Published in final edited form as:

J Am Geriatr Soc. 2013 August ; 61(8): 1331–1336. doi:10.1111/jgs.12358.

Considering the Balance: Development of a Scale to Assess Patient Views on Tradeoffs in Competing Health Outcomes

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Abstract

BACKGROUND/OBJECTIVES—Tradeoffs among competing health outcomes complicate the treatment of older, multimorbid adults, but little is known about patient attitudes towards these tradeoffs. This study describes the development of a scale assessing participants' attitudes regarding two commonly encountered tradeoffs: quality versus quantity of life, and present versus future health.

DESIGN—Observational cohort study.

SETTING—Community.

PARTICIPANTS—Three hundred and fifty seven community-dwelling adults age 65.

MEASUREMENTS—An initial set of 20 items rated on a 5-point Likert scale of agreement was reduced using principal components analysis. Construct validity was evaluated through comparison of the scale with other tools addressing the same tradeoffs and analysis of participant characteristics associated with attitudes favoring quality over quantity of life and present over future health. Internal consistency was assessed with Cronbach's alpha. Test-retest reliability was assessed using intraclass correlation coefficients (ICCs).

RESULTS—The scale consists of two subscales, each addressing one tradeoff, with a total of 10 items. All factor loadings were .5 and subscale scores were significantly different ($p < .05$) in the expected directions when comparing with other tools and with participant race, education, and religious identity. Internal consistency was good (Cronbach's α .85 and .84), and test-retest reliability was fair (ICC .63 and .47). Subscale score medians fell near the middle of each scale with narrow interquartile ranges, but over 15% of the sample scored at an extreme of each subscale.

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Conflict of Interest: The editor in chief has reviewed the conflict of interest checklist provided by the authors and has determined that the authors have no financial or any other kind of personal conflicts with this paper.

Author Contributions Study concept and design: Terri R. Fried. Acquisition of subjects and data: Terri R. Fried, Virginia R. Towle. Analysis and interpretation of data: Siobhan M. Case, Terri R. Fried. Preparation of manuscript: Siobhan M. Case, Terri R. Fried. Editing of manuscript: Terri R. Fried.

Sponsor's Role: The sponsors had no role in the design, methods, subject recruitment, data collection, or analysis and preparation of the paper.

CONCLUSION—This new scale captures patient views on two common tradeoffs in healthcare. While test-retest reliability was modest, its high validity suggests this tool can be used to familiarize patients with common tradeoffs and further explore influences on patient attitudes.

Keywords

Health priorities; decision-making; geriatric assessment/methods; quality of life; comorbidity

INTRODUCTION

The increasing prevalence of multimorbidity amongst older Americans complicates medical decision-making. An estimated 62% of adults age 65 and older live with multiple chronic conditions and nearly half take five or more medications [1, 2]. These multiple illnesses and medications lead to an increased risk of adverse outcomes, including adverse drug events[3], drug interactions[4], and treatments targeted at one condition negatively impacting another. The result of competing adverse and desired outcomes is a tradeoff, requiring patients and providers to prioritize one outcome over another. For example, patients with chronic obstructive pulmonary disease and heart failure taking inhaled beta-adrenergics may experience less dyspnea but increase their mortality risk [5]. Similarly, while medications for primary prevention decrease disease-specific mortality[6], polypharmacy increases risks of weight loss [7], impaired balance[7], and falls [8]. Although such tradeoffs are commonplace, medical decision-making often fails to explicitly incorporate patient preferences.

One way to clarify tradeoffs in decision-making is prioritizing universal health outcomes [9]. Universal health outcomes, such as prolonging life, reducing symptoms, and maintaining independence, provide a common metric across disease-specific outcomes [9]. They are directly impacted by many chronic conditions, suggesting their potential to guide and evaluate treatment in multimorbid patients [10]. Additionally, older adults consider universal health outcomes in treatment decisions and vary substantially in their priorities[11, 12]. While universal outcomes are more commonly evaluated in end-of-life care[13], these also pertain to “everyday” treatment decisions [14].

Methods exist for eliciting patients’ prioritization of universal outcomes, such as decision analytic approaches and multi-attribute theory[15, 16]. However, these methods may not reflect how patients and physicians naturally think about tradeoffs, [12] and can be difficult for older adults to comprehend[17]. The time and training required to administer tools may further contribute to low adoption rates in clinical practice[18]. This suggests the need for simpler tools that more closely mirror how people think about decisions.

This study presents the development of a new tool, the Time and Outcome Preference (TOP) scale, to elicit patient views on universal health outcomes. The scale addresses two common tradeoffs among these outcomes in treatment decisions: 1) quality versus quantity of life, and 2) present versus future health.

METHODS

Participants

Community-dwelling older adults were recruited from three senior centers and an independent/assisted living facility in the New Haven, Connecticut area. Volunteers were solicited through presentations at group events. The only exclusion criterion was a formal diagnosis of dementia, as provided by the assisted living facility’s social worker. The study

protocol was approved by the Yale University School of Medicine Human Investigation Committee.

Scale Development

The authors developed a set of twenty statements to address common tradeoffs based on results from prior qualitative research [12](Appendix) and did cognitive testing with 20 participants to assess understanding and revise items. Participants rated their level of agreement with each statement on a five point Likert scale (Strongly Agree, Agree, Neither, Disagree, and Strongly Disagree). Scoring was reversed for items as necessary so that higher scores indicated greater agreement in the direction of favoring quality of life (QOL) over quantity and present over future health.

Data Collection

Participants completed a face-to-face interview with a trained research associate. The questionnaire collected self-reported information on sociodemographic and health characteristics including gender; race; age; religion; education; health literacy using the seven-item REALM-Short Form (REALM-SF)[19]; chronic conditions; and single-item self-rated health and QOL. All questions, tool scripts, and statements were read aloud by the research associate, and no additional explanations were given for statements.

In the absence of gold standard measures assessing attitudes toward tradeoffs, validity was assessed by using two other new universal health outcome prioritization tools, each addressing one tradeoff. Patients viewed and completed tools on a computer screen. The Health Outcomes tool asks participants to rank four health outcomes on a 100-point visual analogue scale (VAS) [9, 20]. One outcome, “keeping you alive,” corresponds to quantity of life, while “maintaining independence,” “reducing or eliminating pain,” and “reducing or eliminating other symptoms including dizziness, fatigue, and shortness of breath,” correspond to QOL. The Now versus Later tool asks participants to indicate the importance of “My Quality of Life” on two VASs, comparing “now” at one end to 1) “one year from now,” and 2) “five years from now” at the other[21]. The scoring was constructed so that a value of 50 indicated equal importance of current and future QOL, < 50 indicated current QOL was less important than future QOL, and >50 indicated current QOL was more important than future QOL.

Analysis

Item selection for the TOP scale was an iterative process, consisting of multiple rounds of Principal Components Analysis (PCA), in which items with multiple factor loadings and poor loadings (<.40) were removed and analyses were repeated (Figure 1). This process yielded two subscales: 1) quality versus quantity of life, and 2) present versus future health, that are scored as the sum of individual item values divided by the total number of items.

We used medians and interquartile ranges (IQRs) to summarize the subscale scores for the entire cohort because scores were not normally distributed. Discriminant construct validity was assessed with a Spearman correlation coefficient comparing the two subscales. Convergent construct validity was assessed by examining subscale scores according to responses on the other tool addressing a similar tradeoff. We examined scores on the quality versus quantity of life subscale according to participants’ most important Health Outcomes priority. We hypothesized that scores would be lower among participants whose highest ranked outcome was “keeping you alive” versus the other three outcomes related to QOL. We examined scores on the present versus future health subscale according to responses for the Now versus Later tool. We hypothesized that subscale scores be higher among participants with scores of ≥ 50 , indicating prioritization of current QOL over equal to future

QOL, than among participants with scores <50. We used Mann-Whitney U tests to determine the significance of differences in scores. In order to provide a more easily interpretable sense of the magnitude of these differences, we provide mean subscale scores as obtained from T-tests.

Because little is known about characteristics associated with universal health outcome prioritization, we analyzed subscale scores by participant characteristics that have been associated with a similar construct; namely, preferences for quality versus quantity of life in end of life care. Factors demonstrated to be associated with favoring QOL include women[22], older age [23], white ethnicity[24], higher education[22], lower religiosity[25], absence of depression[22], and better functional status[26]. We hypothesized that participants with these characteristics would be more likely to score in the top quartile favoring QOL and present health. The distribution of scale scores did not allow for selecting a cutoff corresponding to precisely 25% of participants; instead, for Subscale 1, scores between 4 and 5 were selected by 37.8%, N=135, and for Subscale 2, scores between 3 and 5 were selected by 28.3%, N=101. We used Chi-squared tests to compare categorical participant characteristics between these groups and the rest of the sample.

Internal consistency was assessed using Cronbach alpha. Test-retest reliability was assessed with intra class correlation coefficients (ICCs) for the first 35 participants, who completed the scale a second time after one week.

RESULTS

Participant Characteristics

Of the 357 participants, three quarters were female and white, with a mean age ($\pm$ SD) of 76 ± 7 . Education was high (mean ($\pm$ SD) 13 years ± 2), as was health literacy with 75% scoring above the 9th grade level. Most of the sample (83%) considered themselves to be deeply or fairly religious. While 69% had four or more chronic conditions, only 26% had one or more IADL disabilities, and 28% reported depression in the past month. Self-rated health and QOL were both high, with just 15% and 10% reporting fair to poor levels respectively.

Items Selection

The final scale after PCA consists of ten items comprising two subscales (Figure 1). Subscale 1, Quality versus Quantity of Life (four items), focuses on tradeoffs among broad health outcome domains occurring in the future, such as living as long as possible, maintaining function, and reducing symptoms. Subscale 2, Present versus Future Health (six items), describes tradeoffs between present inconveniences or adverse effects from treatment and future gains in health. Factor loading ranged from 0.67-0.74 for Subscale 1, and from 0.55-0.79 for Subscale 2.

Subscale Scores

The median score Subscale 1 was 3.8 (IQR 3.0-4.0) indicating agreement with statements prioritizing quality over quantity of life. For Subscale 2, the median was 2.5 (IQR 2.0-3.0), suggesting agreement with statements prioritizing future over present health. Table 1 shows that while the majority of participants fell in the middle of the scale, there was a substantial number at the QOL and future health extremes.

Validity

Low correlation between the two scales supported discriminant validity for the subscales, with a Spearman correlation coefficient of 0.23 (Figure 1).

As hypothesized, the scores for Subscale 1 were significantly higher for participants who selected maintaining independence or reducing symptoms as their most important health outcome versus those who selected prolonging life (Table 2). Subscale 2 scores were significantly higher for participants valuing present health more than or equal to future health on the Now versus Later tool. This difference was seen for both the one and five year items.

Participants were more likely to be in the highest quartile of scores for Subscale 1 if they identified as white versus African American race (44% (N=117/268) vs. 20% (18/89), $p<0.0001$), had education beyond high school versus high school or less (45% (78/175) vs. 31% (57/182), $p=.01$), or were slightly religious, not religious, or against religion versus fairly or deeply religious (52% (32/61) vs. 38% (76/198) vs. 28% (27/98), $p=.01$). Participants were more likely to be in the highest quartile of scores for Subscale 2 if they were white versus African American (32% (86/268) vs. 17% (15/89), $p=.006$). While more adults aged 80 years or older had scores in the highest quartile versus those younger than 80 (33% (41/124) vs. 26% (60/233)), this did not reach statistical significance ($p=.14$). There was no association between subscale scores and gender, number of IADL disabilities, or depression in the past month.

Reliability

Internal consistency was good with Cronbach's α of 0.85 and 0.84 for Subscales 1 and 2, respectively. Thirty-four participants completed the three tools again a week after their first interview. The ICCs for Subscale 1, Subscale 2, and all ten statements were 0.63, 0.47, and 0.47 respectively.

DISCUSSION

This study presents the development of a scale assessing attitudes towards common tradeoffs encountered in medical decision-making among older persons with multiple chronic conditions. The scale responds to a need for a more "common-sense" decision-making tool and was designed to reflect how people naturally think about tradeoffs. Convergent and divergent construct validity were strong, and associations between scores and participant characteristics related to preference for life-sustaining treatment were in the expected direction for race, education, and religious identity. While internal consistency was good, test-retest reliability was modest. Median scores indicated that, among the cohort as a whole, participants agreed with items indicating the importance of quality over quantity of life and future over present health. Despite the narrow IQRs, a substantial number of participants scored at the subscale extremes.

Our analysis is consistent with previous research about the importance eliciting patient attitudes towards health outcome tradeoffs. Starting with the work of McNeil et al [27], investigators have found that many patients prioritize QOL over length of life in decisions involving substantial risks[28]. More recent work suggests that this holds true for decisions about daily management of chronic conditions [29]. Many participants favored future over present health in the second tradeoff, indicating willingness to put up with present burdens to achieve future health gains. This finding might appear inconsistent with people discounting future outcomes in behavioral economics research [30]. However, these studies compare the value of a given health outcome occurring now versus in the future, instead of trading short-term costs for long-term gains. The items included in our scale more directly represent the types of decisions that multimorbid patients face. While it may seem contradictory that an individual would favor both QOL and future health, the two subscales ask participants about very different aspects of QOL. The first subscale includes severe reductions in quality, such as functional disability, that may occur in the future as a

consequence of disease progression. The second asks participants about the typical kinds of immediate adverse consequences that may be associated with treatment of chronic disease.

Overall, many participants sought a balance in both tradeoffs between competing outcomes, as evidenced by the finding that median scores were close to the middle of the response range. Nonetheless, a substantial numbers of participants scored at subscale extremes, demonstrating variability in preferences. These data contrast with implicit assumptions underlying many management decisions and clinical practice guidelines, which maximize length of life or future health without explicitly considering QOL or present health [31]. Variability in patients' priorities suggests a need for multiple treatment options to address chronic disease, each providing a different balance between competing outcomes.

The use of the scale in clinical care and research depends upon a better understanding of the reason(s) for the only modest test-retest reliability. While modest reliability may represent weaknesses in scale construction, it could also reflect improved understanding of the tradeoffs after repeated exposure to the items, which some individuals may not have previously considered [21]. It may also represent evolving values resulting from changes in the individual's health status. Further longitudinal research is necessary to examine differences in health outcome priorities with changes in symptoms, advancing age, disability, and other life experiences. In the meantime, this scale may facilitate conversations about tradeoffs in medical decisions. Presenting multiple statements about tradeoffs can provide an introduction to concepts that patients may find challenging to articulate [21]. Although the scale alone is insufficient to assess patients' choices amongst competing outcomes, it could open a dialogue about values between patients and providers. For example, a patient who experienced significant muscle pain and confusion on a statin could benefit from using the tools to think about balancing these adverse effects on QOL and present health against preventing future complications of hypercholesterolemia.

Responses to the tool items were likely highly dependent upon the specific meaning participants ascribed to the general statements we developed in the attempt to capture broader concepts. Therefore, the provision of different item wording and/or greater specificity in the items may have resulted in different responses. Results may differ among people who chose not to participate in the study, and in groups with more diverse socioeconomic and health characteristic profiles, especially since this sample had relatively high education and self-rated health markers.

The TOP scale provides a valid assessment to capture patient views on two common tradeoffs in healthcare, namely amongst quality and quantity of life, and between present and future health. While its test-retest reliability is below the ideal threshold, its high validity can provide a way to initiate meaningful conversations between patients and providers about competing outcomes.

Acknowledgments

Funding sources: Supported by grant Pioneer 58381 from the Robert Wood Johnson Foundation, and the Claude D. Pepper Older Americans Independence Center at Yale University School of Medicine (#P30AG21342 NIH/NIA). Dr. Fried is supported by grant K24 AG028443. This work was supported by a grant from the Doris Duke Charitable Foundation to the Yale School of Medicine to fund Clinical Research Fellow Siobhan Case.

Appendix 1: Original set of 20 scale statements

1. The most important thing to me is living as long as I can, no matter what my quality of life is.

2. I want to live as long as possible, no matter what condition I might be in.
3. I would rather live a shorter life than lose my ability to take care of myself (daily activities).
4. It is more important to me to maintain my thinking ability than to live as long as possible.
5. If I had to choose between living as long as possible or being free from pain, I would choose living as long as possible.
6. It is more important for me to be as active as I can right now versus being less active now but living longer.
7. I would prefer to take fewer medications now, even if that meant my chances of developing a health problem in the future would be greater.
8. I believe in doing everything possible to lower my risk of dying, even if what I do only changes my risk by a small amount.
9. I am more concerned about my quality of life today than I am about what might happen to me tomorrow.
10. I would prefer to be free from severe symptoms such as shortness of breath, nausea, dizziness rather than living as long as possible.
11. I want to do everything I can to be healthy in the future even if that means giving up things I enjoy now.
12. I would be willing to take as many medications as necessary to help me live as long as possible.
13. I am more concerned with how I feel today than with how I might feel tomorrow.
14. I am willing to have side effects right now if it means I could have a better quality of life in the future.
15. I would prefer to take fewer medications, even if it meant that I would not live as long.
16. I am willing to put up with more doctors' visits and dietary restrictions now if it means that in the future I will be less likely to develop a new disease.
17. I would prefer to have fewer medical tests and doctors visits, even if it meant that I would not live as long.
18. It is more important for me to feel well right now than to feel well in the future.
19. I would prefer to take fewer medications, even if it meant that my chances of dying would be higher.
20. I would want a treatment that would allow me to keep my independence now even if it had a risk of making me more dependent in the future.

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Figure 1.

Factor Analysis. Factor analysis of subscales, including items, factor loading, and Spearman correlation coefficient.

Table 1

Subscale Scores

	Score	Subscale 1: Quality vs. Quantity of Life (N (%))	Subscale 2: Present vs. Future Health (N (%))
1 to 2	8 (2)	60 (17)
	>2 to 3	85 (24)	229 (64)
	>3 to 4	201 (56)	62 (17)
	>4 to 5	63 (18)	6 (2)

Table 2

Subscale scores according to prioritization of Quality versus Quantity of Life and Present versus Future Health

	Tool for Comparison	Comparison Between Competing Universal Health Outcomes	Subscale Score (Mean (95% CI)) *	p-value **
Subscale 1	Health Outcomes	#1 Priority Quantity of Life (Staying Alive)	3.0 (2.8-3.2)	<.0001
		#1 Priority QOL (Maintaining Independence or Reducing Symptoms)	3.6 (3.6-3.7)	
Subscale 2	Now vs. Later at 5 years	Future Health (<50)	2.3 (2.2-2.4)	<.0001
		Equal = Present Health (50)	2.8 (2.7-2.8)	
	Now vs. Later at 1 year	Future Health (<50)	2.4 (2.3-2.5)	<.0001
		Equal or Present Health (50)	2.8 (2.7-2.9)	

*
From T-Test**
From Mann-Whitney U Test