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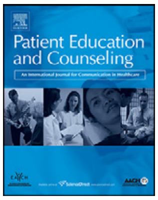

How to ask: Older adults' preferred tools in health outcome prioritization

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ABSTRACT

Objective: To assess older adults' attitudes toward eliciting health outcome priorities.

Methods: This observational cohort study of 356 community-living adults age $\geq$65 included three tools: (1) Health Outcomes: ranking four outcomes (survival, function, freedom from pain, and freedom from other symptoms); (2) Now vs. Later: rating importance of current versus future quality of life; (3) Attitude Scale: agreement with statements about health outcomes and current versus future health.

Results: Whereas 41% preferred Health Outcomes, 40% preferred the Attitude Scale. Only 7–12% rated any tool as very hard or hard. In bivariate analysis, participants of non-white race and with lower education, health literacy, and functional status were significantly more likely to rate at least one of the tools as easy ($p < .05$). Across all tools, 17% of participants believed tools would change care. The main reason for thinking there would be no change was satisfaction with existing care (62%).

Conclusions: There is variability in how older persons wish to be asked about health outcome priorities. Few find this task difficult, and difficulty was not greater among participants with lower health literacy, education, or health status.

Practice implications: By offering different tools, healthcare providers can help patients clarify their health outcome priorities.

1. Introduction

Older persons with multiple medical conditions often face treatment decisions with competing outcomes. Interventions with benefits for one health domain may cause harm in another [1–4]. For example, medications for primary and secondary prevention reduce the risk of individual disease-specific outcomes, but the resulting polypharmacy increases the risk of adverse drug events, balance problems, and weight loss [5]. When faced with competing outcomes, patients' preferences need to guide the decision-making process [3,6]. However, the most effective method to elicit treatment preferences in this population is unclear.

One approach to the elicitation of preferences for persons with multiple conditions is to have them prioritize health outcomes that are applicable across diseases, or universal health outcomes [7]. This approach asks persons to think about which outcomes, encompassing such domains physical and cognitive functioning and life extension, are most important to them both currently and in the future. We refer to this process as "health outcome prioritization." Although several elicitation methods exist for this approach, including decision analytic approaches and multi-attribute theory [8,9], these methods are generally complex, may not be easily understood by older persons [10], and have not been widely adopted in clinical practice.

Developing a tool to elicit treatment preferences requires that the measure be easily understood by and acceptable to patients. Previous research has shown considerable variability in older adults' desired level of involvement in decision-making, or whether they want to be asked. This includes differences in being asked their opinion and their role in making a final treatment decision [11]. However, much less is known about what types of decision-making tools older adults prefer to use, or how they want to be asked. Preference for a tool's fundamental design should be considered, especially given the limited data on what approach is most easily understood and clinically useful for health outcome prioritization. Furthermore, designing tools that recognize patients' feelings about ease of use and expectations for impacting medical care can help anticipate barriers to fuller patient engagement. This type of information is especially important since even when patients desire to be involved in decision-making, they often do not feel empowered to do so [12].

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This exploratory study examines older persons' attitudes toward three different tools to eliciting universal health outcomes. These tools were designed to explore a range of approaches to health outcome prioritization by utilizing both single-item and multi-item questions and different response categories. The main objectives are to assess: (1) participants' preferences for and difficulty with different approaches; (2) relationships between attitudes and sociodemographic and health characteristics; and (3) participants' views of the tools' potential for changing physician care.

2. Methods

2.1. Participants

Three hundred and fifty six persons age 65 and older were recruited for the study from locations selected in order to obtain a socioeconomically and racially diverse population. These included one senior center in an urban, predominately African American community; two senior centers in suburban, predominately white communities; and an independent/assisted living facility with market-rate and subsidized apartments. Participants were solicited by the investigators at events including flu clinics, exercise classes, congregate meals, discussion groups, and presentations. Volunteers did not receive any reimbursement for participation. Exclusion criteria included primary language other than English and, for participants recruited from the housing facility, a diagnosis of dementia provided by the facility social worker. One participant who did not complete the interview was excluded from analysis. The study protocol was approved by the Human Investigation Committee of the Yale School of Medicine.

2.2. Measurements

Participants completed the questionnaire and health outcome prioritization tools with a trained research associate in a face-to-face interview. The research associate used electronic tablets to display the two tools using visual analog scales (VAS) and enter responses.

The questionnaire collected self-reported information on sociodemographic and health characteristics including gender; race; age; education; health literacy using the seven-item REALM-Short Form (REALM-SF) [13]; finances; religion; chronic conditions; functional status based on instrumental activities of daily living (IADLs) [14]; single-item self-rated health and global quality of life (QOL); and depression using the two-item PRIME MD [15].

The tools used for health outcome prioritization address two types of tradeoffs: (1) among different health outcome domains, including between quantity and quality of life, and (2) between current and future health. These tradeoffs stretch across diagnostic labels and are at the core of many treatment decisions, whether addressing primary or tertiary prevention. Furthermore, focus groups suggest that older adults do conceptualize outcomes in this global manner when making treatment decisions [16]. In the absence of prior data on how to best facilitate older persons expressing their health outcome priorities, we developed different types of tools in order to compare their relative ease of use and acceptability. Two of the tools asked participants to do a single-item task, with each task addressing one of the two types of tradeoffs. These tools were based on visual analog scales (VAS) as the response category. The third tool consisted of two multi-item subscales, one addressing each type of trade-off, with responses based on Likert scaling. We describe each of the scales in greater detail below.

The Attitude Scale is composed of a series of statements with which participants are asked to rate the strength of their agreement (Fig. 1). The statements are grouped into two subscales, with one representing each of the two tradeoffs. The health outcome domain subscale includes four statements, for example: "I would rather live a shorter life than lose my ability to take care of myself (daily activities)." The current versus future health subscale includes six statements, for example, "I am willing to have side effects right now if it means I could have a better quality of life in the future". The Now vs. Later tool asks participants to assess the relative importance of quality of life now, versus at one year and at five years in the future on a VAS (Fig. 2). Participants moved a bar along a 100-point horizontal axis, anchored by "quality of life now" at one end and "quality of life 1(5) years from now" at the other. The Health Outcomes tool asks participants to rate the relative importance of four universal health outcomes (survival, function, freedom from pain, and freedom from other symptoms) on a vertical VAS from 0 to 100 (Fig. 3). It has previously been piloted with older adults [17].

After using each of the tools, participants were given a series of questions. To assess difficulty, participants were asked, "How difficult were these questions?" with a five-point Likert response scale ranging from "very easy" to "very difficult," followed by an open-ended "Why?" question. Participants were then asked, "Do you think this tool would change the way your physician cares for you?" with response categories of "yes," "no," or "don't know," again followed by a "Why?" question for an open-ended response. Finally, participants were asked, "Of the 3 exercises which one did you like best?" after using all three tools.

2.3. Analysis

Participant characteristics were described using univariate statistics. Relationships between participants' preferred tool and health and sociodemographic characteristics were analyzed in bivariate analysis, using the chi-square test.

Qualitative data from the two open-ended questions on difficulty and changing care were coded using content analysis, to create a taxonomy suitable for quantitative analysis [18]. Codes were generated inductively, using repeated rounds of coding to generate and refine taxonomy. Each response received a single code from the primary coding category to facilitate subsequent analysis. Codes were assigned hierarchically when a single answer contained more than one idea, with the goal of selecting the participants' most specific critical or negative comment about the tools. The hierarchy included coding difficulty over ease, comments related to specific aspects of the tools over comments related to the more general task of prioritization, and the most detailed categorization possible. A secondary code category was developed for concepts that were not the primary focus of a comment and occurred infrequently, but represented strong emotional and religious responses of individual participants to the content of the tools. Because the secondary codes were infrequent, they were analyzed as number of responses rather than proportions. To assess coding reliability, two investigators independently coded a 10 percent sample of responses, compared and discussed results, and repeated this process until reaching greater than 80 percent agreement for each of the difficulty and changing care responses. A single researcher coded the remaining responses.

Qualitative difficulty codes were organized into a three-point scale of Easy, Neutral, and Difficult. To facilitate comparison with the quantitative difficulty ratings, the quantitative difficulty scale was collapsed into "Easy/Very Easy", "Moderately Hard," and "Hard/Very Hard." Correlation between these scales was assessed using the Spearman correlation coefficient. Differences in quantitative and qualitative difficulty among the three tools were assessed using a chi-squared test.