

Eliciting Values of Patients with Multiple Chronic Conditions: Evaluation of a Patient-centered Framework

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Abstract

Patients with multiple chronic conditions often face competing demands for care, and they often do not agree with physicians on priorities for care. Patients' values shape their healthcare priorities, but existing methods for eliciting values do not necessarily meet patients' care planning needs. We developed a patient-centered values framework based on a field study with patients and caregivers. In this paper we report on a survey to evaluate how the framework generalizes beyond field study participants, and how well the framework supports values elicitation. We found that respondents frame values in a way that is consistent with the framework, and that domains of the framework can be used to elicit a breadth of potential values individuals with MCC express. These findings demonstrate how a patient-centered perspective on values can expand on the domains considered in values clarification methods and facilitate patient-provider communication in establishing shared care priorities.

Introduction

In the United States, two-thirds of adults over 65 have multiple chronic conditions (MCC), and this population continues to grow.^{1,2} Compared to individuals with single chronic conditions, individuals with MCC have poorer quality of life, more physical disabilities, more frequent adverse drug events, and higher mortality.³ Individuals with MCC face competing care demands, especially when self-care for one condition conflicts with self-care for another condition. For example, a patient may want to exercise to improve cardiovascular health and control their diabetes, but if they also have osteoarthritis, exercise could be very painful. Conflicting self-care demands are further compounded by the everyday complexities of living with chronic illness, including individual preferences, resources, and diverse lifestyles.⁴ Choosing the right care priorities for individuals with MCC is important since the ability to self-manage competing demands can affect the quality and length of life.⁵

To help individuals with MCC and their health care providers establish shared care priorities, first we must understand patients' values. Patients' personal values—what they “consider important in life”⁶—underlie the decisions they make about their health and health care. Health services research has emphasized the importance of understanding and honoring patients' values, particularly for establishing shared care priorities with MCC patients.⁷ Although the importance of orienting care around patient-important outcomes is well documented,⁸ few clinical guidelines include ways to incorporate patients' personal values in care planning.^{9,10}

Many research studies have designed and evaluated methods for providers to elicit and clarify patients' values, particularly for shared decision making.^{11–14} While diverse, most values clarification methods (VCMs) focus on specified treatment preferences that are pre-defined without the ability for patients to introduce their own concerns or explore the underlying values that shape their care preferences.¹¹ Since patients with MCC mostly manage health outside of clinical contexts, it is important for patients and providers to communicate about what patients value in their daily lives when establishing shared care priorities. Our prior work underscores this need by revealing that some individuals with MCC filter what they share with healthcare providers because they do not perceive personal values from daily life as pertinent to their healthcare.¹⁵ There is a need to better understand personal values from the perspective of patients to inform the design of tools that can improve patient-provider communication about care planning.

Based on prior field work^{15–17} with 31 individuals with MCC and 17 family caregivers, we formulated a patient-centered values framework that characterizes the types of personal values that patients described as most important to their well-being and health. We conducted home visits that included photo elicitation¹⁸ as part of a semi-structured interview. Prior to the visit we mailed the patient a camera that produced instant photographs and asked them to take pictures to show what was important to their well-being and health in daily life. When we visited the

patient's home, we began the semi-structured interview by asking them to explain what was important in each photograph. Next we discussed topics including daily activities, self-management, tradeoffs (e.g., times when the patient found it difficult to balance what was important to them), how their values related to their health, and how they communicated with their healthcare providers. Interviews were recorded and transcribed verbatim. Analysis of the transcripts was guided by grounded theory methods,¹⁹ and included open coding, focused coding, and writing memos. Two authors (AB, CL) open coded transcripts independently, wrote code memos to define and clarify codes, and met regularly to coordinate, refine, and consolidate codes. Wherever possible, we labeled and defined codes using the language of participants. As codes stabilized, we conducted focused coding on the remaining transcripts, and recoded the initial transcripts to ensure consistency. As we coded, we wrote memos to group codes into themes. These themes are the domains that comprise the patient-centered values framework. Throughout the analysis process, all authors participated in regular meetings to discuss and clarify codes and themes. A paper reporting this field study and the resulting patient-centered values framework is currently under review.

The framework expresses the breadth of patients' personal values across six domains: principles, relationships, emotions, activities, abilities, and possessions. Principles are beliefs and standards to live by, such as honesty or independence. Relationships are connections with others, such as family or friends. Emotions are feelings, affect, or mood, such as joy or serenity. Activities are pursuits such as working, reading, gardening, or volunteering. Abilities are physical or mental capacities or skills, such as mental sharpness or mobility. Possessions are tangible objects or spaces, such as photographs, a car, or a woodshop.

The values framework expands the breadth of domains considered in values clarification methods and could be used to inform patient-provider discussions about shared care priorities. Yet, it is important to evaluate how well this framework translates beyond individuals in our prior field work to other individuals with MCC. The aim of the study we report here was to evaluate the values framework through a survey with a larger sample of individuals with MCC and inform the design of tools that facilitate communication between patients with MCC and their healthcare providers about personal values in the context of care planning. We investigated two research questions:

RQ1. How similar to the framework do respondents frame values? (i.e., Do they generate similar kinds of values that participants in the prior field study described? Do they assign values to similar categories?)

RQ2. Is there a difference in how respondents rate the importance of values from different domains in the framework?

Related Work

We adopt the definition of values from Friedman et al.:⁶ “what a person or group of people consider important in life.” Although values are central to the patient-provider relationship,²⁰ there remain critical gaps in how to elicit patients' values and incorporate them into care planning discussions.¹¹ We investigate how evaluation of our patient-centered values framework could build on and overcome limitations of existing values clarification methods by considering values from the perspective of patients.

There has been significant research into values clarification methods (VCMs), which are techniques to help patients clarify what matters to them in the context of specific health-related decisions, such as decision aids that utilize pros and cons or ratings. Examples of VCMs include decision aids to help patients choose the best treatment for type 2 diabetes²¹ and decision aids to help patients select lifestyle changes for improving cardiac health.²² Witteman et al.¹¹ reviewed 98 VCMs, developed a taxonomy of VCM design features, and discussed limitations of VCMs. Most methods reviewed were designed for patients to complete as an independent activity (59%) rather than with a provider, used closed-ended and pre-set options (61%), and few encouraged patients to explore values as part of an iterative discovery process (9%). These key limitations could increase the chance that providers miss opportunities to identify what is important to patients broadly, and fail to incorporate those values into care planning that is so important for MCC. Furthermore, care planning for individuals with MCC involves juggling multiple concerns and decisions, but existing VCMs generate values about single health conditions. Out of 98 VCMs reviewed, 23 related to chronic illness, but none explicitly addressed MCC. Of the 23 VCMs related to chronic illness, nine focused on cardiovascular health, eight focused on other chronic conditions, and six focused on advance care planning. This suggests a lack of VCMs for care planning for individuals with MCC who face conflicting self-care demands.

The first limitation identified by Witteman et al.¹¹ that is relevant to our goal of informing the design of VCMs for individuals with MCCs is that most VCMs are completed by patients independently. In our work, we conceive of the patient-centered values framework as a conversational tool to stimulate patient-provider discussions about values.

The second limitation of VCMs relevant to our study is that most VCMs are closed-ended and do not enable individuals to generate and incorporate their own attributes or elements for consideration. For example, the VCM designed by Breslin et al.²¹ helped individuals decide which medication to use to treat type 2 diabetes based on attributes such as how each medication affected blood sugar and weight, but these attributes were predefined, not patient-generated. Of the VCMs Witteman et al.¹¹ reviewed, 60 out of 98 did not allow the individual to add elements or attributes to a decision. In this study, we sought to explore the nature of open-ended “free response” elicitation of values compared to closed-ended elicitation of predefined “domain-driven” values. There may be benefits and drawbacks to each approach. Understanding how responses to these types of elicitation methods could vary will inform the design of VCMs to support individuals with MCC.

The third key limitation of VCMs identified by Witteman et al.¹¹ is that VCMs often offer little support for iterative exploration of values. Out of 98 reviewed, 21 VCMs explicitly did not allow users to explore and revise their values, but rather required they identify and express values in a single attempt. Another 65 technically allowed revision (e.g., to page back and change response) but did not explicitly encourage it. It is important for patients to be able to revise their values as their understanding of a decision develops.^{23–26} In this study, our survey structure enables us to develop a better understanding of how elicitation of multiple values in series might affect the kinds of values participants shared. In addition, we can make some judgments about how different kinds of elicitation methods in series (e.g., initial free-response followed by domain-driven followed by a second round of “informed free-response”) might elicit values of different types, specificity, or importance to the patient.

Given these limitations of existing VCMs, we sought to evaluate how our values framework might be used to inform the design of methods for eliciting patient values that are applicable beyond singular health-related decisions to meet the needs of individuals with MCC. Specifically, we explored the utility of “free-response” versus “domain-driven” elicitation of values, and we explored the relative importance individuals place on domains within the framework.

Methods

To evaluate our values framework, we conducted a phone survey to ask patients with MCC to generate and categorize values into domains (RQ1) and then rate the importance of those domains (RQ2). After completing the survey, participants received \$30 by mail. Survey procedures were approved by the Institutional Review Board at Kaiser Permanente Washington Health Research Institute (KPWHRI).

Recruitment

Participants were recruited from Kaiser Permanente Washington (KPW), an integrated healthcare system in Washington State. Participants were required to have type 1 or type 2 diabetes and at least two of the following common conditions: depression, osteoarthritis, or coronary artery disease. Eligibility was determined based on diagnosis codes stored in the electronic health record. We chose these illnesses because all require a high degree of self-management, and self-management tasks for these conditions may either overlap or compete with one another. For example, recommendations to improve outcomes for diabetes and coronary artery disease encourage physical activity, but arthritis might limit significant physical activity. In other combinations, such as diabetes and depression, treating both together is optimal.²⁷

Participants had to have a primary care provider in a KPW clinic, had to be enrolled in a KPW plan at the time of recruitment, and had to have had at least two visits with a primary care physician in the preceding 12 months. Participants were excluded if they had been diagnosed with HIV, AIDS, dementia, or other major psychiatric diagnoses for the preceding 10 years, and were excluded if in the preceding six months they had two or more in-person visits to medical oncology or radiation oncology or if they were enrolled in hospice or palliative care. We purposively sampled for educational status, aiming for a distribution similar to the U.S. population, which is approximately 50% with educational level high school or less, and oversampled minority racial and ethnic populations. Eligible patients who met the sample criteria received a letter explaining the purpose of the survey and the survey procedures, then received a phone call from a member of the KPWHRI Survey program to administer the survey by phone. In total, 54 respondents completed the survey. Of those, 17 had participated in our prior field study and 37 had not.

Procedures and Analysis

The phone survey had three parts: (1) generating and categorizing values; (2) rating the importance of values; and (3) demographics.

Generating and categorizing values: We approached the generation of values in three ways: free-response, domain-driven, and informed free-response (Table 1). The survey first asked respondents to name two things that are important to their well-being and health through free response (values 1-2). Respondents generated these values freely without knowledge of the domains in the values framework (i.e., “free-response”). Second, the survey asked respondents to generate values for each of the six domains from our patient-centered values framework after being read a short definition for each (values 3-8). During this “domain-driven” approach, respondents were given the choice to not provide an example if they felt the domain was not important to them. Third, respondents were given the option to provide up to five additional values of their choosing (values 9-13). These optional additions reflect values elicited through free-response after respondents were exposed to domains of the values framework (i.e., “informed free-response”).

Table 1. Elicitation methods to generate patient values

Free-response <i>“Name two things that you feel are important to your well-being and health.”</i>	Values 1-2
Domain-driven <i>“I will read a list of categories that some people report as important to their well-being and health. I will ask you for an example of something within that category that is important to your well-being and health.”</i>	Values 3-8
Informed free-response <i>“Can you think of anything else important to your well-being and health?”</i>	Values 9-13

For categorizing values, the survey asked respondents to assign the free response values (values 1-2, and 9-13) to the six domains (i.e., principles, relationships, emotions, activities, abilities, and possessions). For each value (e.g., “value x”), participants responded to: *“Earlier you told me that ‘value x’ is important to you. Of the categories we just discussed, where does ‘value x’ belong: activities, possessions, relationships, emotions, principles, or abilities?”* Respondents were given the option to assign a value to multiple domains if they wished. If the respondent did not believe the value fit in any of the domains, the respondent was given the option to name a new domain where the value fit, and to provide a description.

To answer RQ1, we first examined the coverage of values generated through free-response, domain-driven, and informed free-response elicitation methods by counting the number of values resulting from each of the three methods. We then examined how respondents categorized those values by assigning them to domains of our values framework. We inspected values that respondents chose not to assign to one of the six domains and any new domains they suggested. Finally, we compared how respondents categorized values with how the research team categorized those same values. Team-based categorization was reached through consensus and was done in a blinded manner in which team members were unaware of how respondents categorized values. Three members of the research team (“coders”) assigned by consensus each respondent-generated value to one of the six domains from the values framework. Coders assigned values to domains based on domain definitions formulated from our prior field study based on home interviews.¹⁵⁻¹⁷ Values that did not fit any domain, that lacked sufficient context to assign to a domain, or for which consensus could not be reached were distributed to two additional team members to assign to domains independently. The three coders used the independent assignments to reach consensus on categorization of the remaining values. We assessed agreement between respondent-categorized and team-categorized values with Cohen’s Kappa (K). Throughout the coding process, the three coders and two additional team members maintained a record of responses for which reaching a consensus categorization required discussion. This record included notes clarifying the definitions of domains from the values framework and notes about potential extensions to the framework.

Rating the importance of values: The survey asked respondents to rate how important each of the values they generated (i.e., values 1-13) are to their well-being and health on a 5-point Likert scale (anchors were 1 = “important”, 3 = “very important”, and 5 = “the most important”). To answer RQ2, we compared respondents’ importance ratings among value domains with a Friedman test (χ^2) and conducted post hoc pairwise comparisons using Mann-Whitney U tests with a Bonferroni correction. We chose Friedman and Mann-Whitney U as non-parametric tests because the data are Likert ratings and not normally distributed. We applied the Bonferroni correction to reduce the chance of type I error with multiple pairwise comparisons.

Demographics: The survey asked respondents to provide their age, sex, race, ethnicity, and education level, which we summarized with descriptive statistics in Microsoft Excel.

Results

Table 2 shows demographics of the survey respondents.

Table 2. Respondent demographics (n=54)

Age mean (SD)	65.4 (10.7)
Age range	45-87
Sex n (%) Female	31 (57.4%)
Race n (%)	
American Indian/Alaska Native	1 (2%)
Asian	4 (7%)
Black/African American	6 (11%)
Native Hawaiian/Pacific Islander	1 (2%)
White	31 (57%)
More than one race	8 (15%)
Other	3 (6%)
Hispanic/Latino n (%)	5 (9%)
Education n (%)	
Some high school, but not a graduate	4 (7%)
High school graduate or GED	10 (19%)
Some college or 2 year degree	24 (44%)
4-year college degree	5 (9%)
More than 4-year college degree	11 (20%)

Generating and categorizing values

Free-response: The 54 respondents generated a total of 107 values through free-response (i.e., values 1-2). Only one respondent did not generate both values. Free-response values were diverse—some were medically oriented (e.g., “good medical care”, “my heart”, “keeping my cholesterol down”, “good communication with doctors”) whereas others reflected everyday priorities that were personal in nature, such as “family”, “happiness”, and “proper frame of mind”. Respondents categorized 103/107 (96%) of these values into one or more of the six domains of the values framework. In fact, respondents applied 69 of the 103 values (67%) to 2 or more of the 6 domains. The distribution of assignment of the 103 values to domains was: relationships (56%), abilities (55%), activities (54%), emotions (47%), principles (33%), and possessions (22%). Because respondents could assign each value to more than one domain, the total of this distribution is greater than 100%. Respondents suggested new domains for 3 of the 4 uncategorized values, including the domain “self-discipline” to assign the value “get out of pain with my back”, the domain “health provider and patient relationships” to assign the value “concern”, and the domain “diet and exercise” to assign the value “keeping my blood sugar low”. A new category was not suggested by the respondent for the remaining uncategorized value “being independent”.

The research team categorized 88/107 (86%) values generated from respondents through free-response. The 19 uncategorized values lacked sufficient detail for the team to assign to any of the six domains, such as “my weight”, “cost”, “having my health care records be accurate and up to date”, “prompt appointments with my primary doctor”, “getting my medication when I need them”, and “health issues are seen in the context of my life”. Agreement between respondent-categorization and team-categorization of the 88 values was moderate, $K = 0.47$. Because we allowed respondents to assign values to more than one domain (i.e., multiple categorization), this estimate may be higher than if we required each value to be assigned to only one domain; the research team’s categorization could match with any of the domains to which respondents assigned a given value.

Domain-driven: Respondents generated a total of 318 values that were specific examples across the six domains (i.e., values 3-8). Nearly all respondents generated a value for all six domains. Six respondents (11%) were able to generate examples for only five domains. One respondent could not generate an activity and two respondents reported that possessions were not important to their well-being and health. One respondent reported “I don’t know” when asked to provide an example for the “relationships” domain. Two respondents reported “I don’t know” when asked to provide an example for the “emotions” domain.

By the nature of the task, the domain-driven values were categorized by respondents. The research team categorized 310/318 (98%) of these values. The 8 uncategorized values lacked sufficient detail for the team to assign to any of the six domains. Examples included respondent-generated principles “listening” and “caring” and respondent-generated abilities “communication” and “my health.” Agreement between respondent-categorization and team-categorization of the 310 values into the six domains was high, $K = 0.85$. The proportion of respondent-categorized and team-categorized values that agreed included: 96% relationships (n=53), 94% possessions (n=51), 92% activities (n=53), 88% principles (n=52), 86% emotions (n=51), and 68% abilities (n=50).

Informed free-response: After eliciting values through free-response and domain-driven methods, we asked respondents if there was anything else important to their wellbeing and health. Respondents could generate up to 5 additions (i.e., values 9-13) and resulted in a total of 78 values. Thirty-three respondents (61%) added one more value, 19 (35%) added 2 more values, 13 (24%) added 3 more values, 10 (19%) added 4 more values, and 3 (6%) added 5 more values. Examples tended to reflect everyday priorities that were personal in nature (e.g., “family”, “hobbies”, “feel safe”, “being able to go out and do things”) and few medically oriented values (“following closely the directives of my doctor”). Respondents readily categorized all but 2 of these 78 additional values (97%) into one or more of the six domains. The distribution of assignment of the 76 values to domain was: emotions (66%), activities (66%), relationships (63%), abilities (61%), principles (42%), and possessions (34%). This distribution is similar to initial free-response, but the percentage assignment increased for each category. The 2 uncategorized values were “watching my security” and “ability to take off time for myself to not worry about health”. Respondents applied 60 of the 78 values (77%) to multiple domains.

The research team categorized 74/78 (95%) values that respondents optionally added. The 4 uncategorized values lacked sufficient detail for the team to assign to any of the six domains, which included “my health”, “being healthy”, “having challenges”, and also included “watching my security” which was uncategorized by respondents. Agreement between respondent-categorization and team-categorization of the 73 values into the six domains was high, $K = 0.78$. Similar to free-response values, we suspect agreement was high due to multiple categorization.

Relative importance of value domains

Table 3 shows importance rating for values generated through free-response, domain-driven, and informed free-response methods. For domain-driven values, relationships were rated as most important on average whereas possessions were rated as least important on average. There was a significant difference in importance ratings among the 6 domains ($\chi^2 = 44.84$, $p < 0.001$). This analysis excludes ratings for the six respondents who did not generate examples for all six domain-driven values. Post hoc comparisons resulted in 4 significant differences in importance ratings between: relationships and possessions ($U = 639$, $p < 0.001$), relationships and activities ($U = 599$, $p < 0.001$), principles and activities ($U = 671$, $p = 0.002$), and principles and possessions ($U = 707$, $p = 0.004$). These findings follow from the most important (i.e., relationships and principles) and least important (i.e., activities and possessions) according to ratings.

Table 3. Importance ratings for values assigned across methods

Elicitation method	Mean (SD)	Range
1. Free-response (n=107)	4.5 (0.8)	1-5
2. Domain driven (n=318)		
Relationships (n=53)	4.7 (0.7)	1-5
Principles (n=54)	4.6 (0.7)	1-5
Emotions (n=51)	4.4 (0.9)	1-5
Abilities (n=54)	4.2 (1.0)	1-5

Activities (n=53)	3.9 (1.0)	1-5
Possessions (n=53)	3.8 (1.2)	1-5
3. Informed free-response (n=78)	4.5 (0.8)	1-5

Discussion

Principal findings from this survey are that respondents frame personal values in a way that is consistent with our patient-centered values framework—they assigned nearly all values to at least one domain of the framework, and agreement of that assignment with the research team was high (RQ1). Respondents rated the importance of domains of values significantly different—namely, they rated relationships and principles significantly more important than activities and possessions (RQ2). In addition, we gathered insights that open-ended methods may encourage elicitation of both medically oriented and personal values connected with everyday lives outside the clinic, especially when offered the opportunity to express free-response values after learning the domains of the values framework.

Precision and Clarity of Values Domains

The level of agreement between respondents' and team members' categorization of personal values tells us about the precision with which value domains were defined, and the clarity with which respondents perceived the domains. There was moderate to high agreement for each elicitation method, with the highest agreement for domain-driven elicitation. Participants could generate personal values in response to the domains, and the research team consistently placed those values into the same domains from which they were elicited. This finding provides evidence that the definitions of the domains are conceptually precise, and that the wording we used to describe the domains to patients is clear. Table 4 includes each value domain, its definition, and representative examples. We updated the definitions of principles, emotions, and possessions to clarify their meaning. These updates reflect discussions we had during consensus categorization of survey respondents' values. For principles, many respondents shared standards and virtues, which were reflected in the original definition, but respondents also shared aspirations that guided their behavior much like standards or virtues. For emotions, respondents often expressed values that were embodied and experiential, such as comfort, or relief from pain. Finally, respondents highlighted the nature of their relationship to possessions, such as objects being owned or cherished. These updated definitions improve the clarity and accuracy of the patient-centered values framework and boost its utility for use in values elicitation and care planning.

Table 4. Patient-centered Values Framework: Six domains of patient values

Domain	Definition	Examples
Principles	Standards or virtues to live by, including aspirations	Spirituality, independence, truth
Relationships	Connections with others	Family, friends, community
Emotions	Feelings or mood; states of being that are personal, embodied, and experiential	Accomplishment, comfort, serenity
Activities	Pursuits, things people do for work or leisure	Reading, gardening, self-care
Abilities	Physical or mental capacities or skills	Mental sharpness, mobility, vision
Possessions	Tangible things kept, owned, or cherished, including spaces	Computer, '55 Chevy, home, woodshop

Generalizability of Framework

Because respondents could categorize nearly all values from free-response and informed free-response, this provides evidence that the values framework can account for a breadth of potential values patients with MCC express. More work is needed to further substantiate the generalizability of the framework, since it is possible that individuals with characteristics different than our sample might have values that do not fit the framework. Our sample is limited to

individuals in Washington State who have insurance, receive care within an integrated health system, and have a specific spectrum of chronic conditions. Also, 17 of the 54 respondents participated in a previous study in which we asked them to photograph things that were important to their well-being and health, and then interviewed them about those values. Those interviews were included in the 31 used to develop the patient-centered values framework.¹⁵⁻¹⁷ We cannot rule out that this overlap in samples limits the generalizability of the findings.

Utility of Priming for Free-Response Elicitation

Placement of domain-driven elicitation in the middle of the survey allowed for two types of free-recall elicitation: elicitation that occurred before participants learned of the values framework (i.e., “initial free-response”), and elicitation after the framework was introduced (i.e., “informed free-response”). Comparing agreement across initial free-response, domain-driven elicitation, and informed free-response, both the type of elicitation (free-response versus domain-driven) and the participant’s familiarity with the values framework (initial versus informed free-response) may be associated with different levels of agreement on categorization between respondents and the research team. Higher agreement for domain-driven versus initial free-response elicitation may suggest that domain-driven elicitation generates values that align more closely with domains of the framework. Thus, the type of elicitation may influence the level of agreement. However, higher agreement for informed free-response than initial free-response suggests that familiarity with the framework may also influence the level of agreement. Future studies could further explore reasons for these differences, and assess how such insights might inform the design of approaches for eliciting patient values.

Review of survey responses suggests qualitative differences in the content and categorization of values elicited through initial free-response versus informed free-response. Respondents’ values generated from initial free-response tended to be more medically oriented, focused on the healthcare system (e.g., “time at doctor visits”), than values generated through informed free-response elicitation. Our prior work¹⁵⁻¹⁷ suggests that the field study methods used to formulate the values framework (i.e., photo elicitation and extended, semi-structured interviews in participants’ homes) were effective for encouraging participants to think about well-being and health in their daily lives, outside of healthcare contexts. This kind of in-depth values elicitation may not be feasible in clinical settings due to time and resource constraints. We have also found that patients tend to withhold personal values in clinical contexts when they do not perceive those values to be pertinent.¹⁵ Given the time and resource intensiveness of field study methods, it is promising that introducing the domains of the values framework has potential to broaden the values patients share. Domain-driven and informed free-response queries appear to be efficient approaches to eliciting values that might otherwise require in-depth examination. Together, our prior work and the current findings support the idea that priming patients with definitions of values domains should be a key consideration when eliciting values of patients with MCC. Future work could explore how different methods of priming participants yield different kinds of values, as well as the clinical utility of the types of values elicited through different methods.

Relative Importance of Domains

We did not observe a difference in the importance respondents ascribed to values elicited by free-response and informed free-response elicitation. Respondents rated the importance of free-response values very high and these ratings were close to the highest-rated domain-driven values. Further, we observed a significant difference in the high rating of importance for relationship and principles domains compared with the lower rating of importance for possessions and activities domains. More work is needed to understand the care and design implications based on differences in ratings for different domains. A rating of 3.8 or 3.9 still falls between “very important” and “most important,” so our findings support including these domains when eliciting the values of patients with MCC for overall well-being and health. More research is needed to understand what these ratings mean in the context of care planning and decision-making.

Multiple Categorization

When given the choice, respondents often placed free-response values into multiple categories. Multiple categorization probably inflated agreement substantially, since our team’s categorization of a value could match on any domain to which the respondent assigned the value. This choice is both a limitation and a strength of our study design. The fact that respondents employed multiple categorization is interesting and insightful. From a conceptual standpoint, the prevalent use of multiple categorization among respondents supports the idea that the value domains might not be mutually exclusive. This is compatible with findings from our prior work that individuals with MCC often perceive values to be interrelated.¹⁶ For instance, if an individual values “gardening with her granddaughter”, this same value may be categorized under activities (i.e., gardening) and relationships (i.e., with granddaughter). Looking toward the design of tools for eliciting values for planning care, the prevalence of multiple categorization

means it may be more likely that domain-driven elicitation generates values that cross domains than values that do not. As long as individuals are given the opportunity to include more than one value per domain, this approach may also provide a more comprehensive set of values compared to free-response alone. Understanding how values cross domains and relate to other values has implications for care planning. For example, when facing declining health, patients and their health care providers might consider how this could affect a web of related values and values domains rather than focusing solely on medically-oriented effects, such as physical function. Methods and tools could be designed to facilitate discussions that link health concerns with patients' values, and support care planning to mitigate these concerns.

Implications for Informatics

These findings have practical applications for health information technology to support conversations between patients and providers about patients' personal values. A patient-facing questionnaire deployed in a personal health record (PHR) could capture personal values from patients and display them to the provider. This would enable the patient to respond while at home, which could facilitate reflection on personal values in daily life. The questionnaire could be formatted to mimic the elicitation methods tested in our survey. Such a questionnaire would be more likely to elicit a breadth of patient values if it used domain-driven or informed free-response methods. As we know from limitations in VCMs,¹¹ patients would need to be able to revise and elaborate on personal values over time. Patients' personal values could then be displayed in existing locations in clinical information systems, such as alongside patient demographics or social history, or could be incorporated into care planning or decision support tools.

Conclusion

We evaluated how a patient-centered values framework generalizes to a larger sample of patients with MCC. Through a series of free-response and domain-driven queries, we elicited respondents' values, asked them to place those values into the domains of the framework, and asked them to rate the importance of values generated. We found that respondents framed values similarly to the framework, suggesting that the domains of the framework are clear and conceptually precise, and that the framework provides a promising tool for eliciting patient-centered values. These findings provide insight into the potential utility of the values framework for supporting care planning conversations between patients with MCC and their health care providers. Future work should build on these findings by exploring ways to link patient values with health concerns in the context of care planning, what patients' ratings of the importance of values mean in the context of care planning, and the clinical utility of values generated through different elicitation types.

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References

1. Weiss CO, Boyd CM, Yu Q, Wolff JL, Leff B. Patterns of Prevalent Major Chronic Disease Among Older Adults in the United States. *J Am Med Assoc*. 2007 Sep;298(10):1160–1162.
2. Fortin M, Lapointe L, Hudon C, Vanasse A, Ntetu AL, Maltais D. Multimorbidity and quality of life in primary care: a systematic review. *Health Qual Life Outcomes*. 2004;2(1):51.
3. Vogeli C, Shields AE, Lee TA, Gibson TB, Marder WD, Weiss KB, et al. Multiple Chronic Conditions: Prevalence, Health Consequences, and Implications for Quality, Care Management, and Costs. *J Gen Intern Med [Internet]*. 2007 Nov;22(S3):391–395. Available from: <https://doi.org/10.1007%2Fs11606-007-0322-1>
4. Paterson BL. The shifting perspectives model of chronic illness. *J Nurs Scholarsh*. 2001;33(1):21–26.
5. Katon WJ, Rutter C, Simon G, Lin EHB, Ludman E, Ciechanowski P, et al. The Association of Comorbid Depression With Mortality in Patients With Type 2 Diabetes. *Diabetes Care [Internet]*. 2005 Oct;28(11):2668–2672. Available from: <https://doi.org/10.2337%2Fdiacare.28.11.2668>
6. Friedman B, Kahn Jr PH, Borning A, Hultgren A. Value Sensitive Design and Information Systems. In: *Philosophy of Engineering and Technology*. Springer; 2013. p. 55–95.
7. US Department of Health and Human Services. Multiple chronic conditions—a strategic framework: optimum health and quality of life for individuals with multiple chronic conditions. Washington, DC: US Department of Health and Human Services; 2010.
8. National Quality Forum. Multiple Chronic Conditions Measurement Framework. Washington, DC; 2012.

9. Uhlig K, Leff B, Kent D, Dy S, Brunnhuber K, Burgers JS, et al. A framework for crafting clinical practice guidelines that are relevant to the care and management of people with multimorbidity. *J Gen Intern Med*. 2014;29(4):670–679.
10. Boyd CM, Leff B, Wolff JL, Yu Q, Zhou J, Rand C, et al. Informing Clinical Practice Guideline Development and Implementation: Prevalence of Coexisting Conditions Among Adults with Coronary Heart Disease. *J Am Geriatr Soc* [Internet]. 2011 May;59(5):797–805. Available from: <https://doi.org/10.1111%2Fj.1532-5415.2011.03391.x>
11. Witteman HO, Scherer LD, Gavaruzzi T, Pieterse AH, Fuhrel-Forbis A, Dansokho SC, et al. Design Features of Explicit Values Clarification Methods A Systematic Review. *Med Decis Making*. 2016;36(4):453–71.
12. Grant RW, Altschuler A, Uratsu CS, Sanchez G, Schmittiel JA, Adams AS, et al. Primary care visit preparation and communication for patients with poorly controlled diabetes: A qualitative study of patients and physicians. *Prim Care Diabetes* [Internet]. 2016 Dec; Available from: <http://dx.doi.org/10.1016/j.pcd.2016.11.003>
13. Grant RW, Adams AS, Bayliss EA, Heisler M. Establishing visit priorities for complex patients: A summary of the literature and conceptual model to guide innovative interventions. In: *Healthcare*. Elsevier; 2013. p. 117–122.
14. Fagerlin A, Pignone M, Abhyankar P, Col N, Feldman-Stewart D, Gavaruzzi T, et al. Clarifying values: an updated review. *BMC Med Inform Decis Mak*. 2013;13(Suppl 2):S8.
15. Lim C, Berry AB, Hirsch T, Hartzler A, Wagner EH, Ludman E, et al. “It just seems outside my health.” How Patients with Chronic Conditions Perceive Communication Boundaries with Providers. In: *ACM Conference on Designing Interactive Systems* [Internet]. Brisbane, Australia: Association for Computing Machinery (ACM); 2016. Available from: <http://dx.doi.org/10.1145/2901790.2901866>
16. Lim C, Berry AB, Hirsch T, Hartzler AL, Wagner EH, Ludman E, et al. Understanding the Values of Patients with Multiple Chronic Conditions. Under review;
17. Berry AB, Lim C, Hartzler AL, Hirsch T, Wagner EH, Ludman E, et al. How Values Shape Collaboration Between Patients with Multiple Chronic Conditions and Spousal Caregivers. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* [Internet]. Denver, CO, USA: Association for Computing Machinery (ACM); 2017. Available from: <http://dx.doi.org/10.1145/3025453.3025923>
18. Le Dantec CA, Poole ES, Wyche SP. Values as lived experience: evolving value sensitive design in support of value discovery. In: *Proceedings of the 27th international conference on Human factors in computing systems*. New York, New York, USA: ACM; 2009.
19. Charmaz K. *Constructing grounded theory: A practical guide through qualitative analysis (Introducing Qualitative Methods Series)*. Sage Publications Ltd; 2006.
20. Emanuel EJ. Four Models of the Physician-Patient Relationship. *J Am Med Assoc* [Internet]. 1992 Apr;267(16):2221. Available from: <https://doi.org/10.1001%2Fjama.1992.03480160079038>
21. Breslin M, Mullan RJ, Montori VM. The design of a decision aid about diabetes medications for use during the consultation with patients with type 2 diabetes. *Patient Educ Couns* [Internet]. 2008 Dec;73(3):465–472. Available from: <https://doi.org/10.1016%2Fj.pec.2008.07.024>
22. Berger B, Hopp JW, Raettig V. Values Clarification and the Cardiac Patient. *Health Educ Behav* [Internet]. 1975 Jan;3(2):191–199. Available from: <https://doi.org/10.1177%2F109019817500300204>
23. Llewellyn-Thomas HA, Crump RT. Decision Support for Patients: Values Clarification and Preference Elicitation. *Med Care Res Rev* [Internet]. 2012 Nov;70(1 Suppl):50S–79S. Available from: <https://doi.org/10.1177%2F1077558712461182>
24. Vries M de, Fagerlin A, Witteman HO, Scherer LD. Combining deliberation and intuition in patient decision support. *Patient Educ Couns* [Internet]. 2013 May;91(2):154–160. Available from: <https://doi.org/10.1016%2Fj.pec.2012.11.016>
25. Grundstein-Amado R. Values education: a new direction for medical education. *J Med Ethics* [Internet]. 1995 Jun;21(3):174–178. Available from: <https://doi.org/10.1136/jme.21.3.174>
26. Coward DD, Kahn DL. Transcending Breast Cancer. *J Holist Nurs* [Internet]. 2005 Sep;23(3):264–283. Available from: <https://doi.org/10.1177%2F0898010105277649>
27. Katon WJ, Lin EHB, Korff MV, Ciechanowski P, Ludman EJ, Young B, et al. Collaborative Care for Patients with Depression and Chronic Illnesses. *N Engl J Med* [Internet]. 2010 Dec;363(27):2611–2620. Available from: <https://doi.org/10.1056/nejmoa1003955>