ORIGINAL RESEARCH

Understanding What Is Most Important to Individuals with Multiple Chronic Conditions: A Qualitative Study of Patients' Perspectives

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BACKGROUND: To improve care for individuals living with multiple chronic conditions, patients and providers must align care planning with what is most important to patients in their daily lives. We have a limited understanding of how to effectively encourage communication about patients' personal values during clinical care.

OBJECTIVE: To identify what patients with multiple chronic conditions describe as most important to their well-being and health.

DESIGN: We interviewed individuals with multiple chronic conditions in their homes and analyzed results qualitatively, guided by grounded theory.

PARTICIPANTS: A total of 31 patients (mean age 68.7 years) participated in the study, 19 of which included the participation of family members. Participants were from Kaiser Permanente Washington, an integrated health care system in Washington state.

APPROACH: Qualitative analysis of home visits, which consisted of semi-structured interviews aided by photo elicitation.

KEY RESULTS: Analysis revealed six domains of what patients described as most important for their well-being and health: principles, relationships, emotions, activities, abilities, and possessions. Personal values were interrelated and rarely expressed as individual values in isolation.

CONCLUSIONS: The domains describe the range and types of personal values multimorbid older adults deem important to well-being and health. Understanding patients' personal values across these domains may be useful for providers when developing, sharing, and following up on care plans.

KEY WORDS: chronic disease; comorbidity; qualitative research; communication; values.
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INTRODUCTION

Multimorbidity is a growing public health concern, affecting approximately two-thirds of people over the age of 65.[1,2] Individuals with multiple chronic conditions (MCC) experience poorer quality of life, physical disabilities, adverse drug events, and high mortality compared to those with a single condition.[3] Treatments for multiple diseases can conflict, affecting patients' quality of care, their decisions about self-care, and their care priorities.[4–6] Further, patients and their health care providers often disagree on care priorities, which erodes trust and leads to worse health outcomes.[7–9]

Efforts to improve care for patients with MCC note the importance of orienting and assessing care on "patient-important outcomes,"[10] in addition to disease-specific outcomes.[11–13] Clinical guidelines for multimorbidity emphasize the incorporation of patients' preferences in medical decision-making, such as opinions about treatment options and potential outcomes based on priorities.[14] Although much research has focused on elicitation of patient preferences in the context of specific diagnostic or therapeutic decisions,[15–17] much less work has focused on eliciting, from the perspective of patients with MCC, what is most important to them in their daily lives.

In our data collection, we used the language "what is most important to well-being and health" to avoid ambiguous terminology. For purposes of brevity, we use the term *personal values* to refer to what is most important to the well-being and health of patients. We use "personal values" instead of "values," recognizing that the latter has different meanings within and outside health care.[18] While some prior work uses similar definitions,[18] more often, "values" are synonymous with "preferences" in medical literature.[19] Our conception of personal values aligns with the definition of values from value-sensitive design[20]: what a person considers important in life. We adapted this language and asked participants to describe what was most important to their well-being and health, allowing participants to define well-being and health on their own. This approach encouraged a discussion of values likely to be relevant to patient–provider communication about priorities for care, while enabling participants to articulate personal values in their own words.

Understanding personal values is especially important for the care of individuals with MCC, because they mostly manage their health at home and live with the everyday demands of chronic illness care.[14,21] However, prior work found that patients filter what they disclose to providers because they perceive personal values as not pertinent to health care.[22] A comprehensive understanding of personal values is needed in

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order to design ways of supporting better patient–provider communication about personal values and guiding priorities for care planning. In this study we met this need by identifying six domains of personal values from the perspectives of patients.

METHODS

In this qualitative study, we collected data during visits to patients' homes, with the optional inclusion of family members, to understand the perspectives of individuals with MCC.

Recruitment

We recruited participants from Kaiser Permanente Washington, an integrated healthcare system in Washington state. Participants met the Healthcare Effectiveness Data and Information Set (HEDIS) definition for type 1 or 2 diabetes and had at least two of the following common chronic conditions: depression, osteoarthritis, and coronary artery disease.[23] We selected these conditions because they require self-management to achieve optimal health outcomes, and some self-management demands for these conditions overlap while others may conflict. We excluded participants who had HIV, AIDS, dementia, or other major psychiatric diagnoses within the preceding 10 years, had two or more oncology visits in the preceding 6 months, or had enrolled in hospice or palliative care. We purposefully sampled participants to maximize variation in sex, race and ethnicity, and education.

For half of patients agreeing to participate, we sought the optional participation of family members, because they often take on the burden of managing MCC alongside patients.[24–26] Family members' perspectives provided additional context for understanding patients' accounts of personal values. We excluded individuals receiving help from professional in-home caregivers.

Procedures

We conducted home visits, each consisting of a semi-structured interview aided by photo elicitation. Each visit lasted approximately 2 h. The institutional review board at Kaiser Permanente Washington Health Research Institute approved all study procedures.

Photo elicitation is intentionally open-ended and allows participants time for self-reflection.[27] At least 1 week prior to each visit, we sent the participant an instant camera with a written prompt to take up to 10 photos of anything they considered most important to their well-being and health. We began the interview by asking participants to describe each photo and why they took it. This method allowed participants to speak freely, and grounded each interview in the context of the patient's unique personal values. The interview guide covered five issues (Table 1). The semi-structured format ensured uniformity across participants, while allowing for new issues to emerge.

Table 1 Questions

Issues	Example Questions
Personal values	"What is most important to your well-being and health?"
Daily activities	"What do you do on a typical day?"
Self-management	"What do you do to manage your health?"
Tradeoffs	"Tell us about a time when you found it difficult to balance the things important to you."
Communication with healthcare providers and family members	"Do you talk to your healthcare providers about what is important to you?"

Analysis

Interviews were audio-recorded and professionally transcribed verbatim. We analyzed the data using an inductive approach, guided by grounded theory, to identify themes of personal values.[28] Two authors (AB, CL) independently open-coded transcripts to develop an initial set of codes. We then iterated across axial and selective coding, writing memos to define and clarify codes, grouping codes into emergent themes, and clarifying themes. Wherever possible, we labeled and defined codes using the language of participants. We then compared codes for consistency and iteratively discussed, edited, and consolidated codes across 10 transcripts, until a codebook was established. The remaining 21 transcripts were independently coded by two researchers (AB, CL). All members of the multidisciplinary research team met regularly to discuss emergent themes to ensure consistency and rigor in the interpretation of the data. In total, we completed 31 visits to participants' homes until the data reached saturation and no new themes emerged.[28]

RESULTS

Participants

We completed home visits with 31 participants (P1–31; Table 2), 19 of whom (63%) we interviewed with one family member (CG 3, 7, 9, 11, 14, 15, 16, 18, 19, 20, 22, 23, 25–31, corresponding to P numbers), while the remainder ($n = 12$) we interviewed individually. Most family members were cohabiting spouses of patients, while one was an adult child living with a parent.

Six Domains of Personal Values

Six core domains of personal values emerged from our thematic analysis: *principles*, *relationships*, *emotions*, *abilities*, *activities*, and *possessions* (Table 3). We labeled and developed definitions for these domains by staying close to participants' language. We also found that participants rarely discussed a single value in isolation. Rather, they often articulated multiple values that were interrelated. In the

Table 2 Participant Characteristics (n = 31)

	Patient participants (n = 31)	Family member participants (n = 19)
Age	68.7	N/D
Gender		
Female	14	9
Male	17	10
Race/Ethnicity		
White/Caucasian	24	18
Black/African American	2	1
Asian American or Pacific Islander	1	0
Native Hawaiian or Pacific Islander	1	0
White and Native American/Alaska Native	2	0
Hispanic	1	0
Education		
Eighth grade or less	0	1
Some high school, not a graduate	3	0
High school graduate or GED	7	5
Some college or 2-year degree	14	10
4-year college degree	1	1
More than 4-year college degree	6	2

descriptions below, we first characterize each domain using excerpts from interviews. We then provide examples of how participants related personal values across domains.

PRINCIPLES consist of beliefs and standards to live by, such as ideals, virtues, and aspirations. Examples include "having a purpose" (P6), "morals" (P14), or "deep-seated beliefs" (P23): "*My dad and mother instilled in me that you tell the truth. Don't care if it hurts you. You tell the truth. […] Those were the values that I've taken through life.*" (P23, male, age 81) Other participants based principles in religion or spirituality. Central to P2's life was her faith: "*And I learned those principles and those practices through reading God's word. And it helps me in my life.*" (P2, female, age 86)

We include ideals and aspirations, such as maintaining independence, in this domain. P5 described: "*I don't wanna live long enough that I have to [live in a care home] or that I become a burden on my kids, so staying healthy is important. Being independent and being able to care for ourselves is really, really important.*" (P5, female, age 68)

Table 3 Six Domains of Personal Values

Domain	Definition
Principles	Standards or virtues to live by, including aspirations (e.g., spirituality, independence, truth)
Relationships	Connections with others (e.g., family, friends, community)
Emotions	Feelings or mood; states of being that are personal, embodied, or experiential (e.g., accomplishment, comfort, serenity)
Activities	Pursuits, things people do for work or leisure (e.g., reading, gardening, self-care)
Abilities	Physical or mental capacities or skills (e.g., mental sharpness, mobility, vision, problem-solving skills)
Possessions	Tangible things kept, owned, or cherished including spaces (e.g., computer, '55 Chevy, home, woodshop)

RELATIONSHIPS consist of social connections with family, friends, coworkers, neighbors, or community groups. P17 said of his family: "*Now we have four grandkids. They're the most important things to me, my family. That's it.*" (P17, male, age 62) Spouses were often the first personal value participants mentioned. P28's husband was the most important person in her life:

> "*What would I do without [CG28]? Every morning he's up and he puts my eye drops in my eyes for me, because they're very expensive and that way we don't waste any of them. […] you get to feeling sorry for yourself once in a while. And I think that's just a normal thing when you have a chronic disease. But he's always there for me. He just talks to me and lets me know how important I am.*" (P28, female, age 69)

P4's relationship with her granddaughter helped her up each morning:

> "*Well, let's see. This one's my grandbaby, and she's my inspiration to keep going, even though sometimes it hurts and I just want to stay in bed, all day […]. She comes, jumps in bed, 'Grandma! Get up!' So, I have to get up and get moving.*" (P4, female, age 67)

Beyond family and close friends, participants also engaged in meaningful relationships through community groups, senior centers, and faith-based organizations. CG44 cherished weekly meetings with a group of potters:

> "*Pottery. We have a neat group of people up there. You could ask them to do anything; they're that kind of people. And we talk about everything. It's good for social and it's good for your mental health.*" (CG31, female, age 77)

EMOTIONS refer to feelings, mood, or states of being that are personal, embodied, and experiential. Examples include joy, pride, and serenity. Within this domain, comfort and serenity were common personal values, reflecting the need to feel relief from pain or symptoms of anxiety, depression, or PTSD. For P8, who managed anxiety with medication, a perfect day involved avoiding negative thoughts, with help from a prayer emphasizing acceptance of things one cannot change (P8, male, age 87). After losing her parents at a young age, P21 reflected on finding her own happiness:

> "*You have to have belief that you're gonna have a good life, and you have to make your own self happy.*

You can't depend on other people to do it for you. Happiness has a great deal to do with your health. If you're not happy, you're not healthy. It's the other way too, If you're not healthy, you're not happy." *(P21, age 60)*

Pride and a sense of accomplishment motivated participants in daily work and activities. CG19 explained how her husband, P19, had given up sports and driving due to vision loss, shortness of breath, and numbness in his feet. Therefore, P19 felt pride in daily improvements he made to their home:

"*I think a perfect day, you rise with a certain number of goals, and at the end of the day you look back and say, 'I accomplished them.' And if there are ones that didn't get accomplished, you put them on the list for tomorrow.*" (P19, male, age 66)

ACTIVITIES are important pursuits, such as reading, gardening, learning, and medical self-care. They include a range of pursuits for work, leisure, volunteering, improving health, and other purposes. P2 described a weekly emergency food program she organized:

"*the most important program that I'm interested in…at our church, that I'm the director of […]. it's a program that we started over 12 years ago, feeding homeless [people].*" (P2, female, age 86)

Activities include meaningful personal projects, such as P22's genealogy research:

"*I can get consumed in something historical. So that's the reason that I did the book, and the more I dug, the more I kept finding people, and when I printed that book I had over 100 people who wanted the book, and so I printed 200 of them and I sent about 150 to people that I found in my family.*" (P22, male, age 87)

Participants described activities important in their everyday lives, such as P15 who made latch hook rugs to pass the time when she accompanied her husband (CG15) to health care appointments twice a week:

"*I did that on hook latch. I do this when I'm at hospital this year […]. My husband goes to the VA. I'll sit there for hours while he's in his mental health classes […]. I've got inflammatory arthritis on my hands. They've been really hurting […]. So, I can only do so much at a time but when I do, I enjoy it.*" (P15, female, age 60)

ABILITIES include physical or mental capacities or skills, such as mental sharpness, vision, mobility, and problem-solving skills. For many participants, the desire to maintain certain abilities became salient in the face of declining health. P9 was diagnosed with PTSD after experiencing an armed robbery, and often had difficulty leaving her bedroom. She described being healthy as "*being able to enjoy life, without worrying about your health. Or, without any limitations on what you could do.*" (P9, age 61)

Participants expressed concern for noticeable decline in mental sharpness and memory loss as part of aging or medication side effects. While sharing a photo of his mailbox, "*because that's my daily job to go and get the mail,*" P18 (age 80) and his wife (CG18) articulated the extent of P18's abilities due to fatigue. The mailbox symbolized the few daily tasks he could still do.

Maintaining mental sharpness was a personal value shared by many participants. For P25, a foot amputation and use of a dialysis machine limited her ability to leave her bedroom. She prioritized keeping her mind active:

"*I could sit here in this room from 6 in the morning until 7 at night when we hook up the dialysis. I would be insane in a month […]. But the word puzzles help a lot. They keep my brain going.*" (P25, female, age 73)

POSSESSIONS include tangible objects and important spaces. Examples are P1's forested driveway, P13's garden, and P23's vintage automobile: "*And then, my '55 Chevy that I've got. I just had it in a car show Saturday over in [City]….That thing will run down the freeway at 70 miles an hour, no problem.*" (P23, age 81)

Possessions also include objects for daily self-care, such as medications, exercise equipment, and tools to monitor blood glucose levels. P1 managed Crohn's disease since her teenage years and described supplies necessary for personal care:

"*I have an ostomy, so that's just an ostomy bag. And just personal stuff. Medical needs. Personal care. That has to have its part out there, keep me going straight and hopefully continuing to function well.*" (P1, female, age 64)

Participants displayed objects of unique personal meaning, such as family heirlooms, photographs, and collectibles. P19 described his favorite tree outside his home: "*Those are sunlight screening through the leaves of the Japanese maple, outside here. And you can see the shafts of light coming through it, and illuminated leaves have that kind of a glow around them.*"

Interrelatedness of Personal Values

Participants often discussed multiple interrelated personal values across domains rather than articulating single values in isolation. We provide descriptions of ways personal values can relate, each followed by an example illustrating how changes in health and life can affect, and be affected by, multiple related values.

First, interrelated values include those that are explicitly or implicitly stated. For P25, doing stacks of puzzle books was important because they kept her mind active. In this example, P25 explicitly expresses the personal value of doing puzzles (an activity) and implicitly expresses the personal value of keeping an active mind (an ability). P25 describes both as important to her. We deliberately include both implicitly and explicitly stated values in order to honor how participants describe what is important to them.

Participants often discussed values that align. For instance, P5 made clothing for her great grandchildren: "*My sewing is something that's important. We have three new great grandsons […]. So, these are clothes behind you that I made for them this past week.*" In this example, sewing (activities) and family (relationships) align. To account for aligning values, the personal value domains are not mutually exclusive. Some personal values may fit within multiple domains, depending on how they are perceived by the individual.

Interrelated personal values can also be in conflict. This is clear in instances when participants prioritized conflicting values. P17 generally protected his back to avoid physical pain and feelings of depression he had previously experienced with chronic pain (emotions). Despite this, he made an exception to help his sister (relationships) move boxes: "*I went out to her house and loaded them up. Which is unusual for me, because I'm not supposed to lift over 15 lbs. I usually don't do that kind of stuff. [Helping my sister] is important to me.*" (P17, male, age 62) Values in conflict demonstrate that personal values can vary in relative importance, and the relative importance of each value is not absolute.

A change in health or other contextual factors such as financial means, availability of social support, or work environment can impact multiple values. When P24 started taking insulin, he was pushed to retire early from long-haul trucking: "*You are not a [commercial driver's license] holder if you are insulin-dependent, period. You don't get one.*" (P24, male, age 56) Despite his retirement, P24 still identified as a truck driver, and his friendships with other drivers were closely intertwined with his life on the road: "*The worst part of how my life has changed since all this has happened, okay, I'm a 48-state long-haul truck driver. Where are your friends at? In the 48 states.*" P24's ability to maintain friendships was bound up in his work, which was impacted by the progression of diabetes and the external factors of commercial driving regulations. This example illustrates the importance of understanding how changes in health status can affect, and be affected by, multiple interrelated values of a patient.

DISCUSSION

Acknowledging patients' values is a key aspect of patient-centered health care practices[29–31] and central to patient–provider relationships.[32] Honoring values is especially important for the care of individuals with MCC, but this can be challenging for clinicians who must help patients set priorities for care while considering the evidence base for multiple diseases.[12]

Our findings reflect a broader conception of values compared to prior work, which largely defines values as preferences for individual diagnostic or therapeutic choices during medical decision-making.[18,19] Tools for these decisions, such as decision aids and values clarification methods, are typically closed-ended by design and often do not allow users to revise choices.[33,34] To inform conversations between patients with MCC and providers, we sought a broad understanding of patients' personal values within the home setting. The personal value domains and the findings that values shift and vary in relative importance expand upon the demonstrated need for tools that elicit patients' values comprehensively and iteratively over time.

Relevant work in geriatric and palliative care addresses some limitations to existing values elicitation tools, such as the values history[35] and values discussion guide for advanced care planning.[36] Further work is needed to evaluate how these tools can apply to contexts beyond terminal care. Recent efforts to develop taxonomies of values among older adults in cancer care include value domains with some similarity to our findings (e.g., enjoyment and comfort, connection).[37] However, these taxonomies focus on values related to functional and quality-of-life (QoL) concerns, and approach values as prospective and oriented around health goals. In our findings, some domains, such as emotions, may resemble desired outcomes or goals, and others, such as possessions, may seem like strategies. Despite this, we intentionally did not apply a pre-specified hierarchy in our analysis, and we did not draw from existing frameworks to discern discrete and precise categories for clinical applications. In order to keep the domains grounded in patients' expressions of their own values, this study used a grounded approach to achieve an understanding of personal values from the perspectives of people with MCC.

Understanding personal values may be particularly valuable for chronic and comprehensive care programs seeking to establish meaningful priorities for individualized patient-centered care.[38–40] These programs assess patients' needs, functional abilities, goals, resources, and barriers to care[41–43] using standardized instruments such as comprehensive geriatric assessments for hospitalized older adults.[44] In collaborative care models, teams of providers engage patients in assessment, self-management, goal-setting, and monitoring of progress toward targets.[45–48] However, these assessments and care planning processes do not routinely elicit and address patients' personal values to inform care planning.

The domains of some well-being measures—life satisfaction, emotional effects, meaning in life, social health, and

vitality[41–43,49–51]—as well as QoL measures—physical well-being, social relationships, activities, self-realization, and autonomy[52–54]—are similar to some of the domains we describe. This overlap likely reflects shared aspects between the values expressed by individuals with MCC and the favored outcomes of broader populations, measured by well-being and QoL scales. The intent and methods of our study, though, are distinct. We seek to support better patient–provider communication about care planning rather than to evaluate outcomes.

The domains provide a useful template for eliciting values not typically discussed in clinical contexts. Patients perceive many personal values as not pertinent to clinical conversations, or they worry about the consequences of sharing personal values with providers.[22] The photo elicitation method helped capture personal values participants would not usually disclose to providers. Our findings present an opportunity for future work to discover effective values elicitation methods and inform the design of interactive systems that help facilitate reflection, sharing, and discussions about personal values for care planning. Further, we revealed that values and their relative importance can change over time. When personal values shift, there may be opportunities for patients and providers to discuss and reassess care priorities.

Limitations

There are several limitations to our study. First, we may not have captured the entirety of patients' personal values. Patients with different socioeconomic circumstances than those reflected here might describe different values, and it is important to understand how patients with diverse demographics contend with the challenges of balancing personal values with financial constraints and other demands. In addition, this study reflects the unique perspectives of patients struggling with diabetes and a specific constellation of other chronic conditions, including depressive symptoms. Future work is needed to assess the transferability of these value domains across diverse groups of patients, including individuals who do not have diabetes or who are uninsured, unemployed, or in unstable housing situations.

Further study is needed to validate the domains and examine the interrelatedness of values in a systematic way.[55] Finally, understanding the perspectives of providers and their roles is critical to developing tools for eliciting and discussing personal values in clinical settings.

CONCLUSION

We identified six domains of personal values—what is most important for well-being and health—from the perspective of patients with MCC. These personal values were often interrelated, creating dependencies that may be significantly affected by changes in health status. This broader understanding of personal values highlights opportunities for improving priority setting and care planning among patients with multiple chronic conditions.

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Compliance with Ethical Standards:

Conflict of Interest: *The authors declare that they have no conflict of interest.*

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