How Values Shape Collaboration Between Patients with Multiple Chronic Conditions and Spousal Caregivers

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ABSTRACT

Individuals with multiple chronic conditions (MCC) collaborate with spousal caregivers daily to pursue what is most important to their health and well-being. Previous research in human-computer interaction has supported individuals with chronic conditions or their caregivers, but little has supported both as a unit. We conducted a field study with 12 patient-caregiver dyads, all married and living together, to identify partners' values and how they shape collaborative management of MCC. Partners' coinciding values motivated them to empathize with and support each other in the face of challenges related to health and well-being. When their values were asymmetric, they perceived tensions between individual autonomy and their ability to coordinate with their partner. Systems to support partners in this context could help them overcome asymmetric values, but should balance this with support for individual autonomy.

Author Keywords

Multiple chronic conditions; self-management; self-care; caregiver; patient; coordination; collaboration

ACM Classification Keywords

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

INTRODUCTION

Addressing the needs of individuals with multiple chronic health conditions (MCC) is a growing public health concern. One in four Americans have two or more chronic health conditions [2], and among those over 65 years old this rises to two out of three [13,62]. Individuals living with MCC perform activities daily to manage illness and pursue well-being. 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 [7,8,17,38]), 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) [6,18].

Recent research in CHI and CSCW has emphasized that the work to manage chronic illness often involves collaboration between patients and informal caregivers [9,12,44], such as reminding each other to take medications, participating together in discussions with doctors, and establishing new divisions of labor in home chores [17]. But, most design efforts in CHI and CSCW have focused on supporting either the patient or the caregiver [44]. There is a need to better understand how systems can support both patients and informal caregivers in the work they do together.

Individuals 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 [24,46,56]. 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 [23]. Understanding patients' values is key to the provision of high quality patient-centered care [20,32,60,63]. 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 [22,63]. 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.

We conducted a field study that engaged 12 pairs of patients and spousal caregivers in home visits with photo elicitation, 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 health and well-being, 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. Our 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.

RELATED WORK

This study builds on two areas of research: a recent move from supporting individual patients or caregivers to supporting collaboration between them, and efforts to understand and honor the values of patients living with MCC.

Support for Individuals Living With Chronic Illness

Warshaw et al. [61] defined chronic health conditions as "conditions that last a year or more and require ongoing medical attention and/or limit activities of daily living." Avoiding the complications of common chronic health conditions such as diabetes, arthritis, and depression requires patients to perform activities such as eating a specific diet, getting physical activity, and taking medications. Corbin and Strauss [17,18] named three "lines of work" to describe how patients and their caregivers manage chronic illness in daily life. First, "illness work" involves activities like exercising and taking medications. Second, "everyday life work" involves activities like spending time with a spouse, holding down a job, and raising children [18]. Third, "biographical work" involves coping with difficult emotions associated with changes to one's life and identity due to illness [18]. We use the term self-management to refer generally to these lines of work, but we acknowledge there is inconsistency regarding the definition of self-management and related terms (e.g., self-care, c.f., [6,38,50]). Wherever possible, we ground our discussion in the activities themselves instead of referring to self-management or self-care.

Supporting Individuals

Most studies in health services and HCI have aimed to design technologies that enhance how individuals (as opposed to dyads) manage chronic illness [45]. 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 [26,57] or blood glucose [51,57], or facilitating reflection [39] and awareness of symptoms [3]. Indirect support for patients through support for informal caregivers has included supporting information sharing among caregivers of infants [37], facilitating communication between caregivers, friends, and family of persons with dementia [19], and a monitoring system to help caregivers protect elderly patients from wandering or social exploitation [21]. Finally, research focused on caregiver burden [15] 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 [53,58,64].

Supporting Collaboration Between Patients and Caregivers

Recent research has emphasized the collaborative nature of daily care activities performed by patients and informal caregivers. Following Miller et al. [41], 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). Informal caregivers for patients with chronic conditions might help with dressing, eating, or finances, and provide emotional support [53].

Of particular relevance to this study is the need to treat the patient-caregiver pair as the unit of analysis [44]. This is especially true for the population we are studying: married couples that live together. According to the United States census, 57% of adults over the age of 65 are married [65]. This sizeable population warrants attention because spousal caregivers tend to be more vulnerable than family caregivers who are not spouses [49]. For example, spousal caregivers are more likely to face financial strain [35].

Nunes and Fitzpatrick [44] highlighted that collaboration between patient and caregiver changes as illnesses progress and other life circumstances change, and that "collaboration is based on acceptance of the chronic condition and a mutual commitment to its management" [44]. We recognize that collaboration is flexible and changes over time, and we recognize that mutual commitment is likely to be a feature of many patient-caregiver relationships. We also explicitly leave room for the values of patients and caregivers to differ regarding health care and other aspects of daily life. This view enables us to 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 that debated the meaning of "cooperative" in computer-supported cooperative work. For example, Kling [33] highlighted the existence of non-convivial relationships in collective work.

There is a need for more work investigating how technology can support collaboration between patients and caregivers [44]. 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 [16], 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 [9]. In another example, digital family portraits supported family members' awareness and peace of mind regarding seniors' daily activities [43]. However, there has been little research on collaboration between patients and spousal caregivers.

Values and Competing Demands of Chronic Conditions

Definition of Values

We adopt the definition of *values* from Friedman et al. [23]: "what a person or group of people consider important in life." We follow Le Dantec et al. [34] by adopting the perspective that values are local to and situated in the context of each patient-caregiver dyad, not universal. We recognize that some values may be broadly relevant, such as patient autonomy, but we also recognize that even these values will be expressed differently across cultures and social worlds. We follow Houston et al. [29] in considering values as produced and reproduced in action, rather than fixed entities. This orientation suits our focus on patient-caregiver collaboration because its dynamics shift over time in response to changes in health and other life circumstances [44].

Prioritizing Among Competing Demands

Patients with MCC face unique challenges because their health needs are complex. Managing one illness may be difficult due to the symptoms of another illness. For example, a person who wants to exercise to manage diabetes may experience shortness of breath due to heart disease [5]. In addition, patients face tensions between health needs and other life factors, such as money, time, and social support [52]. For individuals who are married, health needs and other life factors are likely to be intertwined. Faced with these competing demands, patients and caregivers are forced to prioritize. This is why it is critical to understand the values of patients and caregivers: values necessarily play a role in how they prioritize the demands of care activities in the context of daily life.

Previous work in health services has highlighted the importance of understanding and honoring patients' values [59]. Clinical practice guidelines for MCC from the American Geriatrics Society recommend incorporating patients' preferences into medical decision-making, and several studies have designed and evaluated methods for providers to elicit and clarify patients' values [22,25,63]. However, this research has largely been limited to clinical contexts, neglecting to understand values from the perspective of patients and caregivers, who manage personal health mostly outside the clinic in everyday life. Some studies have addressed congruence of values between caregivers and patients. Moon et al. [42] found that higher incongruence between patients and caregivers regarding the importance of social relationships was associated with lower quality of life for both. Reamy et al. [48] found that caregivers perceived a variety of patients' values—including autonomy, social relationships, and family—as less important than patients perceived them. However, these studies did not investigate relationships between values and the management of illness, nor did they specifically involve patients with MCC.

Supporting individuals with MCC requires understanding their values, but previous studies with this patient population have focused on values from a clinical perspective. Recent work [36] showed individuals with MCC often do not disclose their values to healthcare providers, which reflects 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:

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?

METHOD

We report on a field study in participants' homes in which we conducted photo elicitation, interviews, and home tours during two-hour visits. Study procedures received institutional review board approval at Group Health Research Institute.

Participants

We interviewed 12 patient-caregiver dyads (P1 and CG1 to P12 and GC12), all of whom were married and living together. Participants were recruited from an integrated healthcare system in Washington State. We required patient participants 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-management than other conditions, and because self-management for these different conditions can conflict. We only recruited participants who were not receiving help from a professional caregiver.

We recruited informal caregivers by asking each patient if there was anyone they lived with who helped manage their health care. We did not require the caregiver to be a spouse,

but every patient-caregiver pair in our sample was married. Table 1 shows demographics of the sample. 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 Black and 11 reported they were White. Caregiver age is missing from the table because we did not collect this information.

Home Visits

The field study consisted of home visits with each patient-caregiver dyad, including photo elicitation [26], 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.

Characteristics	Patient (N=12)	Caregiver (N=12)	All (N=24)
Age			
Mean	65.75	N/A	N/A
Range	25-87		
Gender			
Female	6	6	12
Male	6	6	12
Employment			
Full-time	2	2	4
Part-time	1	2	3
Retired	7	5	12
Unemployed	1	1	2
Disabled	1	2	3
Education			
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

Table 1. Participant demographics.

Analysis

Interviews were professionally transcribed verbatim. Analysis was guided by grounded theory [14]. 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. Two authors (CL, AB) 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 authors participated in meetings to discuss, clarify, and elaborate codes and emergent themes.

FINDINGS

We found that patients' and caregivers' values shaped their daily collaborations. In this section, we first introduce common patient and caregiver values. We then present the themes that emerged on different ways values shaped partners' collaboration in daily life.

Figure 1. Examples of photographs participants took to demonstrate values: a) religious images on display, b) photographs of grandchildren, c) a backyard patio, d) a pair of golden retrievers, e) hats received as gifts from grandchildren.

Values

Values emerged through photo elicitation, in which participants labeled the photos they took (Fig. 1), and through discussion of the photos during interviews. Patients and caregivers commonly referenced values in five domains: principles, social relationships, emotions, activities, and belongings. Principles were standards or virtues, such as spirituality or independence. For example, P4 took a photo of religious images displayed on his living room wall to represent the value he places on faith (Fig. 1a). Social relationships were connections with others, such as family or friends (Fig 1b). Emotions were desired feelings or mood, such as a sense of accomplishment or the serenity of a place for quiet time, such as the backyard patio (Fig 1c). Activities were pursuits such as reading, gardening, or walking the dogs (Fig 1d). Belongings were tangible things such as a car, woodworking tools (Fig 1e). Sometimes participants discussed values that crossed domains, such as hats (i.e., "belongings") received as gifts from grandchildren (i.e., "social relationships") (Fig 1e). Thus participants expressed a wide range of values and they valued many things that were not directly related to health.

Given this brief introduction of things participants valued, we next describe how these values influenced their daily collaboration. Partners' 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 collaboration and 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.

Coinciding Values

In many cases the caregiver and patient both valued the same thing, such as the shared enjoyment of spending time with grandchildren. We discuss this in the *shared values* subsection. In other cases, a caregiver valued something by virtue of its importance to a patient. We discuss this 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.

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 patient and caregiver 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. Some of our participants shared common values that they did not perceive to be wholly 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 the status quo, potentially preventing partners from changing their behavior in ways they perceive as healthy. 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.

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 it to be important to the caregiver, too. In these cases, the caregiver's values coincided with the patient's. When the caregiver observed that the patient faced challenges related to something the patient 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 (Fig 1b). 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 the 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. Since then P3 spent much 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.

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.

Patient's Health, Caregiver's Prerogative?
Spousal caregivers are likely to care deeply about their partner's health, but they cannot necessarily expect their partner 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. 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 didn't handle the situation in the manner she wanted. This example shows the tension some partners face between exercising autonomy and coordinating with one's partner.

Not all patients acquiesced like P7. 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 would react 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 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 to broach this with her for several days. 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.

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 reduce 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 separate meals for herself and CG3, requiring extra work, or she ask CG3 to cook his own meals, which may 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.

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 the care they provided changed as their partner's values and health changed. First we discuss how

patients often performed caregiving work, resulting in mutual support. Then we discuss challenges participants faced when they shifted responsibilities, with special attention to the function of values in these challenges.

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 supporting their partner (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 [44], 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.

Giving Up Valued Activities

When a caregiver takes over an activity that the patient can no longer perform, the caregiver supports the patient by alleviating the patient's responsibilities. 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.

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, P2 said CG2 would 'fill in' for her: *"[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" (Fig 1d). 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 and the caregiver suggests returning duties back to the patient. We know caregivers are motivated by their empathy for the patient, but this empathy may subside if the caregiver perceives that the patient is no longer suffering. The patient may grow accustomed to freedom from particular duties and resist taking them back. This resonates with previous findings showing that differences in values can become entrenched.

DISCUSSION

In the background we discussed how systems intended to support individuals with chronic illness tend to focus on the patient (e.g., [3,39]) or the caregiver (e.g., [58]). Recent work has emphasized that patients and caregivers collaborate in daily care activities [44]. Our findings extend this 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 [17]. We found that caregivers' empathy motivated them to support patients through coinciding values. But, when partners' values were asymmetric, this introduced tensions between individual autonomy and collaboration. We also demonstrated how values influenced the way patients and caregivers shifted responsibilities to support each other, and how this support was mutual when both partners had chronic conditions. Together, these findings illustrate the need for systems that 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.

Designing to Account for Partners' Values

Our 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 [9,44] and the burden of caregiving activities [15,53]. Our findings show how partners' values explain and give context to those phenomena. For example, our focus on values reveals that shifting responsibilities between partners can be particularly difficult emotionally when those responsibilities are tied to the patient's values. As we discuss 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 impacted.

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 [44]. These findings suggest that systems should not enforce strict patient and caregiver user roles. Systems should instead enable either partner to perform activities traditionally associated with "patient" or "caregiver" roles. Furthermore, individual roles should not be assigned 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 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 [3,4,40]. 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 [44] 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 [28], parents and children undergoing bone marrow transplants [30,31], blind and sighted companions [11]). 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 [47]. Our findings suggest that focusing on the values of participants in these caregiving relationships can illuminate how they collaborate.

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., [9,44,53]) has not explored how technology can be designed specifically to support this values-related relationship work. We saw 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). We also saw 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 to pursue health and well-being together. An example is aDBFT, a journaling system for cohabitating partners. In that system, each partner shares snippets of journal entries, fostering reflection and communication [10]. 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) [10]. 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).

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, the 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) 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. [55] investigated the design 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 people inside their social network.

Limitations and Future Work

Our 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 [16,27]. 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 our view of participants' lives at one point in time did not capture the dynamics. Future studies could look at these dynamics over time. Our patient sample 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 [54] described the invisible work individuals in low-resource areas performed as part of their self-management work. Another limitation is that our findings are 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. Conducting our study in areas with different policies may have produced different results. Finally, the way families and patients view illness differs across cultures [66], 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.

CONCLUSION

We uncovered ways that patients' and spousal caregivers' values shaped how they collaborated to manage MCC in daily life. We found many cases in which both partners provided care for each other's illnesses, blurring the boundary between "patient" and "caregiver." 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 are challenging when they challenge 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, we offer suggestions for designers to support partners in overcoming asymmetric values while supporting autonomy for individuals who choose to pursue their values alone.

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