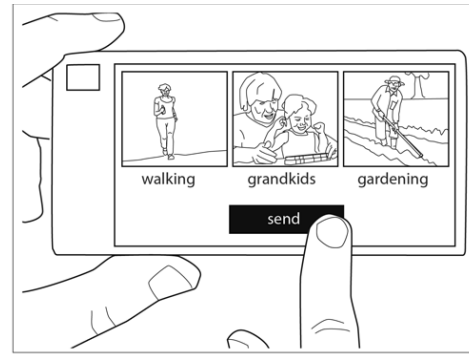


Figure 4. Panel from the Camera storyboard.

5.1.1.4 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 5 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.

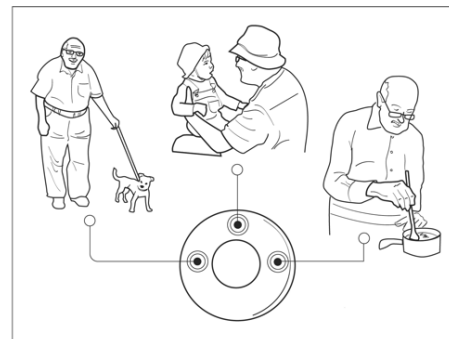


Figure 5. Panel from the Clip storyboard.

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).

5.1.2 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.

5.1.2.1 Participants. Three focus groups included patients and caregivers (n=21) and three included providers (n=19). Table 2 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 2. Participants in 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

5.1.2.2 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.

5.1.2.3 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 that conducted in Part I. The analysis refined the design dimensions and extended our understanding of a key tension between effort and disclosure, as discussed below.

5.2 Part II Findings

5.2.1 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.

5.2.2 Retaining control of disclosure. Participants preferred to retain control over the information disclosed, even if this meant spending more effort to express what matters to them. 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 DISCUSSION

Co-design participants (n=51) generated diverse ideas for supporting patient-provider communication about patients' personal values. We characterized these ideas with seven design dimensions: 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 paper'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 [24], 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. [37] used Johansen's [29] time-space matrix to inform design considerations for supporting caregivers in hospital settings. Similar to the Effort dimension, Ancker et al. [3] showed that people with MCC experience self-tracking as overtly effortful. However, this previous work has focused mostly on individual dimensions. The novelty of our 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 we identified across dimensions. Below we discuss how our findings relate to scholarship in CHI and related fields.

6.1 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 [36]. 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. [15] found that patients and providers had

trouble establishing shared expectations for self-tracking for irritable bowel syndrome (IBS). Schroeder et al. [41] found that when patients and providers collaboratively reviewed visualizations of food intake and IBS symptoms, comprehension and mutual trust improved. Our 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, 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., [9,52])? 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 [33]) and the design dimensions.

6.2 Designing for Guidance

Previous research has shown that people with MCC withhold personal values from providers when they do not perceive values as pertinent to their health care [34]. 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. [8] found that exposing 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 to explore what other kinds of Guidance are useful. In one example, Hong et al. [23] 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 can facilitate communication about values.

Additionally, the Guidance dimension could have relevance for supporting patient-provider communication beyond MCC care. Jacobs et al. [26] 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.

[39] 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.

6.3 Limitations

We 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. [39] 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. In this paper, it is not our position that dimensions like persistence or clarity are not relevant, just that the seven dimensions characterized our participants' ideas coherently.

Our co-design activities encouraged divergent thinking. We developed the dimensions to characterize the diversity of participants' ideas (see 4.1.3). 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 (see 5.2.2). 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. [40].

7 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. Through an iterative co-design process, we identified seven dimensions that characterize how MCC stakeholders envision designing this support: explicitness, effort, disclosure, guidance, intimacy, scale, and synchrony. We also discussed tensions across these dimensions (e.g., effort and disclosure). These findings advance our understanding of

how to design support for patient-provider communication about patient's personal values.

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