
Getting Traction When Overwhelmed: Implications for Supporting Patient- Provider Communication

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Abstract

Patients who fail to reach shared understanding with their providers about their health care priorities can have poorer health outcomes and quality of life. Because patients' priorities often reflect their values—things important and meaningful in their lives—it is important to incorporate values into patient-provider conversations. However, patients often withhold values from providers when they do not perceive them to be pertinent. In a field study with 24 patients with multiple chronic conditions, we sought to understand how participants perceived relationships among their values and their health concerns. We found that participants felt overwhelmed by multiple concerns, but were able to surmount these feelings when they pursued values that were linked to self-care. We discuss implications for incorporating values into patient-provider communication.

Author Keywords

Multiple chronic conditions; values; patient-provider communication.

ACM Classification Keywords

Miscellaneous; J.3 Life and Medical Sciences: Health.

Characteristics	n=24
Age	
Mean (SD)	68 (15)
Range	25- 87
Gender	
Female	12
Male	12
Employment	
Full-time	5
Part-time	2
Retired	14
Unemployed	2
Disabled	1
Education	
Some high school	2
High school grad/GED	6
Some college/2 year degree	11
4-year college degree	1
More than 4-year deg	4
Race	
White/Caucasian	19
Black/African American.	2
American Indian/ Alaska Native	1
Pacific Islander/ Hawaii Native	1
Asian	1

Table 1. Participant demographics

Introduction

Improving patient-provider communication is an active research area in CSCW (e.g., [3]). For patients with multiple chronic conditions (MCC), a critical aspect of patient-provider communication is establishing shared priorities for health care [1]. Agreement on priorities can improve patient satisfaction and health outcomes [1]. However, prioritizing among health concerns is challenging for patients with MCC because health care options (e.g., self-care) for one chronic condition can conflict with those for other conditions. For example, diabetes self-care involves exercise but an individual with diabetes and osteoarthritis may choose not to exercise because it is painful. In these cases, patients' values—things that are most meaningful or important in their lives [2]—influence how they decide on health priorities. One objective for improving patient-provider communication is incorporating patients' values in priority setting [6]. But, our recent work revealed that patients withheld values from providers when they did not perceive values as pertinent to their health care [4]. In order to inform the design of systems to support patient-provider communication that incorporates patients' values, we investigated how patients perceive relationships among their health concerns and their values.

Method

We conducted a field study with 24 patients in their homes, including photo elicitation, semi-structured interviews, and a home tour. Half of the participants included an informal caregiver in the study, but here we focus on patients' accounts. Participants had diabetes and at least two of the following: depression, osteoarthritis, and coronary artery disease. Table 1 shows participant demographics. Before each visit we

sent the participant a Polaroid-style camera and asked them to photograph things important to their health or well-being. We began each interview by asking the participant to tell us what was important in each photo, grounding each interview in the context of their daily lives. Interview topics included values (e.g., "What is important or meaningful to you?"), daily activities (e.g., "What do you do in a typical day?"), self-care (e.g., "What do you do to manage your health?"), tradeoffs (e.g., "Tell us about a time when your health required you to give up something important to you."), and communication with providers. After the interview participants lead a tour of their home and pointed out things important to their health and well-being. Interviews were audio recorded and transcribed verbatim. We conducted inductive thematic analysis that was grounded in the data.

Findings: Overwhelmed by Concerns

In interview responses about values and tradeoffs, participants expressed feeling overwhelmed. Many felt overwhelmed in the past even if they didn't at the time of the interview. Overwhelmed participants had three characteristics in common. First, they perceived that multiple health concerns affected their well-being negatively. Second, at least one health concern was related to mental health. Last, they had additional concerns such as limited financial means or conflicts with family.

Two examples illustrate these characteristics. In the first, a heart attack changed P6's life "*overnight*." She had difficulty following new medication regimens and struggled to learn "*how to deal with the depression and the anxiety*." She photographed a painting she made (Fig. 1) to demonstrate her efforts to replace values

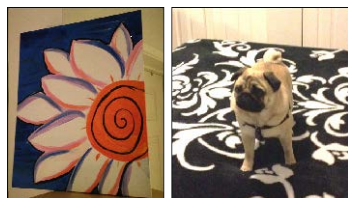


Figure 1. P6 valued finding new creative outlets in painting (left) and walking her dog (right).



Figure 2. P3 valued camping and hiking with her sons.

she had to give up, which included road trips and shopping with friends: *"...so much of what I normally do has changed...I'm looking for things to keep me interested in life...it gets daunting to think of, 'Well, there's nothing out there for me...' I had to find other outlets."* In the second example, P3 said, *"there's been a lot of times that I just tell [my partner] I'm overwhelmed...I don't know what to do."* P3 was having trouble injecting insulin and measuring her blood sugar regularly, and she avoided taking another medication intranasally. She valued performing well at work, but she missed work often because of colds, which were likely a result of skipping medications, as well as feeling fatigued and overwhelmed. P3 also couldn't afford to fill some prescriptions, had been sexually harassed at work, and feared she and her partner would lose his sons because their mother had filed for custody.

Traction and Momentum

Participants like P3 and P6 felt overwhelmed by health and non-health concerns, but they were able to get traction toward mastering those concerns when they pursued values that dovetailed with self-care activities. For example, P3 valued camping and hiking with her sons (Fig. 2). The exercise she got through these activities is part of self-care for diabetes and depression. Similarly, P6 valued her pug (Fig. 1) and said, *"taking [the dog] out...for a walk plays into my getting enough exercise."* After getting traction, some participants built momentum by taking on additional health concerns. P6 said, *"it was the depression, the anxiety I needed to deal with because without dealing with that, I was going to take myself out."* After mastering those concerns she began managing additional conditions: *"with each thing that I conquer, I pick up something new."*

Communication with Healthcare Providers

The way participants communicated with their providers influenced their ability to get traction and build momentum. P6 felt she had to monitor treatments on her own: *"They just throw medications at you...Well, without understanding how they interact with all the other medications you take...you can get yourself in a lot of trouble, and I have."* As a consequence of disagreements with providers on health care priorities, P6 said, *"I've damaged my relationship with my doctors...We don't communicate well anymore."* Now, P6 will *"let things go until they're really bad"* before contacting her doctor, putting her at risk for becoming overwhelmed again. In contrast, P3 liked her providers. She described her doctor's approach as *"gently pushing me hard."* P3's frequent emails and calls with her doctor enabled her to get timely guidance when health concerns emerged.

Future Research and Design

We investigated how participants perceived relationships among their values and health concerns. For some, health and non-health concerns caused them to feel overwhelmed. Participants who were overwhelmed gained traction when they linked something they valued with self-care, and they built momentum by taking on concerns one by one. Positive relationships with providers that involved frequent communication may have facilitated this process.

Future research and design can support patient-provider communication by helping patients with MCC link key values with self-care. Patients need to be able to communicate their values to their healthcare providers. This may require priming and support prior to discussions with providers. Our recent work showed

that patients withhold values from providers when they do not perceive them as pertinent to their health care [4]. Patients can be encouraged that linking values with self-care could lead to feeling less overwhelmed, and that sharing their values with providers could facilitate this process. In addition, patients may need prompting to reflect on their values, since they may not be accustomed to doing so. Existing systems designed to facilitate reflection on one's experience with chronic illness could be extended to promote reflection on values (e.g., [5]).

Future work could identify contexts and modes of patient-provider communication that would be appropriate for linking values and self-care. Providers need to be able to recognize when patients are feeling overwhelmed and could probe for patients' values. Times when patients feel overwhelmed may not coincide with scheduled office visits, so technologies such as secure messaging and virtual visits can facilitate these conversations before and between office visits. Future work can explore how linking values with self-care could generalize to other patient populations.

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