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## “It just seems outside my health”: How Patients with Chronic Conditions Perceive Communication Boundaries with Providers

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### Abstract

To improve care for the growing number of older adults with multiple chronic conditions, physicians and other healthcare providers need to better understand what is most important in the lives of these patients. In a qualitative study of home visits with patients and family caregivers, we found that patients withhold information from providers when communicating about what they deem important to their health and well-being. We examine the various motivations and factors that explain communication boundaries between patients and their healthcare providers. Patients' disclosures reflected perceptions of what was pertinent to share, assumptions about the consequences of sharing, and the influence of interpersonal relationships with providers. Our findings revealed limitations of existing approaches to support patient-provider communication and identified challenges for the design of systems that honor patient needs and preferences.

### Keywords

Chronic illness; patient-provider communication; patient self-disclosure

## INTRODUCTION

Approximately two-thirds of people over 65 years old have two or more major chronic health conditions, a rate that increases with age. Compared to patients with single conditions, older adults with multiple chronic conditions receive more conflicting medical advice and experience worse quality of life, more physical disability, more adverse drug events, and higher mortality [13]. Patients with multiple chronic conditions often encounter competing and conflicting demands for care. For instance, someone who wants to control complications of diabetes through exercise might have difficulty due to pain from arthritis or shortness of breath from lung disease [8]. Competing demands present barriers to effective self-care for patients and their caregivers. Furthermore, patients and their healthcare providers often do not agree on care priorities [48]. For example, providers tend to orient health goals toward the management of individual conditions, whereas patients focus on their capabilities to engage in meaningful activities [3,25]. To improve care for patients with multiple chronic conditions, it is important that patients and their providers communicate about what is most important to patients in their daily lives.

Numerous technologies have been designed to improve patient-provider communication and enhance encounters both in and out of clinical settings [3,14,44,49]. Along with forums to outline opportunities for future work [49,50], the development of new patient-centered communication tools indicate a growing interest in supporting collaboration between patients and providers. However, little is known about how to improve communication in the context of care for patients with multiple chronic conditions.

To strengthen communication between patients and their providers, we sought to understand how patients perceive and communicate about what is important to them. In a qualitative study of 24 home visit interviews with patients and caregivers, we found that patients made decisions to withhold information, reflecting a range of motivations for patients' disclosures. Our work reveals factors that influence how patients perceive and enact communication boundaries. These contributions are important to consider when designing opportunities for patients to share—and for providers to better understand—what is most important in patients' lives.

We begin with a review of related work, including patient-provider communication, self-disclosure in the clinical context, and patient preferences for sharing health information. We then describe our methods, present findings, and discuss implications of our findings.

## RELATED WORK

### Patient-provider communication

Effective communication between patients and providers is associated with positive patient-centered health outcomes [27,42]. Disagreement between patients and providers on care priorities can lead to worse health outcomes and loss to follow-up [10,17]. In a study measuring patient-provider concordance and the prioritization of care, researchers observed lower concordance for patients who had poor health status or non-health demands that conflicted with treatments [51].

Efforts to enhance patient-provider communication have included new tools and approaches to care in the clinic to connecting care at home. Asynchronous communication tools, such as patient portals, telehealth technologies, and personal health records [3,37,40,45] have created new opportunities for patients and providers to communicate. In chronic illness care, researchers have designed patient-center platforms that visualize their observations of daily life [14] in an effort to support both the everyday work of self-management and communication with clinicians. The eDiary for pregnant women with diabetes [2] and similar work have addressed the need for a “continuum of care” [34] between the clinic and the home and improved collaboration between patients and providers. To interpret meaning from telemonitored data, researchers have explored applications for patients to help providers collaboratively make sense of fluctuations in the numbers with additional qualitative and/or narrative information [4,18].

Communication tools directed at patients for use in clinical settings have been shown to improve interactions with clinicians and positively affect health outcomes [44]. However, studies have investigated whether too much technology can create barriers or reduce the

quality of face-to-face interactions [15,16]. The adoption of new communication systems can affect transformations in patient-provider communication and displace rich in-person interactions [7]. Important questions remain about how best to design these tools, given the changes they introduce to the work of patients, caregivers, and providers across clinical and nonclinical settings.

### **Self-disclosure in clinical settings**

Self-disclosure—broadly understood as a statement made about one’s personal experience—has been examined in primary care and psychotherapy settings. In the few studies about patient self-disclosure, fears of negative reactions and shame were possible barriers to sharing, whereas a “strong therapeutic alliance, overall tendency to be disclosing, and time in therapy facilitate disclosure” [21].

Interpersonal skills are an important part of physicians’ training and associated with positive health outcomes and satisfaction from patients [21]. Therefore, more studies about clinical self-disclosures focus on providers rather than patients. Provider self-disclosure is thought to help build rapport with patients but is met with mixed results. Physicians sharing about their personal lives sometimes had no perceivable effect, was seen as distracting [32], and at times violated perceived boundaries between the clinician and the patient [33].

While these studies have laid the groundwork for understanding the importance of self-disclosures in clinical settings, the motivations and factors that influence patient self-disclosures are still largely unexplored.

### **Sharing preferences**

Prior work has found that patients conceal physical signs of their illnesses. Some go to lengths to conceal or disguise health objects from visitors to their homes. For example, patients use false cases or hide medications in discreet locations around the home [6,38]. Worries about judgment or social stigma can influence a patient’s behaviors and attitudes towards revealing or concealing mobile medical devices worn for monitoring diabetes [35]. Benjamin et al. applied the concept of ‘impression management’ to describe older adults with chronic pain who reveal or conceal their symptoms to negotiate disruptions in their social lives and relationships [11].

Previous work in personal health information management has studied the sharing preferences of patients and other stakeholders. Involvement in self-care often necessitates that patients manage and share personal health information with providers [45] and caregivers, who are typically family members [6,39]. Privacy is often the top concern among older patients considering the use of health information management technologies [12]. This is consistent with technology preferences among patients who want to be able to control the content shared with their caregiving networks [24,39]. Some patients choose not to share health information to reduce burdens on family members, though these preferences may change over time [43]. In a study comparing the health information sharing preferences among cancer patients, doctors, and caregivers, researchers found participants to be misaligned [26].

While these studies offer valuable contributions to transform communication both in and out of the clinic, there has been limited work examining the patients' self-disclosure preferences in encounters with providers. As shown in a recent study regarding patient-generated data, patients and providers may not align on their expectations for patient-provider interactions about health information [19]. Good communication is necessary for shared decision-making [36] and for improving health outcomes for patients with multiple chronic conditions. We focus on identifying communication boundaries patients perceive with providers.

## METHODS

This paper reports on a field study in participants' homes in which we conducted interviews, photo elicitation, and home tours during two-hour visits. Study procedures were approved by the institutional review board at Group Health Research Institute.

### Participants

We recruited 24 patients (P1-P24) with multiple chronic conditions from an integrated healthcare system in Washington State. Half of these patient participants (n=12) were interviewed along with one family caregiver, while the other half were interviewed individually. Participants (female = 12, male = 12) were mostly older adults (mean age = 68, SD = 14.8), although ages ranged from 25 to 87. Most had some college or a 2-year degree (46%), or had graduated high school or earned a GED (25%), or had more than a 4-year degree (17%).

All participating patients had diabetes and at least two of the following common chronic conditions: depression, osteoarthritis, and coronary artery disease. These conditions were selected because they all require a high degree of self-management to achieve optimal health outcomes. Many of the self-management activities for these conditions overlap while others are likely to compete. For example, recommendations for physical activity to improve outcomes for diabetes and coronary artery disease may be limited by the demands of arthritis. The medications that treat these conditions are often associated with significant side effects that can impact daily activities.

### Procedures

Home visits included a semi-structured interview aided by photo elicitation and a home tour. The goal was to understand how patients think about care priorities in the context of daily life and how they communicate with healthcare providers about what is most important to them.

We used photo elicitation to help build an understanding of each participant. Participants received instant cameras by mail with a prompt to take photographs of what matters most to their well-being, and we allowed participants to define the term *well-being* for themselves. We sent the cameras prior to scheduled interviews to allow time for participants to reflect and actively participate.

To inquire about patient disclosures, we first sought to understand what mattered most to the well-being of each participant. We started each interview asking participants to describe each photo and why they included it. The photos enabled participants to introduce concrete objects, such as people or hobbies, as well as more abstract notions, such as virtues. Participants described how these were interrelated and connected to their care. The details were helpful for later probes on what participants deemed most in their daily lives and how this related to their care. The semi-structured interview allowed for uniformity and for new issues to arise from participants. Informed by previous work in chronic care, including the dimensions of self-management work defined by Corbin and Strauss [20] and the Chronic Care [48] and Collaborative Care models [47], we structured the interview guide around a set of three broad domains: (1) self-management activities, (2) demands and tradeoffs in chronic care, and (3) information sharing with caregivers and healthcare providers.

The home tour typically began three quarters of the way into the visit. We asked participants to show us objects that supported their health and well-being. Tours were helpful for surfacing new information, providing follow-up details about artifacts or spaces referenced during interviews, and contextualizing daily activities in situ.

We audio recorded the interviews, which were then professionally transcribed verbatim. Our analysis was grounded in the data to identify emergent qualitative themes. Two researchers independently coded transcripts line by line to develop an initial set of codes. We then compared the codes for consistency and iteratively discussed, edited, and consolidated codes until a codebook was established. By writing memos, we were able to track decisions for merging or editing codes, draw conceptual links between codes, and group them together thematically. All members of the research team discussed emergent themes to ensure consistency and rigor in the interpretation of the data.

## FINDINGS

Participants varied widely on whether they communicated with providers about what is important to their well-being. Some participants described themselves as “*private*” (P16) and avoided discussing aspects of “*the social life*” (P2) with healthcare providers. Others perceived no communication boundaries: “*I talk with [my provider] just about anything, you know.*” (P3) However, even those who felt they could share openly with their providers withheld information about what was important to them, details that may have helped develop a shared understanding about care priorities. We found that participants maintained communication boundaries with providers by withholding or filtering information about what was important to them. To describe our findings, we explain communication boundaries through three themes: patient disclosure practices, factors that influence communication boundaries, and how interpersonal relationships with providers affect what patients choose to share.

### Patient disclosure practices

We identified common patterns in patients’ accounts of self-disclosure. By characterizing different disclosure practices we reveal how patients perceived communication boundaries with providers and the factors that influenced barriers to sharing.

**Filtering**—During clinical encounters, participants acknowledged filtering details about non-health aspects important to their well-being. We found that participants omitted this information because they focused on describing symptoms when sharing health concerns with providers.

When P18 and his wife (CG18) retired, the couple built a woodshop behind their home to construct various wooden objects and furniture they sold, donated to charity, or gave as gifts to family and friends. P18's health had declined over the last year, so they were spending little time in the woodshop. However, neither P18 nor CG18 mentioned the shop at all when they spoke to their doctor about P18's health concerns. Instead, they focused on P18's symptoms of fatigue and depression:

“He doesn't come out and say, ‘I can't work in the shop anymore,’ but, ‘I just don't do things like I used to,’ or, ‘can't do things.’ He says I just don't – he's been so tired with it. That's why I think he got depressed because he was so tired all the time. And he didn't like the feeling of being tired all the time.”

–CG18

P18 and CG18 illustrated how participants communicated their concerns by reducing them to a set of symptoms. These disclosure patterns point to lost opportunities for providers to understand why patients prioritize certain symptoms over others (in this case, tiredness) and how these may be linked to other conditions (P18's depression) and the loss of valued activities (woodworking). In addition, the couple did not disclose that P18's tiredness also limited CG18's time in the woodshop because P18 worried for her safety and did not approve of CG18 using woodworking tools on her own.

Details like the importance of spending time in the wood-shop may provide context that is critical for patients and providers to discuss how best to manage symptoms that might allow patients to return to meaningful activities or, if that is not possible, explore alternatives. The act of filtering indicates patients' routinized communication patterns and the possible influence of perceived expectations for how they should focus clinical conversations.

**Making specific requests**—We found patients made specific requests, reflecting the everyday work done by patients and caregivers, who adopt increasingly active roles in managing chronic conditions [31,41,46]. While the clinical context influenced patients' practice of filtering, participants did additional work outside of the clinic in order to make specific requests to doctors, especially about making changes to medications. Patients sought information about their conditions, explored alternatives to their current treatments, consulted with friends and family, and examined their own behaviors. However, the amount of work involved in this process was not visible to providers because details were often condensed into specific requests.

P18 and CG18 wanted to cut one of P18's blood pressure pills in half and space out the intake of other medications. To narrow in on this solution, CG18 had meticulously written down all of P18's pills in a binder, along with his blood pressure readings. They took the binder to the pharmacist and asked about side effects. After doing some online research and consulting with their daughter (a working nurse), CG18 suspected that spacing out the intake

of P18's blood pressure medications could reduce the tiredness he experienced after taking all the pills at once each morning. They discussed this with their doctor, who agreed to the adjustment, and the couple felt this change was effective. However, as previously described, their doctor was not made aware that the concern for feeling tired was linked to the loss of working in the woodshop and possibly depression. This omission is significant because the doctor may have approached the symptoms of tiredness differently to focus less on the medication regimen and more on how the patient might return to working in the woodshop.

Participants made some requests after they explored alternatives to their prescribed treatments. For example, P13 wanted to discontinue depression medication he had been taking since his retirement. He had been attending a bible study where he met people who claimed they had overcome depression without medications. He was inspired to take the same approach—to achieve a sense of agency that he could change his condition and to strengthen his “*mental health and spiritual ability*.” Prior to the visit P13 had decided to talk to his doctor about stopping his depression medication, and his doctor agreed to help make this change. However, he did not share that the decision was important to his spirituality, and instead showed deference to the doctor, who appeared too busy discussing other matters.

Despite the positive outcomes of these cases, these examples uncovered the negotiations that occur as part of the work of self-care, which is often carried out by both patients and their family caregivers. Patients do not always reveal how specific requests relate to the importance of their belief systems or other meaningful activities, limiting the information available for providers to consider when making care recommendations.

**Negotiating care priorities outside of the clinic**—In many cases, participants described how they prioritized family obligations over care recommendations from providers. These choices seemed so obvious to participants, they did not take much time to deliberate over options. For example, when P24 was informed about a cancer diagnosis he elected to postpone a recommended surgery to continue holiday plans with family.

“When I found out I had cancer, they said, ‘We’re gonna do surgery on Friday.’ This is a Wednesday. Well, Sunday was Christmas...My mom and dad are in town. I have kids. You’re not f\*\*\*king up everybody’s Christmas, not over this...[the doctor] he’s like, ‘I don’t understand your attitude. I love it, but I don’t understand it.’”

–P24

Another participant postponed a knee surgery to care for her newborn granddaughter:

“But it’s coming. There’s just other priorities first. Taking care of this baby right now is going to be my priority at the moment. The mom has to go back to work and I do not want this baby going into a daycare... We’ll take care of the [knee] problem, but right now it’s not bad enough to take care, I guess, or I would have taken care of it.”

–CG11

For both P24 and CG11, the decision was simply about prioritizing family over medical procedures. In comparing these examples, participants dictated when and how they communicated priorities with providers. While P24 candidly told his doctor about his reasons to postpone the surgery, CG11 did not intend to notify her provider despite her knee pain disrupting daily activities and her ability to exercise. Instead, CG11 planned to discuss treatment options on her own timeline. Responsibilities and activities pertaining to participants' lives at home, especially with family, were seen as external to providers' domains even if they influenced decisions about care.

**Discussing care priorities with others**—In addition to healthcare providers, participants turned to friends, family, and faith leaders to discuss concerns, challenges, and decisions about their health and well-being. For example, P2 considered giving up one of her most meaningful activities: volunteering to run an emergency feeding program for homeless individuals, a position she held for 20 years. She worried about continuing the physical work of transporting and serving the food, and she had already scheduled days of rest in between days of activity to recover from exhaustion and pain caused by arthritis in her knees. She was concerned that giving up the activity would leave a void that could affect her well-being. P2 explained her process for making this decision:

“After I meditate, time, like, I need to sleep on it. Walk on it, a decision, you know...pray over it, then mention it gradually. Not as detailed as I just did, to somebody I trust. Not that I don't, (laughs), well, I don't trust you. But, my friends. 'What do you think about it?' 'I don't know,' and I'll say, 'well, I'm thinking about it.' And then, after that then I make the decision.”

–P2

Although P2 claimed to have “*the best doctor in the world*,” she had never mentioned the weekly volunteer service to her doctor. Instead, trusted friends were part of her decision-making process. From her perspective, discussing non-health or social aspects of her life was beyond the role of the doctor. Her provider was unaware that symptoms of her arthritis were a threat to this valued activity and that giving up the volunteer role would impact P2's well-being.

Several participants mentioned religious leaders involved in their health, especially mental health. One example is the relationship P9 had with the first lady of her church (i.e., the wife of the pastor). After being a victim of an armed robbery, P9 had been diagnosed with PTSD and depression, which led to days when she would not leave her home or bedroom. P9 saw several psychiatrists and was generally satisfied, but explained that these providers often moved away or were out of network and therefore more expensive. In contrast, the “first lady” of the church was a source of spiritual guidance and mental health support:

“Well, since she's a teacher of psychology, you know, it's like she's there to—not counsel but, or, well, she does what psychologists do, or talk, you know....And, of course, since she's the First Lady, she's always saying, 'You've gotta pray,' you know, 'Just pray it through.' And she always says, 'God won't give us nothing we can't handle.' And she tells me about – she's had PTSD before, and she tells me



about what she went through, also. So she's just, I mean, she's there for me to vent.”

–P9

P9 had a new psychiatrist, but only made appointments if she needed to change or refill prescriptions. On the other hand, as a leader in P9's church community—a very small and close-knit congregation—the first lady filled an important role in her social life and offered continuity her healthcare providers did not. Participants like P9 consulted with friends, family, and religious leaders in the process of negotiating care priorities, which occurred outside of the clinical role of healthcare providers. Regardless of how positively participants viewed their relationships with their providers, how they perceived providers' roles had bearing on what they considered to be pertinent, or even socially appropriate, to discuss with their providers.

### Factors that influence communication boundaries

Patients' decisions to withhold or filter information revealed their perceptions of communication boundaries with healthcare providers. We identified several factors that influence these communication boundaries: pertinence, experience, attitudes about healthcare, conflicting beliefs, and time constraints.

**Pertinence**—Participants described withholding information they perceived to be outside the scope of what their providers needed to know. Decisions to withhold often applied to non-health demands in patients' lives. Participants skipped over or excluded details even if the information might have explained why they prioritized certain health concerns. For example, P16 expressed fears about going blind from retinopathy, a complication of diabetes. She was an avid reader who proudly showed us her book collection and reading room. She was concerned that vision loss would require her to give up reading, and she had already stopped gardening because it was too physically strenuous. Despite this, she did not share these concerns with her doctor:

“I guess it's more my personal fear. I wouldn't ever think of talking to a doctor about things like that. If I have an infection or something, I would talk to them about that. But I'm a pretty private person...It just seems outside my health. Well, it is part of my health issue, but I would never think of it when I went to the doctor to talk about something like that.”

–P16

P16 considered this fear to be extraneous to what she would normally discuss with her doctor. In a similar example, CG7 articulated the benefits of his doctor understanding more about his life. Nevertheless, he also interpreted these issues to be outside the scope of what healthcare providers needed to know:

“It's—I know it's hard for them because their focus is on our health, not so much on the things that we enjoy and that kind of thing. But if they understood that the things we enjoy are the things that make us happy and healthy, I think that would go a long way towards making us healthier.”

–CG7

CG7 determined what was pertinent to share based on what he perceived to be within provider definitions of “health.” This example highlights how patients assume a lack of interest from providers. Given that considerations for care priorities cross into non-health domains, patient perceptions of what is pertinent pose a challenge to the ideal of collaborative priority-setting.

**Patient experience**—Patients who had many years of experience managing conditions developed expertise and were confident in their understanding of what providers needed to know. For example, P1 was diagnosed with Crohn’s disease in high school, and since then she was frequently hospitalized due to complications of her condition. P1 did not think it was important to tell her doctor about non-health aspects of her life, such as her recent layoff from work or her value of living simply. She went to her providers for *“the medical stuff only because they’re involved with that, and I have to get their okay for ostomy supplies and things like that.”*

P1’s handle on self-management affected her perception of what was pertinent. Patient expertise developed over time, as well as professional experience working as an RN gave P1 confidence in her ability to get the care she needed, despite filtering some information:

“I think that it’s taken me a long time, but I’ve learned to ask for what I need....The problem is that I have an inkling of what I need, and not everybody does...Well, I have some insight. I’ve had Crohn’s for years. I had to tell my family doc when I first met him, ‘This is what happens when I get a bowel obstruction. This is what you need to do.’”

–P1

We include this example because it indicates factors that are intrinsic to patients but can change over time. P1’s confidence contrasts with patients who are overwhelmed by the task of managing their conditions or have difficulty facing major life changes as the result of their illnesses. Patient perceptions of communication boundaries can shift as patients learn and adjust to managing their symptoms.

**Attitudes about healthcare**—General attitudes towards aspects of healthcare, such as a bias against mental health or social work services, were reasons for intentionally withholding information from providers. Patients especially avoided topics about the emotional and social aspects of their illnesses. For example, P17 described difficulties with back pain, which prevented him from picking up his ten-month-old grandson. Others had to hand the infant to him, affecting him emotionally. However, he expressed his discomfort with sharing his emotional struggles with his providers:

“Part of the time, it makes me feel like I don’t want to be around. If I can’t enjoy my kids and my grandkids, what’s the sense of being here? Not that I’ve ever thought about [imitating gunshot sound]... Yeah, but your self-worth is gone. I don’t know if there’s anything they can do about that. Send you to mental health doctors.”

–P17

P17 worried that doctors would “*put you in the looney tooney bin.*” His aversion to mental health treatment further complicated the competing demands of treatment for his back and foot pain and his need to engage with his grandchildren. In addition to withholding about his emotional problems, he also assumed that sharing concerns about pain with his doctor would only lead to more pills, which he wanted to avoid because he attributed a previous experience with symptoms of depression to the side effects of post-surgery pain medications.

In situations like P17’s, participants set communication boundaries based on assumptions about the outcomes of sharing. Decisions to withhold were very intentional and reflected strong desires to shape responses from providers. This breakdown in patient-provider communication indicated patients’ willingness to control the type of care a patient received—or in P17’s case, the type of care he wanted to avoid. However, P17’s omission about his mental health also influenced the care recommendations he received for his back pain.

**Conflicting beliefs**—Some patients avoided talking with their providers about topics that were sensitive or if they perceived their views to conflict with the beliefs of healthcare providers. For example, religion and spirituality were important to the well-being of many participants who generally preferred not to discuss spirituality with their providers.

Involvement in community at their church was important to P5 and her family. P5 was also very ambitious with her sewing and quilting projects, which kept her active in local groups and well-known in online communities. She had an entire room in her home devoted to storing supplies and in-process projects. However, what was not immediately apparent is that her crafting activities were intertwined with her religious beliefs and health conditions.

“Part of the reason I have so much stuff here is a year and a half after [husband’s name] and I got married, I got really sick and was diagnosed with multiple sclerosis. I lived, then, with the knowledge that someday, I wouldn’t be able to do these things, and those were all the things I thought I’d do after I retired, but with MS, I wasn’t gonna be able to do those things. Well, about 12 years into MS, I received a healing and my doctors didn’t buy it because they’re so non-healing, but I know that I received the healing from God.”

–P5

Contrary to her doctors’ beliefs, P5 believed the religious healing had enabled her to continue sewing and quilting. Religion and spirituality are examples of topics that participants avoided because they were thought to be unwelcome by healthcare providers.

Tensions between religion and healthcare were not equally present for all participants who considered their religious beliefs to be important to their well-being. For P11, faith and family were central to his well-being. In fact, he described health issues as “distractions” from his devotion to faith and family. He felt that “*faith and doctors were never meant to be removed from each other.*” Yet, the importance of his faith was not something that he normally communicated with his doctor. He would share if prompted: “*It’s not something that is on the forefront, but if it comes up, there’s no sense hiding it. It’s who you are.*”

Despite the significance he placed on his faith in his daily life, P11 would only share this information if he were asked, indicating that providers heavily influenced the content of communication.

**Time constraints of clinic visits**—Participants expressed feeling pressure from the time limitations of clinic visits, which prevented them from sharing details about what was important to them. Filtering or withholding was often the result of a common preparation practice among participants: making a written or mental list of the most bothersome or painful concerns that patients wanted to cover within the time frame of visits. As P20 described, *“It makes me go in there with the top two important things, and then I put the rest on the back burner until they are more severe. And I say, look, this is how long this has been going on. Please fix it.”* The making of lists based on urgency revealed implicit acts of setting aside non-health demands.

Fears about having to give up important activities due to declining health were among some of the concerns participants did not share due to perceived lack of time. For example, P4 aspired to have her mobility and agility back so that she could return to taking spontaneous camping trips with her family:

“Well, there’s really never any time for talking about stuff I’d like to be doing. I just basically talk to him about what’s bothering me and what hurts and...I usually just don’t even try to talk to them about that kind of stuff because it doesn’t seem like it’s pertinent.”

–P4

Like the example of P18 and CG18, P4 perceived time constraints influenced her to focus on communicating her symptoms rather than take time to share details about activities meaningful to her. Omissions due to pertinence were an outcome of perceived time limitations.

### Interpersonal relationships with providers

Relationships between patients and their healthcare providers influenced communication boundaries. Reciprocity, continuity, and feelings of trust and validation were thought to be important for facilitating open communication.

**Provider disclosures**—Participants felt more at ease opening up to providers who disclosed information about themselves. For example, P9 talked about her family members after she learned about her provider’s child. When P10’s primary care doctor was also diagnosed with diabetes, they *“compared notes”* about managing the disease. P18 and his wife CG18 described why they felt they could talk with their primary care doctor about *“anything”*:

“But he’s very thoughtful. He’s not a quick, ‘do this, do that, like that. And he’s always interested in what we’re doing. In fact, the next day, he told us, he was leaving on a cruise for Alaska. We were there Thursday. And we said we’ve been up there a couple times on a cruise...It’s just so nice. We know a little bit about him now.”

–CG18

Although P18 and GC18 were receptive to provider disclosures, they filtered communication and did not talk about how P18's symptoms threatened their ability to work in their beloved woodshop. Despite the perception that provider disclosures encouraged patients to open up, reciprocity did not always facilitate communication about what was important to patients. In fact, participants who were motivated to share often mirrored what providers shared with them. In other words, when providers talked about their vacations, patients also shared about vacations. Other studies about provider self-disclosure show that reciprocity can produce inconsistent results when used as a method of improving relationships with patients [5,9].

**Continuity of provider relationships**—Participants often said staying with the same provider for many years helped build knowledge and rapport. Continuity with providers also helped establish comfort with communication styles, such as the candor and humor exchanged between P11 and his doctor:

“My doctor retired but we established a relationship where we'd talk one on one... And every time I'd go in there, he'd say: you still smoking? I'd say yes and he said, 'you dumb shit, it's gonna kill you.' But that's the type of relationship him and I had.”

–P11

P3 described her provider's communication style to be very direct and that she could talk to her about anything. P3 attributed their lasting relationship as one reason she was able to discuss the entanglement of health and non-health demands that were difficult to balance:

“I've been with her for eight or nine years, which is nice. She's a part-time doctor and I've been with her for a long time. Yeah, and she knows about the boys...you know, I just say, 'Yeah, there's so much going on and I don't have energy to do all of everything.' You know, take care of the house, take care of the boys, deal with the what if's...”

–P3

P3 and CG3 later clarified that P3 avoided making appointments because she was worried about the financial cost of the co-pay. Despite this, the relationship she had built with her doctor enabled her to express concerns over the phone or through secure messaging.

**Breakdowns in provider relationships**—Feelings of trust and validation were important for building and maintaining relationships, both in the long-term and during each encounter. Participants described how breakdowns in relationships with previous providers affected subsequent communication. For example, P16 had received a notice that her primary care doctor's practice was too large, and she would be moved to another doctor. She assumed this was because the doctor did not like her. Afterwards, she was reticent to make appointments unless symptoms were intolerable, such as a recent sinus infection.

“Well, I really trusted him because I felt he was a great doctor. And he seemed to always – he helped me. It's like you go to your favorite mechanic. And he was really good. And I felt very comfortable with him. Now, I'm all stressed about

going to the [new] doctor because I don't want to go too much, or maybe that's why they kicked me to the curb. You know? It's just very different.”

–P16

P6's relationships with providers became a barrier to getting the care she needed. Several times, she felt sick and drove herself to urgent care but the staff told her there was nothing wrong with her. After finally discovering problems with her heart, she had a bypass surgery, which forced her to make major adjustments to her lifestyle.

“And then now since I've spent the last five years learning to deal with it [heart condition] and deal with the anxiety and the depression and find a new life, I've damaged my relationship with my doctors. My doctor doesn't wanna deal with me. We don't communicate well anymore. It's hard not to dwell on what happened in the past when it affects your future. So my goal is to not go to the doctors as often as possible. So you let things go until they're really bad before you bother going in because if it's little, they don't— they look at it as, ‘So what's the problem?’”

–P6

Her sentiments toward healthcare providers were so strong that she was compelled to avoid medical attention altogether, which is an extreme example of communication boundaries with providers. In fact, to her embarrassment, her coworkers had to call an ambulance for her when she exhibited severe symptoms at work because she wouldn't seek care on her own. P6's experience underpins the lasting effects that interpersonal relationships can have on what patients choose to share with their healthcare providers.

## DISCUSSION

This study examines the range of practices, factors, and interpersonal relations that influence patient disclosures in communication with healthcare providers. Tools to facilitate collaborative priority-setting will have to overcome or bridge these communication boundaries in order to enable providers and patients to develop a shared understanding of what is most important to patients' lives. The findings presented here provide a foundation for approaching patients' preferences and needs. Additional work is needed to understand and account for the needs and preferences of providers, along with the resources and constraints in the clinic.

### Limitations of existing communication systems

To improve care for patients with multiple chronic conditions, it is useful for providers to understand what is most important in patients' lives, which can include details such as important activities or relationships that are not normally discussed in the clinical context. This is because patients' care demands are entwined in almost every aspect of daily life, to a greater extent than those with simpler healthcare needs. We describe how our findings point to opportunities for improving patient-provider communication.

First, the communication needs we refer to involve qualitative information. Existing interactive technologies for asynchronous and synchronous communications focus on enabling the exchange of mostly quantitative data. For example, the tools that allow patients

to track and monitor health indicators such as blood sugar levels and blood pressure could also be used to share narrative data with providers [7,23]. The focus on exchanging quantitative data leaves out the richness of patients' experiences that we heard in interviews. Furthermore, platforms that aim to capture and import this richness into clinical encounters do so by anchoring visualizations of qualitative data, such as patients' observations of daily life, to the chronological tracking of symptoms [14]. Although these systems help bridge the gap between the clinic and the home [2] and create opportunities to share qualitative information, they are not designed to elicit and capture information about what is most important to patients in their lives, especially more abstract aspects such as values and beliefs.

Second, our findings demonstrate that we cannot presume patients' willingness to share information about what is important to them. Patients have a right to exercise their privacy and doing so may not impact their health, such as P1 who relies on the expertise she developed while managing Crohn's for decades and can get what she needs from her provider. On the other hand, the omissions we describe indicate that patients are unaware of what information is pertinent and valuable to their providers.

Reciprocity, continuity, trust and validation are well known characteristics that impact the strength of the patient provider relationship, but our study highlights how these factors impact whether a patient with multiple chronic conditions decide to disclose information that could be important to their healthcare discussions and decision-making with providers. The current training that helps providers to elicit patients disclosures in clinical settings [49] may be insufficient for breaking through some of the communication boundaries we have discussed. Moreover, these barriers are further complicated when patients face multiple chronic conditions, as seen in P17 who avoided talking about emotional or mental health problems, which precluded him from communicating about issues intertwined with pain in his back and feet, ability to exercise, and relationships with his grandchildren.

### Implications for design

In an effort to understand broader implications of patient behaviors and preferences, we did not focus on a specific communication modality. It is important to note that participants often referred to their use of phone calls and secure messaging, but predominantly discussed in-person communication during appointments. With this in mind, we discuss the implication of our findings.

**Creating opportunities to share**—In the clinic, both patients and providers feel pressure from operational constraints, such as time. Some patients are discouraged from delving into the details of their lives because their providers appear to be too busy and have limited time. Therefore, patients who want to attend to numerous concerns can be driven to wait until problems get worse before moving those items to the top of the list. These patient practices revealed that when patients make written or mental lists, information is deprioritized, especially details about non-health demands in patient's lives. The challenge is to create opportunities for sharing additional information that may influence care, such as qualitative or narrative information, despite the limitations of providers' time and resources.

On the other hand, our work may also help providers avoid spending wasted time focusing on things not important to the patient.

The preparation prior to clinic visits may be an opportune moment to prompt patients about what is important to them. A tool that helps make these deliberations more transparent could provide more context for how health concerns affect patients in their daily lives than is currently supported. Previous efforts to help patients manage their care-related information and plan for visits, such as the HealthWeaver mobile application, provides groundwork for approaching support for patients in between visits [28].

**Unpacking negotiations that occur outside the clinic**—Beyond the preparation practices for individual visits, our findings showed that patient disclosures reflect broader assumptions about how they perceive what is and is not appropriate to share with healthcare providers.

There was some indication that communication boundaries were associated with certain topics, such religion and spirituality. As a personal and potentially political topic, examining how participants discussed their beliefs revealed the influence of social and cultural norms. On the tour of P5's home, for instance, the co-existence of religious rituals and self-care activities were materially present at the kitchen table, where bibles, pill bottles, and food were kept together. The table is where P5 and her husband shared a morning routine of eating breakfast, taking medications, and reciting their daily devotions. Although patients have divergent opinions about the tensions between religion and healthcare, these tensions highlight that there is no binary division between health and non-health domains in the home. Aarhus and Ballegard applied the integration-segregation continuum to describe the material appearances of the boundary work of patients who introduce self-care into the home [1]. P5's kitchen table is a reminder of the presence of care demands in the daily life of patients with chronic conditions. In communication with healthcare providers, however, patients may compartmentalize information as they adapt to the context of the clinic, leaving out how health concerns relate to other aspects of their lives.

These findings suggest that while certain topics can trigger tensions between patients and providers, communication boundaries are context dependent. Prompts for disclosures in the course of patient-provider communication could likely surface certain topics that patients might never express without encouragement. The nature of the prompt is critical to setting the right context for breaking down assumptions.

Tools for breaking down communication boundaries should also enable the unpacking of care priorities enacted as part of the daily work of self-care. We described how patients risk postponing or putting off procedures to prioritize other obligations, such as financial priorities or family duties. These are examples of how patients enact care priorities outside of the clinic and in the absence of providers. When patients withhold information about the negotiations leading to their decisions about care, this minimizes the ability of providers to make care recommendations in accordance with patients' priorities.



Allowing for moments of reflection is one possible approach for unpacking negotiations made out of the clinic. In previous studies with chronic care patients Mamykina et al. created opportunities for reflective thinking in tools for diabetes management [30]. Their approach was informed by insights into the experience of patients who constantly readjust to the demands of self-management. Similarly, support for reflection in priority-setting could increase awareness about everyday negotiations and tradeoffs along the illness trajectory. Details such as how health affects the ability of P18 and CG18 to spend time in the woodshop would add meaning to the symptoms that concerned patients most. In keeping with the preferences of patients, the option to share this information with providers could help build continuity through provider changes or across a team of providers.

**Eliciting preferences for communication boundaries**—Our findings show that patients are cautious about sharing information based on assumptions about actions that providers might take. In some cases, patients knowingly omitted information about the emotional aspects of managing chronic health conditions. Preferences to avoid communication about emotional issues is compatible with a study that found the health information sharing preferences of cancer patients and their providers deviated significantly around the topic of loneliness [26]. For example, P17 admitted to his fear of a psychiatric evaluation, which he avoided for years by refusing to mention feelings of depression to his providers. P17 preferred to talk to his pastor and son who served as alternative resources for addressing his mental health concerns. Clarifying some of these fears and addressing questionable assumptions could reduce the burdens of sharing. The challenge, however, is that the ability of healthcare providers to honor patient preferences relies on an awareness of those preferences. At the same time, patients need to be assured that making their sharing preferences transparent will help honor their needs to maintain communication boundaries.

### **Need for a sociotechnical approach**

Our findings indicate the need for systems that incorporate communication technologies and changes to culture and policy. Patients are not accustomed to communicating with providers about what is important to them. To create opportunities for patients and providers to develop a shared understanding of patients' care priorities, we need to account for the social and cultural factors that influence patient-provider communication. Additionally, a sociotechnical approach would take into consideration the constraints of providers' time, training, and resources within the clinic.

We found that many patients disclosed different information to providers than to friends, family, and religious leaders. These patients had champions in their lives with whom they disclosed what was important in their lives. P17's preference to open up to his pastor and son regarding his depression is just one example. These findings imply the design of systems should account for the participation of these champions.

Interpersonal relationships between patients and their providers heavily influenced patient disclosures. Strategies or tools can empower providers to better elicit information that might not normally emerge in clinical conversations. For example, previous research offers guidelines for training physicians to prepare responses to sensitive subjects (e.g., religious

beliefs) that can enable them to more effectively enact patient-centered strategies [29]. This approach can also be applied to other topics that might be sensitive or typically considered outside of health domains. Communication strategies may also be helpful for patients, who are shifting into increasingly proactive roles in the clinic. They should also have access to tools to empower them to make their communication preferences and needs known to providers. This transparency may help break down the barriers that cause patients like P17 to carefully navigate care by withholding their health concerns.

### Future work

The implications of this study, including the strategies, motivations, and nature of how patients disclose what is important, inform future work to address sociotechnical problems in chronic illness care. This study focuses on an analysis of the patient perspective. However, our results are limited to patients who have health insurance and receive care through an integrated healthcare delivery system in the U.S. Individuals with different healthcare coverage or those located in other countries would likely have different experiences. We encountered patients whose financial resources influenced decisions about care (e.g., avoiding co-pay), but results may be different for those who are uninsured, unemployed, in unstable housing situations, or do not have experience utilizing healthcare. Future work is needed to focus on different demographics and to understand disclosure behaviors across a diverse sample of patients.

To design tools for patient-provider communication, we also have to understand providers' needs and preferences and the factors that influence their communication patterns, including resources and constraints such as providers' time and training. Research on providers' perceptions of communication boundaries will be useful for identifying points of conflict and alignment between providers and patients. Additionally, patients with multiple chronic conditions often see numerous specialists. Future work should examine how providers collaborate and share information about what is most important to patients. Observations of these interactions in the context of the clinic could help to reinforce or challenge findings about the factors that influence both patients and providers. We will need more holistic approaches to understand and account for the complexity of factors that influence valuable communication between patients and providers.

## CONCLUSION

Setting the right care priorities can impact health outcomes for patients with multiple chronic conditions. This work brings light to the complexity and importance of how patients disclose what is important in communication with healthcare providers. Our findings provide a critical foundation to inform the design of sociotechnical solutions that improve communication about care by bringing patients and providers in alignment.

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