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Expectations Regarding Aging Among Older Adults and Physicians Who Care for Older Adults

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BACKGROUND. Understanding older adults' expectations regarding aging is important for both clinicians and policy-makers.

OBJECTIVES. 1) To identify the content for a survey to measure expectations regarding aging; 2) to qualitatively compare older adults' and physicians' expectations regarding aging.

SETTING. Three senior centers and one university-based internal medicine faculty practice.

PARTICIPANTS. Forty-nine adults (mean age 78 years); 11 primary care clinicians (mean age 37 years).

MEASUREMENTS. A facilitator conducted five focus groups of older adults and two of physicians using a standardized script designed to elicit expectations regarding aging. Qualitative analysis by two independent reviewers identified domains of expectations, with a 3rd reviewer used to resolve discrepancies. A corresponding coding scheme was applied to each line of the transcripts. Content and frequency of expectations regarding aging and beliefs regarding care seeking were examined and compared.

RESULTS. Content analysis identified 26 domains of expectations regarding aging. Each of the seven most frequently mentioned domains of expectations was mentioned by at least 50% of participants. Of 760 unique statements coded, the most frequently described domains in both the older adult and physician groups were physical function, cognitive function, social function, pain, and sexual function. Older adults differed from physicians by describing five mental-health related domains: anxiety, emotional-well-being, happiness, sleep, and length of life/death.

CONCLUSIONS. Using focus groups of older adults and physicians, we identified consistent content for a closed-ended patient-centered survey to measure expectations regarding aging. Further study should determine whether physicians address mental health aspects of aging valued by older persons.

Key words: Aging; focus group; expectations; attitude to health; care-seeking. (Med Care 2001;39:1025–1036)

Historically, conditions such as functional impairment and cognitive decline were considered to be part of normal aging. More recently, however, researchers have shown that these and other

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age-associated conditions are not an inevitable part of the aging process.[1,2] In a landmark paper in 1987, Rowe and Kahn pointed out that many age-related changes regarded as normal aging are preventable;[3] they proposed the model of "successful aging" as an alternative to "usual" aging. This model includes three main components: low probability of disease and disease-related disability, high cognitive and physical functional capacity, and active engagement with life.[4] A greater percentage of older adults are living up to this model, and succeeding at living independently and without disabilities.[1,5]

The extent to which older adults embrace this model of successful aging remains unclear, however. Unfortunately, chronic disease and disability continue to serve as significant challenges for most older adults, with approximately 80% of people older than age 65 having at least one chronic health condition,[6] and more than 20% living with disability.[5] As many as 60% of older adults attribute health conditions and disability to old age itself.[7,8,9] One concerning question this raises is whether physicians trained to promote the function-oriented model of successful aging are equipped to address the expectations and goals of older adults who do not expect to "succeed" on these terms.

Because older persons' medical care involves shared decision-making with physicians, it is essential that physicians understand older adults' expectations regarding aging. Unfortunately, physicians often fail to understand patients' values and beliefs;[10,11] discrepancies between patient and provider values may be exaggerated when patients have disabilities or chronic medical conditions.[12] Illuminating older adults' actual expectations regarding aging and beliefs regarding health-care is thus a critical prerequisite to: 1) enabling patients and their physicians to establish mutually-agreed-upon goals of successful aging that will influence treatment decisions; and 2) designing health care policies that will enhance the aspects of life most valued by older adults.

As an initial step in understanding older adults' expectations regarding aging, we set out to: 1) identify appropriate content for a survey to measure expectations regarding aging that would be meaningful to older adults with diverse characteristics; and 2) qualitatively compare older adults' expectations regarding aging and beliefs regarding health-care-seeking for age-associated conditions with those of physicians who care for older adults.

Methods

Decision to Use Focus Groups

Our objective—identifying expectations regarding aging and beliefs regarding health-care seeking for age-associated conditions among older adults—was exploratory by nature, and thus required a qualitative data-generating format. A focus group is a planned discussion designed to obtain perceptions on a defined area of interest in a permissive, nonthreatening environment.[13] Unlike in qualitative interviews, in focus groups participants influence each other by responding to ideas and comments in the discussion. This format has proven successful for identifying perceptions among older adults on many previously unexplored topics,[14,15,16] and was well-suited to our objectives.

Study Population—Older Adults

To identify expectations and beliefs held by older adults with varying perspectives, we recruited participants from multiple settings to ensure participant diversity in terms of ethnicity and socioeconomic status. We chose to recruit many participants from senior centers so that our sample would not consist exclusively of older adults receiving regular health care. With the assistance of the City of Los Angeles Department on Aging, we identified three community-based senior centers in different geographic regions. Each provides low-cost hot meals to low-income seniors. Because the project's resources did not allow for non-English translation, we selected centers in which most clients spoke English. Though we did not plan to segregate groups by race/ethnicity, because the senior centers served primarily a single racial group, groups based at senior centers were either 100% black (one group) or 100% white (two groups). Likewise, though we did not deliberately segregate by socioeconomic status, one of the senior centers was located near a more affluent part of Los Angeles, and in general served white participants with greater financial resources. At each senior center, we worked with staff to recruit volunteers willing to participate in one of the 90-minute focus groups held at the senior center. We also recruited volunteer participants from the UCLA geriatrics clinic, which serves a largely middle and upper income mostly white popula-

tion. To recruit participants for these focus groups, we telephoned patients who were identified by their geriatricians as potentially eligible; 80% of those telephoned agreed to participate. Eligible participants needed to be at least 65 years old, speak English, and not have hearing impairment or dementia so severe as to preclude meaningful participation. Participants recruited at UCLA were offered transportation. In addition, older adult participants were paid a small honorarium.

Study Population—Physicians

Full-time primary care clinicians in the UCLA Divisions of Geriatrics and General Internal Medicine were sent letters inviting them to participate in one of two 90-minute focus groups at the UCLA Medical Center. Physician participants were given lunch and paid a small honorarium.

Development of Focus Group Script

To explore: 1) whether we could successfully initiate discussion with older adults concerning expectations regarding aging; and 2) the manner in which older adults conceptualize and verbalize expectations regarding aging; we conducted six face-to-face structured open-ended qualitative interviews[17] with community-residing older adults from a variety of socioeconomic and demographic backgrounds referred by gerontologic researchers we consulted. The interviewer (CS) took notes, and an iterative process was used to modify subsequent interviews to incorporate language and examples of expectations regarding aging elicited during early interviews. Notes from these interviews were used in conjunction with knowledge of the literature on successful aging[18–27] to develop a draft focus group script, which included: 1) open-ended questions asking patients to describe "things that you expect to occur when you get older"; and 2) six vignettes describing older adults experiencing age-associated changes (such as forgetfulness, functional decline, and wisdom) with follow-up probe questions. This draft script was reviewed by the project psychometrician (RH) and sociologist, and revised. The script was pilot-tested in one senior center-based focus group of older women (n = 12); a professional focus group researcher with more than 20 years of experience leading focus groups (SB) led this group. After reviewing the transcripts from this focus group, the study team decided that the open-ended questions were occasionally confusing to participants, but that the vignettes succeeded in eliciting expectations regarding aging; therefore, the script was revised to include 10 vignettes describing older adults experiencing common age-associated changes. Each vignette was followed by probes asking whether: 1) the scenario described changes expected to occur with aging; and 2) one would seek medical care if these changes occurred (Appendix A).

Conducting the Focus Groups

For this study, we conducted seven focus groups: three of older men (n = 25), two of older women (n = 13), and two of male and female physicians who care for older adults (n = 11). Due to the sensitive nature of some topics addressed (incontinence, sexuality), we segregated groups of older adults by gender to increase the likelihood that participants would feel comfortable participating in the discussion. Before the start of each focus group, participants provided written documentation of informed consent, and completed brief demographic questionnaires. Older adults also completed a questionnaire asking whether they were able to independently carry out the 13 activities from the Katz Basic[28] and Lawton Instrumental Activities of Daily Living Scales.[29] A trained facilitator led each focus group using techniques to ensure that no single person dominated the discussion and that each person was heard from. To supplement the data generated by the vignettes, approximately 15 minutes before the end of the focus group the facilitator asked if there were any other expectations people had regarding their aging process that had not come up. The script was uniform across all older adult and physician groups except that the woman depicted in a scenario about urinary incontinence was modified to be male in the all-male groups. All groups were audiotaped and transcribed. Each time a participant spoke, the moderator softly stated the speaker's first name into a private microphone; the transcriber participant could thereby link 99.6% of statements to an individual. Transcripts were reviewed for accuracy and distributed to each member of the study team.

Coding of Transcripts

Because our objective was to identify older adults' expectations regarding aging and to examine whether providers are in agreement with these expectations, we used the five older adult-group transcripts to identify domains for coding, and then used the same coding template for all seven transcripts. To identify the domains of expectations regarding aging which would be used for the coding template, two investigators (CS, CM) independently reviewed the five transcripts from the older adult groups and made a list of each domain of expectations regarding aging described. The lists were compared; where the lists disagreed, a third investigator who had also reviewed the transcripts (RH) was called upon to cast a tie-breaking vote. Using these agreed-upon domains as a template, a trained data specialist then read through each line of all seven transcripts and recorded each comment made pertaining to expectations regarding aging. The investigators provided the data specialist with a detailed description of each domain to guide her coding (available from the authors by request). She recorded: 1) the primary domain being described by the comment; 2) whether the comment was addressing an increase or a decrease in this domain; 3) whether the person commenting stated that this was something one would expect to occur with aging or not; and 4) whether the person commenting stated that this was something for which one would or should seek medical care. For example, the comment: "I think walking more slowly is just something that happens naturally when you get old; why should you go see a doctor?" would be coded as: 1) domain "physical functioning"; 2) declining; 3) yes—expectation of aging; 4) no—seeking medical care. To assess the reliability of this coding scheme, a randomly identified 5% of the transcript lines were also independently coded by one of the investigators (CS). The percentage of time that a statement was classified into the same domain by both the trained data specialist and the investigator was calculated for the random 5% of transcript lines.

Analysis

To determine which domains of expectations were mentioned most, unadjusted frequencies of comments made pertaining to expectations regarding aging were calculated. We ranked each domain by the frequency of mention by all participants, and separately by older adults and by physicians. In addition, to examine whether similar results were obtained across groups, we examined group-level rankings of the top five most frequently mentioned domains for older adults and physicians overall.

To determine whether one survey could address the expectations regarding aging of older adults of varying age, ethnicity, and functional status, we calculated the number and percent of participating individuals who addressed each of the 15 most frequently mentioned domains of expectations regarding aging.

To examine the extent to which each of the identified domains of expectations regarding aging were felt by participants to represent something people actually expect to occur with aging, for both older adults and physicians, we calculated the ratio of the number of participants stating that each domain was an expected part of aging versus the number of participants stating that the domain was *not* an expected part of aging. Individuals who did not comment on a particular domain were not included in that domain-specific analysis. Likewise, to examine beliefs regarding health-care seeking, we calculated the ratio of the number of participants stating that the domain was something for which health care should be sought versus the number of participants stating the domain was something for which health care should *not* be sought. The domain-specific ratios of statements by older adults and physicians were examined and compared qualitatively.

Results

Characteristics of the 49 focus group participants are shown in Table 1. The mean age of participants in the older adult focus groups was 78 years; the range was between 65 and 91 years. Close to half of older adults reported at least 1 disability: 16% reported one disability, 8% reported two disabilities, and 21% reported three or more. Physician participants had a mean age of 37 years; the range was between 30 and 51 years.

We identified 26 domains of expectations regarding aging addressed by focus group participants. These domains are listed in Table 2, along with verbatim examples of comments corresponding to each domain. Qualitative content analysis of