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Development and Testing of a Frailty-focused Communication (FCOM) Aid for Older Adults

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Abstract

The concept of frailty as it pertains to aging, health and well-being is poorly understood by older adults and the public-at-large. We developed an aging and frailty education tool designed to improve layperson understanding of frailty and promote behavior change to prevent and/or delay frailty. We subsequently tested the education tool among adults who attended education sessions at 16 community sites. Specific aims were to: 1) determine acceptability (likeability, understandability) of content, and 2) assess the likelihood of behavior change after exposure to education tool content. Results: Over 90% of participants “liked” or “loved” the content and found it understandable. Eighty-five percent of participants indicated that the content triggered a desire to “probably” or “definitely” change behavior. The desire to change was particularly motivated by information about aging, frailty and energy production. Eight focus areas for proactive planning were rated as important or extremely important by over 90% of participants.

Keywords

Aging; Frailty; Prognostication; Decision aid; Communication

Introduction

Frailty is a state of vulnerability to intrinsic and external stressors and a primary marker of biologic aging.^{1,2} As humans age, the body experiences a slow and gradual loss of the ability to generate energy to sustain itself,³ characterized by increasing functional limitations and other chronic health conditions.^{4,5} Although frailty affects one of six community-dwelling older adults (age 65) globally,⁶ frailty and subsequent disability is the leading cause of mortality.^{7–9} Moreover, frailty accounts for a disproportionate percentage of hospitalization days and health care spending.^{10,11} Frailty is a major turning point for aging

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adults and recent publications have called for integration of the concept of frailty into clinical practice and for proactive interventions to mitigate trajectories of frailty to preserve independence, physical function and cognition.^{6,12,13} Age-related decline in skeletal muscle is detectable in the fourth decade of life and accelerates after age 50.¹⁴ Experts advocate for earlier interventions that empower individuals with knowledge to take responsibility for their health status and for nurses and other health care providers to facilitate proactive planning regarding counteractive strategies that mitigate frailty.^{1,15}

While the word “frailty” is familiar to most people, the concept of frailty as it pertains to aging, overall health, and well-being, is poorly understood by older adults and the public-at-large.^{16,17} Most people are unaware of the vulnerability associated with frailty since few, if any, resources exist to educate the public about frailty.¹⁶ Resources related to “healthy aging” or “successful aging” are insufficient because they fail to educate on the biological links between aging and frailty and the life course reality that aging eventually leads to end of life.^{18,19} As individuals age, this lack of understanding is a barrier to behavior change that could prevent or delay frailty, or mitigate untoward outcomes (i.e. falls, futile/aggressive medical care).^{20,21} Recommendations to advance understanding of how aging leads to frailty include the use of general prognostic information about frailty and communication strategies that focus on the lifespan or reframing aging using a life course perspective.^{22–24} In response to these recommendations, we developed a novel aging and frailty education tool for use with primarily older adults, recognizing that other age groups might find it useful. We wished to increase awareness and risk perception about aging and frailty, but also the inevitability of death. We wished to present measures that individuals could implement to mitigate frailty and poor outcomes and to increase readiness for eventual end of life. After the development phase, we tested the education tool, *Aging: Important Things to Know* in a convenience sample of community-dwelling adults. We aimed to: 1) determine acceptability (likeability, understandability) of the education tool content, and 2) assess the likelihood of behavior change after exposure to education tool content. We hypothesized that the education tool would be acceptable in at least 80% of the sample, and that over 70% of all age groups would report probable or definite likelihood of engaging in behavior change. The following sections report on the development and subsequent testing of our novel education tool.

Aging and frailty education tool development

The aging and frailty education tool was designed for use with adults across the aging/frailty continuum from non-frail to frail. Development was guided by the International Patient Decision Tools Standards (IPDAS) collaboration guidelines.^{25,26} Content of the tool was derived from a step-wise process undertaken to develop a lay-friendly booklet that could be given to adults at all ages in multiple settings to change awareness about aging that could lead to improved decision-making. First, relevant literature addressing best communication practices to facilitate goal-concordant care with adults was reviewed, including the use of visual prognostication tools.^{23,27–30} Second, a panel of ten experts in trauma care, palliative care, patient-centered communication and geriatrics provided input on initial education tool content. Third, group engagement sessions were held with frail and non-frail community-dwelling older adults (N=16) and detailed feedback was obtained on wording of content, as

well as pictures and graphics. Fourth, an initial draft was evaluated by the Vanderbilt Center for Effective Health Communications (VCEHC). Validated instruments were utilized to assess suitability, understandability, and actionability of the tool.

The Suitability Assessment of Materials (SAM)³¹ for evaluation of health-related information for adults was designed to assess the following domains: content, literacy demand, graphics, layout and type (font), learning stimulation and motivation, and cultural appropriateness. The Patient Education Assessment Tool for Printable Materials (PEMAT-P)³² was designed to evaluate understandability and actionability of communication materials. Supplementary Material A provides a summary of the VCEHC assessment from these instruments as pertaining to the tool. Based on recommendations, we modified the content and developed a prototype aging and frailty education tool (booklet) for pilot testing.

Aging and Frailty Education Tool (booklet)

The prototype version of the aging and frailty education tool (Supplementary Material B) titled, “Aging: Important Things to Know,” begins with an introduction to the word “frailty” followed by information about the association of frailty in older adults with falls and outcomes (functional decline, mortality). Prognostic information about frailty, injury and one year outcomes is presented in tested pictographs³³ with simple explanations. Following the prognostic information, frailty is described in terms of “energy” needed for strength and endurance. The link between physical activity and energy availability is depicted in pictures and layperson language. Possible aging pathways are shown and a dotted line illustrates how a person can improve expected decline to a more steady state to prevent and/or delay frailty. The next section points out that all aging pathways eventually come to an end and labels the final phase of life as a time for *anticipatory care* and planning. Common emotions and symptoms in the final phase of life are described, highlighting that when adults are able to contemplate the final phase of life, they often live longer and experience a higher quality of life. The final section of the aging and frailty education tool pivots to eight evidence-based focus areas for proactive planning related to aging^{34–36} modeled after the Wheel of Health successfully used in other patient-centered interventions.^{37,38} Focus areas include safety, food and nutrition, physical activity, relationships and community, sleep and rest, health care decisions (i.e., advance care planning), finances and aging, and mind/body health. The aging and frailty tool (booklet) concludes with a page for the reader to rate his/her current satisfaction level with each focus area. Individuals may choose to set goals in one or more areas for tailored proactive planning. This approach was adapted from the literature on health and wellness coaching and patient-centered processes based in behavior change theory.^{39,40}

Innovation: Our aging and frailty education tool is novel in two distinct ways. First, aging is presented from a life course perspective that includes proactive measures for early planning, but also includes a snapshot of what one might expect (emotions and symptoms) in the final phase of life.⁴¹ This section is designed to normalize aging and end of life, and emphasizes the importance of readiness and maintenance of dignity.⁴² We utilize the term “anticipatory care” to encourage individuals to contemplate their mortality and their care needs and preferences in the final phase of life.^{43–45} Second, since the underlying biology of

frailty begins years before frailty physically manifests, we incorporated a section on mitochondria or “energy engines,” and we explain that energy engines can be renewed through physical activity.^{46–48}

Methods

Participants

The study was conducted at local community sites via education sessions targeted to older adults (e.g., senior centers, senior adult church groups). We were primarily interested in older age groups and aimed to obtain a sample of at least 75% of participants age 55 and 50% of participants age 65. Attendees who were younger than age 55 were allowed to participate in the study because the tool could also have value to younger age groups.

Data Collection

A self-administered questionnaire was utilized to collect study measures. Measures: a) Demographics included age, gender, race, level of education and household income. b) Baseline understanding of frailty (prior to the session) was assessed with a single question about prior understanding of frailty. Participants indicated “no understanding,” “some understanding,” or “a lot of understanding.” c) Measures of acceptability (likeability, understandability) were assessed via 4-point Likert scales. d) Likelihood of behavior change was assessed through two questions: 1) How much did the information make you want to make a plan <change behavior> to address aging and frailty? (5-point Likert scale), and 2) which part of the program influenced your <behavior change> decision? e) Importance of content focus areas was assessed on a 4-point Likert scale ranging from “not important” to “very important.” f) Interest in health coaching to facilitate behavior change was assessed with a final “yes/no” question. The question about health coaching was for information purposes only and participants were not offered health coaching after the sessions.

Procedure (Aging and Frailty educational sessions)

A flyer was provided to each facility in advance containing the title and a brief description of the presentation, as well as the scheduled date and time of the session. The principal investigator (PI) presented each educational session in a standardized format using PowerPoint™. Four content areas of the education tool were presented, including: 1) frailty and falls, 2) frailty and outcomes after an injury (fall) (prognostic information), 3) frailty and energy production, and 4) making a plan to address aging and frailty. The presentations lasted 25 to 30 minutes. Participants could ask questions during and after the presentation. Questionnaires were distributed immediately after each presentation for self-administration. To encourage completion of the questionnaire, the PI guided participants through each section by reading each question aloud and allowing time for participants to complete each item. Questionnaires were anonymous; a research assistant collected completed questionnaires at the end of each session.

Data analysis—IBM SPSS Statistics (version 26) was used for analysis. With exception of years of age (mean, SD), all other study variables were summarized using frequency distributions. Cross tabulations of those distributions, along with graphical methods, were

used to illustrate patterns in the participant responses by subgroups (e.g., age groups). Tests of differences in those patterns used Chi-Square tests of independence maintaining a Type I error of .05 ($p < .05$).

Results

Aging and frailty presentations were held at multiple types of settings. The majority of participants attended sessions at senior centers (41.3%, $n=86$), churches (19.7%, $n=41$), and income-supported senior apartment communities (12.0%, $n=25$). Other sites included two YMCAs (6.7%, $n=14$ of 208), a hospital (6.3%, $n=13$ of 206), a library and an academic setting (13.9%, $n=29$ of 208). Participant characteristics are summarized in Table 1. The mean age was 65.4 years ($SD=14.8$) with 78.2 % ($n=161$ of 206) being 55 years or older and 59.7% (123 of 206) 65 years or older. Of the participants providing information, 87.2% ($n=133$ of 170) were female, 24.0% ($n=35$ of 146) were Black or African American, and approximately a third had 12 years of education or less (32.2%, $n=46$ of 143, see Table 2).

Most of the participants reported at least some understanding of the concept of frailty prior to the presentation (95.0%, $n=191$ of 201). As summarized in Table 2, most of the participants (89%) indicated that they “liked” or “loved” each of the four education content areas (Falls: 89%, 178 of 199; Injury: 93%, 184 of 198; Energy production: 94%, 182 of 194; Making a plan: 92%, 178 of 194). Similarly, more than 90% reported that the content was “Understandable” or “Easily understandable” (Falls: 92%, 183 of 200; Injury: 93%, 183 of 196; Energy production: 91%, 181 of 198; Making a plan: 94%, 182 of 194). Furthermore, as shown in Figure 1, each of the eight focus areas for making a plan related to aging and frailty were rated as “Important” or “Very Important” by more than 87% of the participants providing a rating. The area with the lowest ratings of importance was “Finances” with 11% (13 of 117) reporting feeling it was either “Not Important” or “Felt Neutral”.

In terms of likelihood of engaging in behavior change, approximately a third of the participants 65 years or older reported that they were already doing all that they could do (65–74: 33%, $n=21$ of 64; 75+: 35%, 19 of 55). In contrast, less than 20% in the younger age groups made such a report (<45: 14%, 3 of 22, 45–54: 17%, 4 of 23; 55–64: 18%, 7 of 38). Of the participants who did not report doing all they could, 85% (127 of 149) reported that the content triggered a “probable” or “definite” desire to make a personal plan for aging (probable: 24%, 36 of 149; definite: 61%, 91 of 149). As illustrated in Figure 2, within that subgroup, the percentages for triggering possible change were highest for those in the younger age groups (<65 years: 90–95%) with the percentage decreasing to 75–80% for the older groups of participants (see Figure 2). Of the 126 participants who indicated that the content triggered a possible change and provided information about the specific areas, the highest percentage (68%, 85 of 126) reported that the area of “Energy Production” was influential. “Making a Plan” was next with approximately half reporting it was influential (48%, 60 of 126), followed by the other two areas at approximately 25% (“Falls”: 25%, 32 of 126; “Injury”: 23%, 29 of 126). As illustrated in Figure 3, the influence of the “Energy Production” content was statistically significantly higher in the younger age groups than it was in the older ages ($p = .024$). Eighty-eight percent of those <45 years of age (15 of 17)

reported that area influenced their decision while slightly less than half of the oldest age group reported such (75+: 46%, 13 of 28). While not statistically significant, there was an apparent increase in the influence of the “Making a Plan” area with increasing age (< 45: 35%, 6 of 17; 75+: 57%, 16 of 28, $p = .547$).

A final question asked if the participant had the opportunity to receive coaching about establishing a plan for aging and frailty, would they take the opportunity. Of the 171 participants who responded, 66% ($n=113$) indicated that they would take advantage of such an opportunity if available.

Discussion

Our aging and frailty education tool is an age-friendly resource for older adults to gain understanding about the aging process. It is also a tool that health care providers could utilize to talk to adults of all ages about aging to facilitate behavior change. Preliminary testing of the education content shows promise for its use as an intervention to influence behavior in all age groups, suggesting increased awareness about why we become frail triggers the need to address aging trajectories earlier in the life course. In terms of older adults, this study and prior work by this team demonstrates that older adults are surprised but welcoming of information about aging and frailty because they are able to relate the information to personal observations about themselves, family and friends.^{16,33} Participants indicated that the section on frailty and energy production helped in changing their awareness about the link between physical activity, a healthy lifestyle and the risk for health decline and development of frailty. Not surprising, attendees under the age of 55 (23%) also had positive responses to the aging and frailty content, indicating potential value as a tool to encourage contemplation of aging earlier and before aspects of aging become harder to imagine and harder to bear.⁴⁹

Study results indicate that a better understanding of “why” humans become frail in relationship to the body’s ability to make energy triggers a desire to change behavior as it related to physical activity. This underscores the importance of interactive health literacy, whereby individuals extract information and derive meaning that translates to recognition of the need to change behavior.⁵⁰ Our findings link interactive health literacy with behavior change theory that describes advancement in readiness for change from pre-contemplation to contemplation or planning.⁵¹ This was particularly apparent in middle age groups (45–54, 55–64) indicating that individuals comprehend that they can influence their own course of aging through proactive planning, physical activity and other focus areas described in the education tool. Higher ratings suggest that younger age groups perceive that they still have the time and ability to make lifestyle changes. Although a greater percentage of older age groups (65–74, 75+) tended to feel that they were “already doing all they could” as it related to their lifestyle (e.g., nutrition, physical activity, community), 75% to 80% still reported probable or definite likelihood to change behavior. Moreover, high ratings for health care decision-making as an area for proactive planning suggest that inclusion of advance care planning (ACP) as one of several focus areas is regarded as an important consideration in planning for aging and frailty. Earlier discussions about ACP may normalize the ACP process vs. waiting until end of life is imminent to broach the subject. Longitudinal studies

are needed to determine if the desire to change (contemplation, planning) based on a heightened understanding of aging and frailty leads to actual behavior change (action, maintenance) over time, such as improvements in nutrition, physical activity, community engagement and/or advance care planning (i.e., anticipatory care).

Regarding the aging and frailty education tool focus on anticipatory care and trajectories of aging that lead to end of life, recent publications call for greater public awareness that frailty and dying are normal final stages of life.^{1,18,52–54} The tool promotes a life course perspective acknowledging that life eventually comes to an end for everyone, but that individuals who contemplate their aging, vulnerability and mortality experience a higher quality of life and better deaths than those who don't.^{55,56}

Strengths and Limitations

Although the study had a relatively small sample size, the sample was diverse in terms of gender, race, and socioeconomic status, and we collected data from a diversity of sites, including YMCAs to income-assisted housing. In terms of limitations, missing data was a major flaw and our results could reflect non-response bias. Our questionnaire was self-administered and we did not track, observe and facilitate completion by all participants. Another limitation was the small sample of adults in the 85+ age category (n=9, 4.4%). We also did not follow participants longitudinally to determine the extent to which they implemented change in the eight focus areas of the aging and frailty education content. Future work should include more “old, old” adults and address impact of the education tool on outcomes. Finally, since participants were a convenience sample of English-speaking adults, testing of the tool among ethnically diverse older adults is warranted.

Next steps include testing the education tool in different populations, communities and clinical settings (hospital and primary care) and assessing the influence of the education tool on lifestyle behavior change, advance care planning and goals of care discussions, and well-being. We also intend to develop training workshops for nurses and other health care providers on aging and frailty to empower them to hold discussions with patients about aging and frailty and to facilitate creation of specific plans to prevent frailty and to mitigate untoward outcomes.

Population aging is a public health crisis and earlier interventions that educate about the aging process are warranted. Change is needed in how clinicians, administrators and health care settings address aging, frailty, and end of life. Contemplating aging with an understanding of frailty and a broader perspective about end of life can empower older adults to manage their personal trajectories of aging, preserve dignity, and restore the significance of a life well lived.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Highlights

- The concept of frailty as it pertains to health/well-being is poorly understood by older adults despite the eventuality of frailty in many who reach advanced age.
- A developed/tested frailty-focused communication (FCOM) aid advances layperson understanding of frailty and changes awareness that may lead to behavior change.
- Information about frailty, in particular how the body makes energy, increases awareness about the importance of physical activity, a healthy lifestyle and the risk for health decline and development of frailty.

Figure 1.
Summaries of the ratings of importance of each aging & frailty education content area.

Figure 2.

Desire to make a plan for aging based on aging and frailty education content for the subsample not already doing what they can by age group (N=147)

Figure 3.

Influence of each area with aging and frailty education content toward desire to make a plan for the subsample not already doing what they can by age group (N=124)

Table 1.

Characteristics of aging and frailty presentation participants (N=206)

Characteristic	Mean (SD)
Age (years)	65.4 (14.8)
Age group (years)	N (%)
< 45	22 (10.7)
45–54	23 (11.2)
55–64	38 (18.4)
65–74	64 (31.1)
75–84	50 (24.3)
85 +	9 (4.4)
Gender	
Female	133 (64.6)
Male	37 (18.0)
Missing data	36 (17.5)
Income	
< \$10,000	3 (1.5)
\$10,000 – 25,000	39 (18.9)
\$25,000 – 60,000	30 (14.6)
\$60,000 – 100,000	26 (12.6)
> \$100,000	22 (10.7)
Missing data	86 (41.7)
Race	
White	104 (50.5)
Black	35 (17.0)
Other	7 (3.4)
Missing data	60 (29.1)
Education (years)	
< 12	13 (6.3)
12	33 (16.0)
13 – 16	70 (34.0)
> 16	27 (13.1)
Missing data	63 (30.6)

Table 2.

Summaries of the acceptability of the education tool content (N=206)

Falls			
	N (%)		N (%)
Did not like	3 (1.5)	Did not understand	2 (1.0)
Liked a little	18 (8.7)	Understood a little	15 (7.3)
Liked a lot	131 (63.6)	Understood	71 (34.5)
Loved	47 (22.8)	Easily understood	112 (54.3)
Missing data	7 (3.4)	Missing data	6 (2.9)
Injury			
Did not like	3 (1.5)	Did not understand	5 (2.4)
Liked a little	12 (5.8)	Understood a little	8 (3.9)
Liked a lot	132 (64.1)	Understood	71 (34.5)
Loved	52 (25.2)	Easily understood	112 (54.4)
Missing data	8 (3.9)	Missing data	10 (4.9)
Energy Production			
Did not like	4 (1.9)	Did not understand	4 (1.9)
Liked a little	8 (3.9)	Understood a little	13 (6.3)
Liked a lot	111 (53.9)	Understood	68 (33.0)
Loved	71 (34.5)	Easily understood	113 (54.9)
Missing data	10 (4.9)	Missing data	8 (3.9)
Making a Plan			
Did not like	2 (1.0)	Did not understand	3 (1.5)
Liked a little	14 (6.8)	Understood a little	9 (4.4)
Liked a lot	106 (51.5)	Understood	70 (34.0)
Loved	72 (35.0)	Easily understood	112 (54.4)
Missing data	12 (5.9)	Missing data	12 (5.9)