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Views of Older Persons with Multiple Morbidities on Competing Outcomes and Clinical Decision-Making

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Abstract

Objectives: To examine the ways in which older persons with multiple conditions think about potentially competing outcomes, in order to gain insight into how processes to elicit values regarding these outcomes can be grounded in the patient's perspective.

Design: Qualitative study consisting of purposefully sampled focus groups.

Setting: Community

Participants: Persons age ≥ 65 years taking ≥ 5 medications.

Measurements: Participants were asked their perceptions about whether their illnesses or treatment interacted with each other, goals of their treatment, and decisions to change or stop treatment.

Results: Although participants were largely unaware that treatment of one condition could worsen another, many had experience with adverse medication effects as a competing outcome. Participants initially discussed their conditions in terms of disease-specific outcomes, such as achieving a target blood pressure or lipid level. In the context of decision-making, participants shifted their discussion from disease-specific to global, cross-disease health outcomes, such as survival, preservation of physical function, and relief of symptoms. Despite having some misconceptions regarding the likelihood of these outcomes, they weighed the outcomes against one another in order to consider what was most important to them. Their preference was for the treatment that would achieve the most desired outcome.

Conclusions: Because of their experience with adverse medication effects, older persons with multiple morbidities can understand the concept of competing outcomes. The task of prioritizing global, cross-disease outcomes can help to clarify what is most important to seniors who are faced with complex healthcare decisions.

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Keywords

Decision-making; chronic disease; multiple morbidity

INTRODUCTION

The care of patients with multiple chronic health conditions is highly challenging. Patients with multiple conditions are at high risk of adverse outcomes, including mortality, hospitalization, and disability.^{1, 2} Although the development of disease-specific guidelines has led to improvements in outcomes for patients with individual conditions, the application of these guidelines to persons with multiple conditions is less clear.^{3, 4} The patient with coronary artery disease, hypertension, and diabetes taking multiple medications to reduce stroke risk, for example, incurs an increased risk of postural instability⁵ and falls.^{6, 7} Moreover, treatment associated with one condition has the potential to worsen another, such as the use of steroids in the patient with an inflammatory arthritis and congestive heart failure. This potential for harm suggests that all desirable outcomes in the management of chronic conditions may not be achievable simultaneously and/or may only be achieved at the cost of increased burden of treatment.

Traditional disease-focused decision-making tends to ignore the potential for competing outcomes. With its focus on achieving a certain disease-specific outcome, this approach to decision-making considers unintended outcomes, such as medication adverse effects, as unfortunate “side effects” that need to be tolerated.⁸ However, because of the increased risk and serious nature of these adverse outcomes among older persons with multiple chronic conditions, they may instead best be conceptualized as competing outcomes, or, in other words, outcomes important in their own right that may result from a given intervention. Given this potential for competing outcomes, health care decision-making for patients with multiple conditions needs to be done in the context of patients' values and preferences,^{9, 10} with the patient identifying which outcome is most desirable.

Decision aids, which provide patients with information about the treatment options available for specific conditions and help them to clarify their values regarding these options, have been shown to improve agreement between patients' preferences and subsequent treatment decisions.¹¹ However, it would not be feasible to construct such aids for the multitude of decisions that persons with multiple conditions face involving competing outcomes. Moreover, several studies have demonstrated that, although patients want their values to guide decision-making, many do not want to participate in the decision-making process.^{12, 13} How best to engage patients in the process of reflecting upon and articulating their values such that they can inform the decision-making process therefore remains unclear.¹⁴ There is growing evidence that high-quality reasoning can be derived from honing intuitive processes.¹⁵ Therefore, the purpose of this study was to examine the ways in which older persons with multiple conditions naturally think about potentially competing outcomes, in order to gain insight into how processes to elicit values can be grounded in the patient's perspective.

METHODS

Participants

Participants were 65 years of age or older and were taking 5 or more daily medications. We selected these eligibility criteria to identify persons who were undergoing treatment for multiple conditions. We excluded persons who were non-English speaking, had severe hearing loss precluding participation in a focus group, or who had cognitive impairment,

defined as inability to remember ≥ 2 items on a 3-item test of short-term recall.¹⁶ Eligibility criteria were determined during a telephone screen.

Participants were recruited from sites selected to promote purposeful sampling by providing access to a population of older persons of diverse ethnic/racial, socioeconomic, and functional status. A total of 13 focus groups were conducted. Each group consisted of between 3 and 8 participants and was conducted at the site of recruitment (9 at senior centers, 3 at physicians' practices, and 1 at a congregate housing site).

The Yale University School of Medicine Human Investigations Committee approved the protocol, and all participants provided written informed consent.

Data collection

Focus groups were conducted by a single trained moderator using a discussion guide, which evolved over the course of the study to incorporate insights from the initial focus groups. The use of focus groups allowed participants to reflect upon and respond to the ideas offered by other members of the group, which helped individuals to clarify their own thoughts in comparison to what others were saying. In addition, the focus group methodology can encourage participation from those who are reluctant to be interviewed on their own.^{17, 18} The guide began with questions asking participants about their perceptions of whether their illnesses or treatment interacted with each other in any way. The guide then asked participants what they believed were the goals of their treatment, both from their own and their physicians' perspectives, whether they had any adverse effects from their treatments, and whether they had ever made a decision to change or stop a treatment. The early focus group results revealed that participants most readily understood the concept of competing outcomes in terms of medication adverse effects. Therefore, participants in later groups were asked in the final portion of the interview to consider how they would make a decision if faced with the following two scenarios: 1) they were having severe pain and the only effective medication treatment was associated with an increased risk of a heart attack, 2) the only available medication to decrease future risk of heart attack caused them fatigue and dizziness. At the end of the interview, participants were asked once again to think about the goals of their medical treatment.

Prior to starting the focus group, participants completed a questionnaire regarding sociodemographic and health status.

Data analysis

Focus groups were audiotaped and transcribed by an experienced medical transcriptionist. Using the constant comparative method,¹⁹ analysis of the transcripts took place simultaneously with data collection, so that issues arising in earlier focus groups could be explored in greater depth in later groups. Initially, small blocks of text were coded into discrete concepts using a coding scheme developed in an iterative process, in which 2 of the investigators each coded several interviews and met to review the scheme. These concepts were then compared within and across focus groups to organize them into larger themes. Sample size was determined by theoretical saturation; i.e. focus groups were conducted until no new concepts emerged.

RESULTS

The 66 participants had a median of 5 (range 3-8) chronic conditions and took a median of 7 (range 5-14) daily medications. Additional descriptive characteristics are provided in Table 1. The themes that emerged from the focus groups were organized into 3 broad categories:

- 1) Recognition of competing outcomes; 2) Understanding of the likelihood of outcomes 3) Disease-specific versus global outcomes.

Recognition of competing outcomes

Concerns about one condition or its treatment affecting a second condition were rarely raised, suggesting that participants had little knowledge regarding the potential for their diseases and treatments to interact with one another. However, many participants discussed the adverse effects of medications as a competing outcome that influenced their treatment decision-making. Some participants were concerned that these effects were adverse outcomes of equal, if not greater importance, than the beneficial outcomes the medications could provide. Rather than being thought of as a “side” effect that they were required to experience in the effort to achieve some other outcome, these participants viewed these effects as outcomes so undesirable that they would make the decision to stop the medication:

If you have side effects, you don't have a choice. You just stop taking the medication because it could lead to something else happening.

I don't think that anything that has an immediate bad side effect would be good for your long-term effect. What other part of the body would it damage?

I have high cholesterol. I took something but.. I had such pain in my calf, so I was taken off whatever that was. I think [my cholesterol] is 241, and I'm willing to live with that.

Although many participants could understand the concept of competing outcomes by considering the adverse effects of medications, there was nonetheless variability in participants' beliefs about the need to decide among potentially competing outcomes. Some participants believed that adverse consequences of one medication could be ameliorated by another:

You have to take those [medications.] So then they should be able to give you something to counteract the side effects.

Understanding of the likelihood of outcomes

Participants showed little appreciation regarding the risk reductions associated with preventive therapies, instead believing that these medications were necessary to prevent immediate death and conceptualizing outcomes in absolute terms:

I think the Zocor is doing me harm. But what's the alternative here? [Interviewer: OK, so what is the alternative?] [With a nervous laugh]: Death?

If you have a heart condition, you don't want to cut [the medications for your heart] out or else you won't be here.

Participants only rarely recognized the fact that many outcomes might not occur with certainty. Discussing the scenario of taking a medication to relieve pain, one participant asked:

I mean what was the chance [of a heart attack]? If it was 10%, if it was 40%, that's a big difference.

Shifting from disease-specific to global, cross-disease outcomes

The participants in each of the focus groups—who were willing and able to engage in a consideration of competing outcomes caused the focus groups to shift in the way in which they discussed these outcomes from the beginning to the end of the focus group. When initially asked what outcomes they thought their therapy was meant to accomplish, many

mentioned disease-specific goals, including prevention of stroke or heart attack and reaching certain target numbers:

[The doctor] says to me, 'Your numbers are perfect.' That's all I have to hear.

The goal is to keep my blood pressure as low as possible.

The last time I saw the cardiologist, he was practically tap dancing in the office he was so happy. [The medication] has knocked all those numbers down to nothing.

Asking participants to consider explicitly the potential trade-offs among competing outcomes caused many of them to discuss outcomes in more global terms, such as quality of life, expressed in terms of symptoms and function, and survival. When participants thought about outcomes in these global terms, they were able to weigh these more general outcomes against one another, in order to reflect on what was most important to them. Participants used these global outcomes to explain how they thought about their own medications. Several participants were more concerned about their current function than about the effects of medications on their future health. One participant said that he stopped taking a medication that caused leg pain "because of the effect on my life. I couldn't even go to the grocery store or anything." A second participant said:

I have been trying to convince my doctor that I don't need the cholesterol medication any longer, because it has zapped me of my strength, and it is debilitating.

Participants also used these global outcomes to reason through the medication scenarios, and the outcomes they valued most highly showed inter-individual variability. When considering a medication that could extend life but would have an adverse effect on physical or cognitive function, several participants prioritized their function:

If you don't feel good, you can't take care of yourself and you have to depend on somebody else, what's the good of living another 10 years?

I never would like to take anything that would slow me down too much mentally.

In contrast, another participant focused on the importance of the effect of the antihypertensive on survival and her willingness to put up with any symptoms that the medication might give her:

You will have a stroke or a heart attack from your blood pressure but you won't be dizzy when you die. I think it doesn't even bear asking. You have to be dizzy.

When asked whether they would be willing to take a medication that would take away pain but increase their risk of a heart attack, many participants preferred living with the pain to taking on this risk. However, several participants weighed this risk against the effect of the pain on their functional status. These participants had a threshold of functional disability at which their outcome priorities changed:

I would take it when I am flat on my back and cannot walk anymore.

I didn't want to be at home bedfast, didn't want to depend.... I wanted my independence.

The consideration of more general outcomes facilitated participants' consideration of decision-making across different diagnoses. When asked about how she would decide between treating her arthritis and heart disease, if therapy for one had the potential to make the other worse, one participant reduced the two diseases to their common denominator:

I think I would go back to the thing that I fear most, being incapacitated and living, so I would choose whatever would prevent that.

At the end of the focus group, participants were asked again to consider what outcomes they would hope to achieve and to avoid with the interventions they received from their physicians. Participants moved away from disease-specific outcomes, instead providing a spectrum of general domains, as provided in Table 2.

DISCUSSION

In this qualitative study of older persons with multiple conditions, their experiences with adverse medication effects provided some with readily understood examples of the concepts of trade-offs and the need to prioritize among potentially competing outcomes. When asked about medications with potentially competing outcomes, participants shifted from thinking about outcomes in disease-specific terms, such as achieving a target blood pressure or lipid level, and instead considered more global, cross-condition health outcomes, such as survival, symptoms, and function. In contrast to their perceptions of medications, participants had little awareness that the presence of multiple conditions themselves placed them at risk for adverse outcomes. In addition, they frequently had overly optimistic beliefs regarding the benefits of the therapies they were receiving and generally conceptualized outcomes in absolute terms.

The participants' lack of awareness regarding the potential for competing outcomes arising from the presence of multiple conditions stands in contrast to an earlier qualitative study which asked persons with 2 or more chronic conditions to list barriers to self-management of their conditions.²⁰ In that study, whose population was younger, in poorer health, and of lower socioeconomic status as compared to the current study population, participants frequently cited aggravation of one condition by the symptoms or treatment of another as a barrier. It is difficult to know whether the difference in findings of these two studies is a result of differences in the populations and/or the questions posed to the participants. Nonetheless, because participants in the current study most readily understood the concept of competing outcomes in terms of medication adverse effects, we asked them to describe how they had made decisions regarding their own medications and how they would make decisions regarding medications with competing outcomes. The way in which participants approached these decisions provides some fundamental insights into how older persons might be engaged in the process of thinking about what is most important to them when faced with potentially competing outcomes.

Central to the process of prioritizing their concerns was a shift in how participants thought about the outcomes of treatment. Their initial conception of these outcomes was in disease-specific terms, such as achieving a given blood pressure or lipid level. However, when faced with the need to prioritize among a number of different outcomes, many participants discussed these outcomes in more general, cross-disease terms. For example, when asked about taking a medication to treat hypertension that caused dizziness, participants spoke of weighing the adverse effect on quality of life caused by dizziness against the possibility of dying from a stroke or heart attack. Yet other participants, when considering whether they would take a medication that would increase their risk for heart attack in order to treat pain, defined thresholds of decreased function at which they would become willing to assume a greater risk of cardiovascular mortality. When taken to its logical extreme, this process allows all outcomes to be reduced to a single common denominator, as illustrated by the participant who would consider the effect of all of her diseases and their treatments on her function and then choose the therapeutic option that would prevent her from becoming incapacitated.

These results suggest that one approach to eliciting older persons' values when faced with competing outcomes would be to ask patients to prioritize among a small number of global

outcomes by selecting the outcomes that are most important to them to achieve or avoid. Physicians could then determine the course of care that would be most likely to meet these priorities. Asking participants to prioritize among a set of outcomes potentially offers several advantages compared to the alternative and more common strategy of asking patients to choose among a given set of treatment options. First, the results of this study suggest that the process of prioritizing outcomes may be easier for patients to do than to understand all of the complexities inherent in the specific risks and benefits of alternative treatment options. Second, such an approach may have greater acceptability to the sizeable proportion of patients who do not want to participate directly in the process of making medical decisions. Third, patients' priorities regarding these global treatment outcomes may be applicable to a wide range of specific treatment decisions,²¹ so that they would not have to engage in a separate decision-making process for each of many decisions regarding competing outcomes that they may face. Finally, it has been argued that decision-making based on identifying desired outcomes and selecting the path that can best achieve those outcomes is superior to decision-making based on choosing among a set of predetermined alternatives.²²

The results of this study also highlight additional challenges to the task of engaging patients with multiple conditions in the process of medical decision-making. First, many patients and physicians may not recognize that they cannot achieve desired outcomes without risking undesired outcomes. This lack of recognition is reflected in the belief expressed by participants that adverse effects of one medication could be treated by additional medications. In addition, this approach would require a shift in physician decision-making from its current focus, fostered by the existing specialty orientation of medical care, on individual diseases and disease-specific outcomes to a consideration of global, cross-disease outcomes. Despite the ever increasing recognition of competing risks, they are being measured as disease-specific outcomes.²³⁻²⁴ The patient who wishes to maximize her likelihood of independence but suffers from both diabetes and falls can participate in the decision whether to take a thiazolidinedione, for example, with its increased risk of hip fracture,²³ only if the effects of both diabetes under different treatment strategies and hip fracture on function are known. Second, it will need to be determined how sensitive the outcome priorities of older persons are to transient, and particularly affective, factors such as anxiety or pain, in order to understand the extent to which they do or do not reflect core, long-term values.²⁵⁻²⁶ Third, for patients who can understand the concept, the prioritization of outcomes would need to be done in the context of acknowledging and assessing patients' attitudes toward uncertainty. The finding in this study of a belief in the absolute benefits of certain interventions suggests the importance of an accurate understanding of outcomes for patient-centered decision-making. Previous studies have demonstrated that many people want greater benefit than can be achieved by preventive medications in order to choose to take the medication.²⁷⁻²⁸ In addition, it has been shown that patients are more likely to prefer a medication when they believe it eliminates the risk of a given outcome rather than merely reducing the risk, even if the absolute risk reduction is equivalent.²⁹

As a qualitative study, the results of this analysis can be used only to understand how older persons with co-existing conditions think about their illnesses and interventions and not to draw conclusions about the frequency of their knowledge or perceptions. By enrolling older persons from different recruitment sites, we sought to elicit the opinions of persons from a range of ethnic/racial and sociodemographic backgrounds. However, because we conducted the focus groups only in English we may have not included the full spectrum of perceptions.

Health care decision-making for older persons with multiple conditions is complicated by the potential for competing outcomes, and involving patients in the decision-making process is challenging. Asking older persons to prioritize among a set of global outcomes that can be

applied across a spectrum of specific diseases may be one easily understood approach to eliciting values in a manner that can inform a range of health care decisions.

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Table 1

Description of the 66 participants

Characteristic	Value
Age, mean (\pm SD)	75 (6)
Education, mean (\pm SD)	13 (3)
Female, (%)	67
Latino ethnicity, (%)	3
Race, (%)	
White	76
Black	23
Other	1
Married, (%)	39
Living alone, (%)	48
Self-rated health, (%)	
Excellent/Very good	15
Good	48
Fair/Poor	37
Quality of life, (%)	
Best possible	23
Good	57
Fair/Poor	20
≥ 1 IADL * disability, (%)	35
Number of medications, median (range)	7 (5-14)
Number of chronic conditions, median (range)	5 (3-8)
Selected conditions, (%)	
Hypertension	88
Diabetes	38
Ischemic heart disease	52
Congestive heart failure	11
Chronic lung disease	24
Depression	24
Arthritis	73
Falls	14
Urinary incontinence	21
Osteoporosis	20

* IADL = Instrumental Activities of Daily Living

Table 2

List of potential treatment goals as generated by participants at the end of the focus group

Desired outcomes	Undesired outcomes
Life extension	Life extension without quality
Preservation of physical functioning	Pain
Preservation of social functioning	Nausea/ Upset stomach
Preventing disease or preventing worsening of existing disease	Drowsiness
Improving symptoms:	Dizziness
Pain	Mental slowing/ foginess
Shortness of breath	
Depression	