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Older Adults' Recognition of Tradeoffs in Healthcare Decision Making

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Abstract

Objectives—To examine older persons' understanding of healthcare decision making involving tradeoffs.

Design—Cross-sectional survey

Setting—Primary care clinics

Participants—Community-living persons age 65 years and older

Measurements—After being primed to think about tradeoffs with a focus on chronic disease management, participants were asked to describe a decision they had made in the past involving a tradeoff. If they could not, they were asked to describe a decision they might face in the future and were then given an example of a decision. They were also asked about communication with their primary care provider about their priorities when faced with a tradeoff.

Results—Of the 50 participants, 44 (88%) were able to describe a healthcare decision involving a tradeoff; 25 provided a decision in the past, 17 provided a decision they might face in the future, and 2 provided a future decision after hearing an example. One participant described a non-medical decision and two participants described goals without providing a tradeoff. Of the healthcare decisions, 26 involved surgery, seven were end-of life decisions, seven regarded treatment of chronic disease, and four involved chemotherapy. When asked whether their providers should know their health outcome priorities, 44 (88%) replied yes; 35 (70%) believed their providers knew their priorities; however, only 18 (36%) said that they had a specific conversation about priorities.

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Conclusion—The majority of participants were able to recognize the tradeoffs involved in healthcare decision making and wanted their providers to know their priorities regarding the tradeoffs. Despite being primed to think about the tradeoffs involved in day-to-day treatment of chronic disease, participants most frequently described episodic, high-stakes decisions including surgery and end-of-life care.

Keywords

Decision making; tradeoffs; chronic disease

INTRODUCTION

Many common, “every-day” treatment decisions for older persons with multiple medical conditions (MCCs) require a consideration of tradeoffs. Medications prescribed to improve one common chronic condition may make a second condition worse.¹ Preventative medications with potential benefits in terms of reducing risks in the future can be associated with undesirable adverse effects in the present.² In addition, increasing the number of medications may increase the likelihood of adverse outcomes, including adverse drug events, dizziness, and falls.³ When faced with these tradeoffs, older persons vary in the relative importance they place on the different potential outcomes of treatment.⁴ Decision making for patients with MCCs therefore requires consideration of a variety of treatment options according to the tradeoffs between potential benefits and harms, with the optimal choice determined by patients’ specific outcome priorities and treatment preferences.

This model of decision making has become widely accepted for certain clinical scenarios, such as end-of-life care, as reflected in the recent Institute of Medicine report endorsing the importance of frequent clinician-patient conversations about end-of-life goals and preferences.⁵ However, this process only rarely occurs in office practice for more routine treatment decisions.⁶ While the majority of individuals say that, in general, they want to be offered options and to be asked their opinions,⁷ it is not clear whether patients understand the role of tradeoffs and their preferences in every-day decisions. The purpose of this study was to examine older persons’ understanding of and attitudes toward healthcare decision making involving tradeoffs.

METHODS

Participants

A sample of 40 male volunteers was identified from primary care outpatient clinics at the West Haven campus of VA Connecticut Healthcare System. Recruitment occurred by providing an information sheet to patients age 65 years and older when they checked in to clinic and having clinic staff direct interested patients to one of the investigators (SC) at the end of their visit. To recruit female participants, we subsequently targeted female veterans age 65 years and older with a letter introducing the study and follow-up phone call. Of the 50 women contacted by telephone, two were deceased and 23 opted out of the study. Interviews were completed with 10 of the 25 women who agreed to participation. Of all potential participants approached for the study, three were excluded because of their

inability to explain the key points of the study after reading an information sheet. The protocol was approved by the Human Subjects Subcommittee of VA Connecticut and the Yale IRB.

Data collection

Of the 50 interviews, 48 were performed in person and two performed by telephone at the participants' request. Participants were primed to think about every-day management decisions involving tradeoffs by asking them to complete two tools designed to help individuals clarify their health outcome priorities when faced with such decisions, the Time and Outcome Preferences (TOP) scale⁸ and the Health Outcome Prioritization tool.⁴ The tools ask participants to prioritize health outcomes that are common across illnesses and decisions, such as maximizing length of life, promoting independence, or relieving symptoms. This approach was developed to reflect how patients naturally think about treatment decisions.⁹ The TOP scale asks participants to rate their agreement with a series of statements divided into two subscales, each addressing one type of tradeoff. The Quality versus Quantity of Life subscale contains statements such as, "I would rather live a shorter life than lose the ability to take care of myself," and the Present versus Future Health subscale contains statements such as, "I am willing to have side effects right now if it means I could have a better quality of life in the future."⁸ The Health Outcome Prioritization tool asks participants to order four health outcomes on a 100-point visual analogue scale: "keeping you alive," related to quantity of life; and "maintaining independence," "reducing or eliminating pain," and "reducing or eliminating other symptoms including dizziness, fatigue, and shortness of breath."⁴

Participants were then asked if they had an experience in the past where they had thought about similar types of priorities and tradeoffs when making a medical decision and to describe the decision. If they had not, we asked if they could think of an example of a treatment decision in the future when they would consider priorities and tradeoffs. If they could not, we provided the example of a patient with high cholesterol who experienced muscle pain when taking a statin that affected her ability to ambulate and asked if they could think of an example that would apply to them.

We next asked about communication with providers about priorities, including: 1) if they believed their provider knew their priorities; 2) if they had a specific conversation; and 3) if their provider should know their priorities. Participants were asked about their sociodemographic and health characteristics, including: age; gender; race/ethnicity; education; self-rated health; global quality of life; and physical function, assessed using the modified Rosow-Breslau scale, which asks about the ability to perform each of four activities without help.¹⁰

Analysis

Descriptive statistics (proportions, means, and standard deviations) were used to describe the cohort. We applied content analysis to the examples of decisions involving tradeoffs in order to create discrete categories. Initially, two of the investigators independently coded a subset

of responses. Differences were compared and reconciled to create the taxonomy of categories. A single investigator then used the taxonomy to code the remaining responses.

RESULTS

Participant characteristics

The demographic and health characteristics for the 50 participants are displayed in Table 1. Participants' mean (\pm SD) age was 72 ± 7 years, 20% were women, and 82% were white. They had a mean of 14 ± 2.2 years of education. While 58% had four or more chronic conditions and 50% had one or more impairments in physical function, only 30% rated their health as fair or poor and 26% rated their quality of life as fair or poor.

Understanding tradeoffs

A total of 50% (N=25) of participants could give a description of a decision they had made in the past that involved a tradeoff similar to the ones presented in the tools, 34% (N=17) could think of a future decision, and 4% (N=2) provided a future decision after hearing the example provided by the interviewer. One participant provided an example of a tradeoff for a non-medical decision, involving a change in living situation, and an additional two participants described their goals for the future without describing a tradeoff. The remaining 6% (N=3) of participants could not provide any sort of response even after hearing the example.

Of the 25 past decisions that participants described, 18 involved surgery, six were decisions about whether to take medication or institute a lifestyle change to treat chronic disease, and one was a decision regarding chemotherapy. The majority of the surgical descriptions included a tradeoff between risks of surgery and potential improvements in quality of life. About one-quarter of the surgical decisions (5/18) described the tradeoff in such extreme terms that having surgery appeared to be the only reasonable treatment option. For example, one participant described the decision to undergo surgery for sleep apnea as, "Operation tradeoff was to live or to die," and second participant characterized the decision to undergo gastric bypass as, "Stay obese and die, or have the operation and live." The lifestyle/medication decisions included descriptions of weighing the inconveniences or adverse effects of intervention against potential or actual health benefits.

Of the 19 future decisions, seven were related to medical decisions the patient currently had, and were therefore decisions the patient was likely to face. These included possible surgery (N=6) and chemotherapy (N=1). The remaining 12 descriptions were of hypothetical decisions, including surgery (N=2), chemotherapy (N=2), end-of-life decisions (N=7), and medication for chronic disease (N=1). Table 2 provides verbatim examples of the decisions described by participants.

The two additional participants who talked about future decisions in terms of their goals indicated the health states they would most want to avoid, including loss of vision, hearing, and mobility for one and disability and nursing home placement for the other. Of the three participants who could not provide an example of a decision, one stated, "Hard to come up with situation because I will always go with what doctor says."

Talking with doctors about priorities

When asked whether their providers should know their health outcome priorities, 88% (N=44) replied yes. A total of 70% (N=35) believed their providers knew their priorities; however, only 36% (N=18) said that they had a specific conversation about their priorities with their providers.

DISCUSSION

In this study of older veterans receiving primary care at a Veterans' Affairs medical center, participants were asked to complete several exercises in which they considered their health outcome priorities when faced with medical decisions involving tradeoffs. After completing these exercises, almost all (88%) were able to describe either a medical decision they made in the past in which they faced a tradeoff or a future decision that would involve a tradeoff. Of the 44 decisions described, 33 involved either surgery or end-of-life decision making, with only a few participants describing decisions about medications or lifestyle changes to manage chronic disease. When asked about discussing their priorities with providers, most participants thought their doctors should know what these were, but only 36% reported having a specific conversation.

The desire of most participants in this study for their doctors to know their health outcome priorities mirrors findings from a national survey of adults in the US, in which 96% wanted to be offered choices and to be asked their opinions by their doctors.⁷ One of the biggest challenges to achieving this goal is recognizing when there are multiple options available to the patient. It is encouraging that many participants understood the concept of tradeoffs and could recognize situations involving different treatment options with different balances between benefits and harms, either that they had already encountered or could face in the future. However, the large majority described what could be characterized as high-stakes, episodic decisions by citing surgery and end-of-life care. A proportion of participants who discussed surgery presented the decision in an extreme way, citing such dire outcomes associated with the option of not having surgery that it appeared they had only one reasonable option available. With little empirical study of how surgeons communicate with their patients regarding the benefits and harms of surgery, it is difficult to know whether this finding represents patients' lack of understanding of the tradeoffs or the manner in which surgery is discussed.

Despite completing tools that primed participants to think about the tradeoffs involved in more routine decisions made on a daily basis to manage chronic diseases, such as weighing the burdens of multiple medications and doctor visits against the potential for improvements in health, few participants described these sorts of decisions. Prior research suggests that these tradeoffs are infrequently discussed between patients and clinicians when making chronic management decisions. A study of a probability sample of English-speaking US adults age 40 years and older (n=3010) examined their reports of decision making about medications for hypercholesterolemia or hypertension, finding that, while nearly all discussions included the pros of the medication, only about 50% included the cons. Similarly, nearly all participants reported their provider expressed an opinion but only about one-half were asked for their preference.¹¹ The frequency with which older persons

experience medication adverse effects¹² and the burdens of complex regimens¹³ suggests that many of these patients may be experiencing the tradeoffs associated with chronic disease management, even if they are not recognizing they are doing so.

Several forces discourage the consideration of multiple options with different tradeoffs. The treatment recommendations included in disease management guidelines and pay-for-performance measures foster the notion that there is a single correct way to manage chronic diseases, and the reduction of variability in healthcare delivery has been argued as a means to improving the quality and cost-effectiveness of care.^{14,15} Nonetheless, it is becomingly increasingly recognized that treatment outcomes can vary considerably based on the unique set of comorbidities and risk factors of individual patients, and that patients vary in the importance they place on these outcomes. These characteristics of decision making for chronic disease supports the provision of personalized approaches to chronic disease management.¹⁶ Further research is required to establish the clinical scenarios in which patients might benefit from explicit consideration of an expanded range of treatment options offering different balances between treatment burden, harms, and benefits. The study results, demonstrating that older persons understand the concept of tradeoffs, supports the call for clinical practice guidelines to incorporate patient preferences and to avoid making strong recommendations when the optimal treatment choice depends upon patients' priorities when faced with tradeoffs.¹⁷ At the same time, the study results demonstrate that many, but not all, patients will want their priorities to help to identify the optimal choice, supporting the need to individualize the extent to which patients are involved in making treatment decisions.

The generalizability of the study is limited by the small sample consisting of volunteers receiving care at the VA and by our lack of data on those who did not volunteer or who opted out.

Among this cohort of older persons receiving primary care at the VA, many participants recognized the tradeoffs involved in decisions they had either faced in the past or may face in the future. The decisions most frequently described were surgery and end-of-life treatment. Although there is growing evidence of the tradeoffs involved in treatment of chronic disease, few participants described decisions involved in chronic disease management.

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Elements of Financial/Personal Conflicts	SMC		JO		NK		MET		TRF	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Employment or		x		x		x		x		x

Elements of Financial/Personal Conflicts	SMC		JO		NK		MET		TRF	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Affiliation										
Grants/Funds		x		x		x		x		x
Honoraria		x		x		x		x		x
Speaker Forum		x		x		x		x		x
Consultant		x		x		x		x		x
Stocks		x		x		x		x		x
Royalties		x		x		x		x		x
Expert Testimony		x		x		x		x		x
Board Member		x		x		x		x		x
Patents		x		x		x		x		x
Personal Relationship		x		x		x		x		x

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Table 1

Participant demographic and health characteristics (N=50)

Male, %	80
Age, mean (\pm SD), yrs	72.4 (\pm 6.9)
Non-Hispanic/Latino, %	100
Race, * %	
White	82
African American	18
Other	18
Education, mean (\pm SD), yrs	13.9 (\pm 2.2)
Chronic conditions, %	
0-1	4
2-3	38
4+	58
1 impairment in physical function	50
Self-rated health, %	
Excellent/Very Good	36
Good	34
Fair/Poor	30
Global quality of life, %	
Best possible	30
Good	42
Fair/Poor/Worst Possible	28

* Participants could choose more than one category

Examples of descriptions of decisions participants have either made in the past or may have to make in the future

Table 2

Decision Type	N	Example
Decision that occurred in the past:	25	
Surgery	18	I had double knee operations. I thought it would increase my quality of life, where in fact it really didn't. Tradeoff was risk of surgery versus quality of life.
Medication/lifestyle change	6	I had diabetes and didn't know it. Had to give up a lot of things with diabetes. I had lost eyesight, knew I had to go with their program. Willing to put up with inconveniences of diet and exercise because health is important.
Chemotherapy	1	I'm loaded with cancer. I don't worry about it, though. I didn't accept any therapy. I was supposed to die a year ago, and I feel great. Shorter length of life for keeping quality of life.
Decision that may occur in the future based on patient's health	7	
Surgery	6	I was thinking about getting shoulder replaced. But it's RA and there's no cure for RA at this time. Other than pills or injections which keep it the way it is, not worse. Would make decision to go to surgery to relieve pain, that's my priority.
Chemotherapy	1	I have bone cancer which is doing very well. But if they were going to treat me with chemotherapy I would never take it. Tradeoff would be just leave me alone and let me go. I feel that's going to kill you anyway, so I might as well go with dignity. The side effects wouldn't be worth living that quality of life.
Hypothetical future decisions	12	
End-of-life care	7	Willing to live shorter life based on what else is going on with health. I have a living will; don't want to be a plugged in vegetable
Surgery	2	If I had a heart problem. I would be bothered to have a big operation like that. Not being able to do my normal activities - I work on cars and trucks - and when it snows and I have to do physical work. I worry that surgery would limit me from doing those things.
Chemotherapy	2	If I had cancer, I wouldn't do chemo or heavy medications. I would go to a marijuana program for pain, and mental stress. Side effects and outcome of chemo are not worth it.
Medication	1	If they told me to take medications and tests, I would be willing to do it, whatever the test was; even if bothersome.