

PREVENTING CHRONIC DISEASE

PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY



*PCD Collection:
Healthy Aging*



Throughout the world, public health workers conduct research and implement programs and policies to improve the health and well-being of communities. Public health professionals have different backgrounds and areas of expertise that are all important to the success of this effort. In addition to traditional public health workers, community members and professionals from other sectors are often engaged in improving public health. The goal of public health professionals and their engagement with partners and stakeholders is to reduce disease and premature death and to help all people achieve optimal health. *Preventing Chronic Disease: Public Health Research, Practice, and Policy (PCD)* recognizes the importance of bringing the experience and perspective of diverse public health professionals together to examine and improve health.

Successful interventions, programs, and policies must be followed by publication to achieve their full public health impact. Publication is necessary to share successes and challenges and facilitates widespread implementation and adoption to multiple settings. *PCD* is dedicated to reporting practical scientific research, programs, and policy efforts to improve the health of communities. Our articles advance current knowledge and contribute to the welfare of people beyond the interventions they describe. Advances in technology have helped to turn this knowledge sharing into a fast-paced, dynamic, and global collaboration. We hope this collection of previously published research informs and inspires all readers — researchers and community members, practitioners and patients, experts and novices — to implement science-based interventions with community-based preferences that improve the health of all populations. We encourage you to share your work by publishing in *PCD*.

Samuel F. Posner, PhD
Editor in Chief
Preventing Chronic Disease

Preventing Chronic Disease

Preventing Chronic Disease (PCD) is a peer-reviewed electronic journal established to provide a forum for public health researchers and practitioners to share study results and practical experience. The journal is published by the National Center for Chronic Disease Prevention and Health Promotion.

The mission of the journal is to address the interface between applied prevention research and public health practice in chronic disease prevention. *PCD* focuses on preventing diseases such as cancer, heart disease, diabetes, and stroke, which are among the leading causes of death and disability in the United States. The journal also seeks to address health issues and disparities affecting specific populations: racial, ethnic, adolescent, adult, maternal, aging, sex-related, health-vulnerable, urban, rural, and others. For more details, visit www.cdc.gov/pcd.

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EDITORIAL

Addressing the Caregiving Crisis

Rosalynn Carter

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This issue of *Preventing Chronic Disease (PCD)* focuses on a set of concerns that is likely to challenge the public's creative spirit and resourcefulness for the next 30 years. Public health is the science and art of preventing disease, prolonging life, and promoting physical and mental health. What we are beginning to see is that success in any one of these areas raises new challenges and presents new problems for us to solve in the other areas. For example, advances in science, better nutrition, and improvements in health care have allowed people around the world to live to unprecedented ages. But this blessing of long life presents us with a new set of formidable challenges: soaring rates of dementia and untreated mental health problems among the elderly, a growing burden of chronic illnesses that affects our communities, disturbing problems of elder abuse, and an unparalleled demand for the services of both professional and family caregivers. All progress comes with costs and challenges, but in the 21st century we will experience this burden on a scale and at a speed that we have never seen before. So, we must prepare ourselves.

I am particularly interested in two issues in this unfolding scenario: mental health and caregiving. When addressing chronic diseases, we must not forget the importance of depression, particularly late-life depression. Depression frequently accompanies chronic illnesses, sometimes emerging as a result of them and other times acting as a risk factor for other illnesses. In either case, depression substantially and independently increases the risk of mortality (1). *PCD* helped address the issue of mental health in its article on The Carter Center Mental Health Program (2); in this editorial, I would like to provide some comments and reflections on the issue of caregiving.

My interest in caregiving goes back to my childhood. I was deeply influenced by how chronic illness affected and shaped my family and by the heroic and selfless efforts of health care providers, including Jimmy's mother, Lillian Carter. She was among the most dedicated and skilled nurses imaginable, and I was in awe of her as I observed the expert care she provided. The type of assistance that Lillian provided as a nurse is increasingly being provided today by family members. In fact, the backbone of our country's long-term, home-based, and community-based care systems is the family caregiver. The approximately 15 million caregivers in the United States provide \$306 billion worth of unpaid services each year (3). That amount is almost twice as much as is spent on homecare and nursing home services combined (\$158 billion) (4). The number of family caregivers is likely to increase in the upcoming years, as is the intensity of these caregivers' work, not only because of our country's aging population but also because of the changing fabric of our family networks. With the aging baby boomer population, the life expectancy and quality of life in the United States cannot continue to rise, or even remain stable, without increasing the burden on caregivers. But the strains on our society and on these individuals as a result of providing care are becoming apparent:

- A 25-year body of research shows that family caregivers are at risk for a wide range of problems in health and mental health, finances, employment, and retirement. For instance, a recent study found that one-third of family caregivers of people with dementia were depressed (5).
- Caregivers experiencing strain have a 63% higher risk of mortality than noncaregivers, even when adjusting for chronic disease and other risk factors (6).
- Family caregivers are largely neglected by the health and long-term care systems. They frequently are not

trained on how to deliver complicated care, not treated as partners in the patient's care, or not encouraged to maintain their own health.

- Professional caregivers work under difficult conditions and are vulnerable to many of the same problems as family caregivers.
- The cost to U.S. businesses attributable to the lost productivity of working caregivers is estimated at between \$17.1 billion and \$33.6 billion per year and growing (7).

To address this "caregiving crisis," all sectors of society must come together to develop solutions. A broad and coordinated response should address workforce development, community planning, and caregiver education and support, including regulatory and financing issues, more effective use of technology, and development and dissemination of evidence-based practices in caregiving. Building an infrastructure of supports for caregivers will improve caregiver effectiveness and reduce the harm, injury, and burden that can be associated with caregiving in isolation. Most importantly, I believe there must be a fundamental shift in how we value and support caregivers.

I have had a unique opportunity to address the caregiving crisis. With the assistance of many partners, the Rosalynn Carter Institute for Caregiving at Georgia Southwestern State University in Americus, Georgia, was created. Our hope is to play a key role in developing better supports for both family and professional caregivers. As part of our work, we have developed a network of community coalitions (CARE-NETS) that provides a forum for addressing the needs of caregivers in a concerted and coordinated way. In 2007, we launched a new venture. With the support of Johnson & Johnson, the National Quality Care Network (NQC�N) was formed to serve as a vehicle for innovation, dissemination, and networking, and to stimulate partnerships for action in our communities. The aim of the NQC�N is to support a network of stakeholders in the United States committed to promoting quality in long-term, home-based, and community-based care. Working together with scientists and leaders from many fields, I am very optimistic about our prospects for building communities of care to address the challenges that come with the gift of an aging society.

For more information about the Rosalynn Carter Institute visit www.RosalynnCarter.org.

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EDITORIAL

Looking Back and Looking Forward

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Consider the world of the 1950s. Ten percent of American households had a television, which displayed only in black and white. Telephones had rotary dials and party lines, and they were used only for conversation. The average life expectancy at birth was 69 years (1). Massive randomized clinical trials were in progress to test a new vaccine for polio (2) and streptomycin and isoniazid treatments for tuberculosis (3). Heart disease and stroke were gaining recognition as the leading noninfectious causes of death in the United States. Dwight D. Eisenhower was the President. And, were it not for President Eisenhower, I might not have had the opportunity to write this editorial for *Preventing Chronic Disease*.

I am the second child of two remarkable people who came to the United States many years ago. In the early 1950s, as a newly trained and highly skilled biochemist, my father was recruited to be a member of the antibiotic discovery group of Chas. Pfizer & Co., Inc. Because he was a scientist with the specialized skills necessary to fulfill an urgent national need, his application for permanent U.S. residency was rapidly approved. Confident that his wife's and child's applications would also be approved as his dependents, my father left India in 1954 to begin his new job.

At the time, a quota system severely restricted the number of immigrants into the United States from non-Northern European countries. Obtaining an immigrant visa involved a mountain of paperwork and numerous clearances. While examining my mother for the medical clearance, the physician in Bombay noticed her slender build and suspected a parasitic infection as the underly-

ing cause. An extensive evaluation ensued, which involved tests for various communicable diseases, including one for tuberculosis (the results were negative) and a prolonged course of empiric treatment for possible dysentery.

Obtaining the medical clearance for my mother took a year. By the time she and my sister were approved to travel, their authorization for immigrant visas had expired. With the immigrant quota for South Asian applicants filled for more than 10 years into the future, it appeared unlikely they would ever be able to join my father. Understandably, my father told his supervisor that he planned to return to India. Concerned about losing a valuable employee, Pfizer attorneys contacted Senator Herbert Lehman (D-NY) for assistance. On August 1, 1956, Senator Lehman introduced private legislation (4) which was passed by both houses of Congress and signed by President Eisenhower granting special permission for my mother and sister to immigrate into the United States. They arrived before the year's end.

The 1950s is not only an important time in my family's history but is also a period of key advances in population health. By the middle of the 20th century, the public health community had become interested in collecting data on possible risk factors related to chronic diseases. In 1956, President Eisenhower signed the National Health Survey Act, authorizing a continuing survey "to secure accurate and current statistical information on the amount, distribution, and effects of illness and disability in the United States" (5). As a consequence, the National Household Health Interview Survey (1957) and the National Health Examination Survey (1960) were created. Now known as the National Health Interview Survey and the National Health and Nutrition Examination Survey, respectively, these surveillance systems, along with research from the Framingham cohort study (1948), produced data that

advanced our understanding of the risk factors for cardiovascular disease, cancer, and other chronic conditions; they also led to the development of public health interventions and new medical treatments.

Since the 1950s, the average life expectancy at birth has increased from 69 to 78 years (1). Today, people 65 years of age can expect to live an additional 18.7 years, or 5 more years than their counterparts during the 1950s (1). The 1950s also were the early days of the baby boom generation, a group that will contribute substantially to the growth of the aging population. By 2030, 20% of the entire U.S. population will be adults 65 years or older (6). As people live longer, their expectations regarding quality of life throughout the lifespan are changing. And, although chronic diseases such as cardiovascular disease, cancer, and diabetes remain important public health concerns as major causes of illness, disability, and mortality among adults older than 65, we are beginning to see a greater focus than heretofore on other health and lifespan issues, including cognitive and emotional health (7,8), caregiving (9), and end-of-life issues (10).

In this issue of *Preventing Chronic Disease*, we highlight emerging topics related to the health of older adults (i.e., adults aged 50 years or older). We are honored to include former First Lady Rosalynn Carter's editorial, which focuses on her important work related to caregiving (11). Chapman and Perry (12) and Snowden et al (13) focus on depression among older adults. Glass and Nahapetyan (14) analyzed qualitative data to describe the perspectives of baby boomers and older adults on planning for the end of life. Mayer et al (15), Batik et al (16), and Nguyen et al (17) focus on efforts to promote and measure physical activity among community-dwelling older adults. Shenson and colleagues (18) describe their experiences adapting a preventive service approach for older adults that was successful in New England communities for a community in the U.S. Southeast. Because data indicate that limited health literacy is an important problem among older adults, Friedman and Kao (19) assessed the reading level and cultural appropriateness of Web sites containing information about prostate cancer. Finally, Aldrich and Benson (20) discuss the practical aspects of emergency preparedness as it applies to older adults.

December 10, 2006, marked the 50th anniversary of my mother's arrival in the United States. Like any family, mine experienced many changes during these 5

decades. My parents went on to have two more children, my brother and me, and to build their life in the United States. My mother transformed herself from a quiet young woman from a small village in south India who spoke little English to a full-fledged American citizen who speaks fluent English and enjoys discussing domestic and international issues with family and friends. Over time, my mother has changed from someone who was the major family caregiver to a woman who accepts modest assistance from her children. Although she moves slowly now because of severe arthritis, she has the youngest spirit of anyone I know.

Because of improvements in population health, my siblings and I have had more quality time with our parents than they had with their parents. I suspect that we are not alone in this regard. We should consider the growth of the aging population a public health triumph. At the same time, we must also recognize that addressing the needs of a sizeable population of older adults with chronic disease will be a challenge for public health. Time will tell how well we meet this challenge.

Acknowledgments

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ORIGINAL RESEARCH

A Comprehensive Assessment of the Difficulty Level and Cultural Sensitivity of Online Cancer Prevention Resources for Older Minority Men

Daniela B. Friedman, PhD, Elaine K. Kao

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Abstract

Introduction

Older men are at increased risk for prostate cancer. As seniors turn to the Internet for cancer information, it is important that the resources they locate about lifestyle behaviors and screening are culturally appropriate and easy to understand. This study was a comprehensive analysis of prostate cancer risk as portrayed on the Internet with assessment of content readability and cultural sensitivity.

Methods

We selected Web sites about prostate cancer risk and prevention by comparing common sites across three top-rated search engines (Google, Yahoo!, and MSN). A total of 70 Web sites on prostate cancer containing a Web page on risk factors or prevention or both for racial and ethnic populations were included. We assessed readability of one page per Web site using Simple Measure of Gobbledygook (SMOG), Flesch-Kincaid (FK), and Flesch Reading Ease (FRE) measures. Cultural sensitivity of the Web page was evaluated using the Cultural Sensitivity Assessment Tool (CSAT) and questions from a cultural sensitivity checklist.

Results

Mean readability of Web pages was Grade 12.90 (high school graduate level) using SMOG and Grade 11.20 according to FK. Mean FRE was 45.04 (fairly difficult to read). The mean CSAT score was 2.78 and classified as culturally sensitive. Of the 36 Web pages considered culturally sensitive (CSAT > 2.50), 75% did not portray images of representative racial or ethnic individuals as intended readers or as being at high risk for prostate cancer. Older adults and seniors were identified as intended readers on 73% of Web pages.

Conclusion

Online cancer resources are targeting appropriate age groups (high-risk older adults). However, the pages required fairly high-level reading skills and had limited cultural sensitivity. These factors make the pages unsuitable for diverse Internet users.

Introduction

Prostate cancer is a leading cause of death among men in the United States, with an estimated 27,050 deaths expected in 2007 (1). Mortality from prostate cancer among black men (65.1 deaths per 100,000 black men) is over two times higher than that for whites (26.7 deaths per 100,000 white men). Older adults require accurate, reliable, age-relevant, and culturally sensitive information about prevention because they are at increased risk for chronic diseases such as cancer (1). Communicating prostate cancer prevention to older adults with the intent that they will act on the information to prevent disease is

essential for healthy aging. This is a challenging task, however, because of the complexity of the information itself and the often conflicting medical reports regarding the benefits and efficacy of screening examinations. In a recent review of prostate cancer screening guidelines, researchers found that data supporting the efficacy of prostate specific antigen (PSA) testing are not entirely compelling and that screening should not include men at average risk for prostate cancer if they are younger than 50 years of age or older than 75 years of age (2). The lack of consensus on prostate cancer screening recommendations is evident in the variable quality of online resources (3,4).

Along with such varying descriptions of screening guidelines for prostate cancer, the reading level of cancer information often is high (5,6). Therefore, it is not surprising that older men assume a passive role in their healthcare. Specifically, men with prostate cancer often defer treatment decisions to physicians and family members (7). These men need to receive clearer information about prostate cancer prevention so that they are better informed when making personal health and lifestyle decisions.

Despite being the leading incident cancer among men (1), awareness and coverage of prostate cancer in the mass media is limited compared with that for breast cancer, the leading incident cancer among women (5,8). Inadequate communication may reflect fewer advocacy groups for prostate cancer and reluctance of men to be vocal about an illness linked to sexuality. One study conducted with men aged 38 to 80 on their perceptions of prostate cancer screening found that older participants were especially concerned about their sex life if ever diagnosed with prostate cancer (9).

Cancer prevention messages in mainstream media rarely frame cancer content in an age-specific or culturally tailored manner that would inform diverse seniors about preventive health actions (5,8). Individuals may consider information about cancer to be irrelevant if it does not include their cultural and spiritual beliefs and attitudes about disease (10). One key recommendation to improve cultural suitability of resources is to involve stakeholders and laypeople from targeted minority communities in the development and evaluation of cancer resources (11). Unfortunately, health and media organizations may not have the resources or time available to tailor or to pretest health messages for difficult terminology or cultural inap-

propriateness when the information must be disseminated in a timely manner.

We must consider literacy levels of intended Internet end users in the development and posting of online cancer information. More than 75 million adults have basic or below basic literacy abilities and are unable to understand materials such as prescription labels or hospital consent forms. Results of the most recent National Assessment of Adult Literacy (NAAL) survey showed that 34% of adults aged 50 to 64, and 59% aged 65 or older, had below basic or basic levels of literacy (12). In the context of this research on the reading level of health resources for minority men, this is especially alarming. Specifically, 67% of blacks have basic or below basic literacy skills compared with 32% of whites (13). Men also have lower literacy skills than women. Online cancer information often is written at high reading levels and is difficult for average readers or individuals with poor literacy skills to understand (6,14,15). Despite this finding, interviews with breast and prostate cancer patients showed that they prefer the Web as a source of disease information, social support, and personal stories about the cancer experience (16). Being able to use the Internet and access this information provided them with feelings of competence and control.

More than 50% of African Americans searched for health information online in 2000 (17). Close to 45% of African Americans who are online report that the Internet helps them get health care information, compared with 35% of whites (17). In one study with breast cancer patients, receipt of overall and tangible social support through the Internet was significantly higher among minority women (black and Hispanic) than among white female users (18). Furthermore, an Internet health intervention at churches for both African American men and women resulted in improved nutrition. Both nutrition and physical activity improved when the Internet intervention was combined with support within the church (19). Research on black men's use of the Internet for cancer prevention information has not been conducted.

A number of studies have been conducted on prostate cancer patients' involvement in treatment decision making (20-22), and health literacy has been examined in the context of late-stage diagnosis and disease treatment (23-25). One study showed that lower prostate cancer knowledge among patients was associated with lower literacy scores, indicating that low literacy may affect patient under-

standing of the treatment decision-making process (24). However, health literacy and cultural sensitivity have not been systematically explored in online information about prostate cancer prevention.

Objectives of this study were twofold: 1) to assess the reading level of prostate cancer prevention resources on the Internet that are intended for minority men, and 2) to evaluate the cultural sensitivity of prostate cancer prevention information on the Internet. This is the first study to examine both the readability and cultural sensitivity of prostate cancer prevention information across a sizable number of Web sites. Other studies have examined readability of multiple cancer types (e.g., breast, colorectal, prostate) on fewer sites (6,14), or included some cancer Web sites in a larger analysis of general health resources on the Internet (13). Cultural sensitivity of cancer information on the Internet has not been comprehensively assessed. Data obtained from this research on existing Internet resources on prostate cancer will help contribute to the development, implementation, and evaluation of a culturally appropriate education program to enhance the health literacy of older black men at risk for prostate cancer.

Methods

Web site selection

On January 25, 2007, we selected consumer-oriented prostate cancer Web sites that are accessible through the three top Internet search engines (Google, Yahoo!, and MSN, as identified by Nielsen ratings [26]). This search strategy has been employed in previous Internet research (6,14) because most people locate health information using search engines (27). The search terms used were *prostate cancer* in combination with *risk*, *prevention*, or *screening*. A Web site was excluded if it 1) was not operational at the time of the search; 2) was a directory or provided only links to other Web pages; or 3) was not intended for consumers (e.g., research library, health care professional Web site). Although individuals express the desire for accurate and reliable health information on the Internet (including medical center Web sites and research-based resources) (28), they most often use search engines to find information that links to Web sites for commercial products. Therefore, we included commercial Web sites for analysis.

We compiled a comprehensive list of Web sites from

each search engine. The top-ranking 70 Web sites from each search engine were scored, in which ranking first on a search engine was awarded 70 points, and ranking 70th on a search engine was awarded 1 point. Average scores were tallied for each of the ranked Web sites across all search engines. The 70 Web sites with the highest overall ranking across the three search engines were selected for analysis.

Readability and cultural sensitivity testing of Web pages

Web pages identified by the search engines were opened to the Web site's home page. The first Web page within the Web site mentioning minority groups as intended readers or as high-risk groups for prostate cancer was selected for readability and cultural sensitivity analysis. The first page was identified either by clicking on links from the home page or by searching the site for prostate cancer information. The three readability measures we used were Simple Measure of Gobbledygook (SMOG), Flesch-Kincaid (FK), and Flesch Reading Ease (FRE) (29-31). SMOG is conducted on 10-30 sentences in a sample of writing and measures difficulty of content by the number of polysyllabic words. If the Web page being analyzed had 10-30 sentences, all sentences were included. If the Web page contained >30 sentences, readability was determined from the first 30 consecutive sentences on the page. FK and FRE scores were determined using tools available in Microsoft Word 2003. The score derived from the FRE formula, referred to as the FRE scale score, ranges from 100 (very easy to read) to zero (unreadable). The FK formula is a modified version of the FRE that generates a school grade-level score to indicate the education level needed to understand the material. SMOG is estimated to test for 100% comprehension; Flesch tests for 75% comprehension of the material (32).

We evaluated the cultural sensitivity of the 70 Web pages using the Cultural Sensitivity Assessment Tool (CSAT) (33). The CSAT scale ranges from 4 (strongly agree that the information is culturally sensitive) to 1 (strongly disagree that the information is culturally sensitive) on three format questions (category 1), 11 message questions (category 2), and 16 visual message questions (category 3). Scores calculated for each of the three categories are then averaged for the overall CSAT score. Print materials with overall scores of ≤ 2.50 are classified as culturally insensitive. The CSAT was selected because it is the only published instrument for the numeric assessment of the

cultural sensitivity of cancer materials. It has not been validated in the literature, has not been previously used on Web-based cancer information, and is not intended for minority groups other than African Americans. Therefore, we also used a cultural sensitivity checklist for a more comprehensive assessment (34). Checklist questions included the following:

- Is the intended racial or ethnic group mentioned? (Directly? Indirectly?)
- Is the racial or ethnic group described as a high-risk group for cancer or as the intended readers of the cancer information?
- Does the information address the perceptions of cancer risk in the intended racial or ethnic group?
- Are complementary and alternative medicines presented as acceptable methods of cancer prevention or treatment?
- Are these cancer prevention or treatment options presented in a manner that is understandable and appropriate for the intended readers?
- Is mobilizing information (i.e., information allowing the reader to contact someone for more information) or cues to action provided?
- Is the contact person or the organization that is identified as a source of information of the same racial or ethnic group as the intended readership?
- Is the cancer message linked to credible and accessible sources?

Web pages were read thoroughly and coded independently by the researchers for a number of variables. Domains were coded as .org, .com, .gov, .edu, or other. Authorship was coded as Web site writer, freelancer, or wire service. The Web page focus was coded as risk factors, screening, or lifestyle. Readability was coded using SMOG, FK, and FRE. Cultural sensitivity was coded according to CSAT and the cultural sensitivity checklist. Also coded were the date the resource was posted or reviewed, the presence of visuals, the target minority, and the target age group. These factors have been coded in previous research (5,6,32). Readability and CSAT values were analyzed using nonparametric tests (frequencies, chi-squares; Mann-Whitney U and Kruskal-Wallis rank measures for readability data). Significance was set at $P < .05$. We also noted representative terms from the Web pages to determine the tone of prostate cancer risk messages and to provide a more complete description of the framing of prostate cancer information on the Internet.

Results

General description of Web sites and Web pages

Most of the 70 Web sites had domains of .com (35 [50%]) and .org (26 [37%]). Fewer Web sites had domains of .gov (3 [4%]) or .edu (2 [3%]). The average number of clicks from the home page to the Web page used for this analysis was 2.1.

We observed three main areas of focus on Web pages: risk factors, lifestyle behaviors, and screening. Most pages focused on both risk factors and lifestyle (17 [24%]), followed by risk and screening (15 [21%]), risk (13 [19%]), screening (12 [17%]), and lifestyle (8 [11%]). Three pages covered all three topics, and two pages covered both screening and lifestyle.

One-quarter of Web pages did not specify the age of intended readers. Another one-quarter mentioned middle-aged adults (30–49 years), older adults (50–64), and seniors (65 or older). The next most common age groups mentioned were both older adults and seniors (16 [23%]), followed by all ages, seniors only, middle-aged or older adults, and middle-aged adults alone. Most references to age were in the middle of the page (27 [39%]) and in introductory paragraphs (26 [37%]).

Web pages were also coded for references to minority groups (e.g., black, white, Asian, Hispanic). Both blacks and whites were mentioned most often (29 pages [41%]), followed by whites, Asians, and blacks (10 pages [14%]). Few pages (7 [10%]) discussed risk of prostate cancer among whites alone. Blacks alone, Asians alone, and whites, blacks, and Hispanics together were mentioned on one page each. Ten pages did not mention explicitly specific minorities at risk for prostate cancer, although they stated that certain races or ethnicities were at higher risk for prostate cancer.

Presence or absence of contact information was also recorded. No organizational contact information was provided on 29 (41%) Web pages. Links to other Web sites appeared on 28 (40%) pages. The remainder had multiple types of contact information including Web site links, telephone numbers, and addresses.

Readability and cultural sensitivity of online prostate cancer resources

The mean readability score of the cancer Web pages was Grade 12.90 (95% confidence interval [CI], 12.35–13.45) using SMOG and Grade 11.20 (95% CI, 10.75–11.64) according to FK. Mean FRE was 45.04 (95% CI, 41.98–48.11) (difficult to read). Reading grade level differed by domain type, with the level being higher for .edu pages than for .gov pages. Differences were significant according to FK ($X^2 = 10.26$, 4 *df*, $P = .04$). Table 1 presents readability scores by domain type.

Although not significant, differences in reading grade level were apparent according to Web page focus (Table 2). For instance, pages on lifestyle (diet and physical activity) were hardest to read according to SMOG, FK, and FRE measures. Pages that included both risk factor and lifestyle content were easiest to read according to SMOG, and pages on all three topics (risk factors, screening, lifestyle) were easiest to read according to FK and the FRE scale.

Samples of technical language from Web pages written at more difficult reading levels included these two examples:

Prostate biopsy prompted by abnormal findings on digital rectal exam (DRE), such as nodularity or induration of the prostate leads to a diagnosis of prostate cancer in only 15%–25% of cases. This compares with prostate cancer prevalence of less than 5% among men of similar age without abnormal DRE. Although neither accurate nor sensitive for prostate cancer detection, abnormal DRE is associated with a 5-fold increased risk of cancer present at time of screening. (SMOG for rest of Web page = 14.57; http://www.cancer.med.umich.edu/prevention/prostate_cancer_detection.shtml.)

The research team reported that the gene seems to contribute to prostate cancer risk in a number of ethnic backgrounds, including African-American families. The study suggests that approximately 1 in every 500 men possesses an altered version of the gene. Researchers estimate that alterations in the HPC-1 gene are responsible for at least a third of familial prostate cancer, which accounts for about 1 in 10 cases of the disease. Scientists were optimistic that the HPC-1 gene may help

unlock the mystery of why African-American men are exceptionally vulnerable to the disease. (SMOG for entire Web page = 14.06; <http://prostateaction.org/diagnosis/lethal.html>.)

Samples of easier, plain language information included these two:

Prostate cancer is more common in some racial and ethnic groups than in others, but medical experts do not know why. Prostate cancer is more common in African-American men than in white men. It is less common in Hispanic, Asian, Pacific Islander, and Native American men than in white men. (SMOG = 9.33; <http://www.cdc.gov/cancer/prostate/publications/decisionguide/index.htm#diagnosis>.)

Your doctor may examine your prostate by putting a gloved, lubricated finger a few inches into your rectum to feel your prostate gland. This is called a digital rectal exam. A normal prostate feels firm. If there are hard spots on the prostate, your doctor may suspect cancer. (SMOG = 9.22; <http://familydoctor.org/online/famdocen/home/common/cancer/types/361.html>.)

The mean overall CSAT score of the 70 pages studied was 2.78 (95% CI, 2.64–2.93), which is in the culturally sensitive range. Specifically, 36 (51%) Web pages were culturally sensitive (CSAT overall scores of >2.50). A significant number of these pages (27 [75.0%]), however, did not present images of intended minorities ($t = 3.31$, 39 *df*, $P = .002$). Of the pages that were culturally sensitive and that mentioned racial or ethnic populations, all except two listed specific high-risk racial or ethnic groups. Table 3 shows the mean CSAT scores for all the Web pages by the race and ethnicity discussed on the pages. Results from the cultural sensitivity checklist found that none of the Web pages mentioned racial- or ethnic-specific perceptions of cancer risk, cultural beliefs about health, or alternative medicine.

Mean CSAT scores also differed significantly by focus ($F = 2.89$, 6 *df*, $P = .02$) (Table 4). The most culturally sensitive pages with the highest CSAT scores were on risk factors, screening, and lifestyle (3.26; 95% CI, 1.79–4.72). The mean CSAT score for pages on lifestyle alone was <2.50 (2.32; 95% CI, 1.98–2.67).

Readability scores as measured by SMOG and FRE were significantly associated with “familiarity of terms” — a measure on the CSAT scale examining language difficulty of consumer health information (SMOG: $X^2 = 9.30$, 3 *df*, $P = .03$; FRE: $X^2 = 8.55$, 3 *df*, $P = .04$). We classified terms as familiar more often on Web pages that were easier to read.

Message tone

Web pages were examined for cultural sensitivity and language suitability by searching for terms on tone, that is, positive or negative messages about prostate cancer and words of certainty and uncertainty regarding the link between prevention and outcomes (Table 5). Few pages used positive words or terms of certainty such as *hope*, *positive*, *proof*, or *proven*. More Web pages contained negatively charged terms such as *deadly*, *fatal*, *negative*, and *victim*. The term *evidence* as applied to prostate cancer prevention and health outcomes was used on 22 pages and mentioned 44 times, providing some assurance to readers about the associations among risk factors, prevention, and prostate cancer. Proof of such associations, however, was mentioned on only nine Web pages.

Discussion

This study of information about prostate cancer prevention on the Internet revealed that difficult and untargeted consumer-oriented resources are being posted on the Web. While previous research showed that cancer prevention information had high reading levels (6,13,14), this is the first study to focus additionally on cultural appropriateness of Web-based resources for prostate cancer risk and prevention. As diverse groups turn to the Web for health information (35), cancer prevention resources must be culturally respectful. Although half of the Web pages analyzed were classified as culturally sensitive, one-quarter did not present images of representative racial or ethnic individuals as intended readers or as high-risk groups for prostate cancer. Many Web pages also contained negatively charged terminology, which could deter people from reading them. Culturally insensitive pages were cluttered with generic messages and images, and with unfamiliar terms.

As defined by Resnicow and colleagues (36), cultural sensitivity is “the extent to which ethnic/cultural char-

acteristics, experiences, norms, values, behavioral patterns, and beliefs of a target population’s relevant historical, environmental, and social forces are incorporated in the design, delivery, and evaluation of targeted health promotion materials and programs.” Cultural sensitivity consists not only of surface characteristics, such as behavioral features and appearance of the targeted population, but also cultural, social, historical, and environmental factors (that is, deep structure sensitivity) that can influence people’s health behaviors and perceptions about disease prevention. Having culturally appropriate resources, which incorporate spiritual and religious beliefs as well as the importance of family and social support, has positively influenced African American men to participate in cancer education and screening programs (37,38). Use of the CSAT showed that some Web pages were indeed culturally appropriate for minority men; however, truly culturally sensitive information should include both surface and deep structure components. Results using the cultural sensitivity checklist containing items about spiritual health and cultural risk perception (34) showed that these particular aspects of health and illness are not being considered on the Web. To improve the development and usefulness of health communication materials, health resources must be created and evaluated with intended users before dissemination.

Public health educators are considering vulnerable, hard-to-reach populations in the development of prostate cancer prevention programs. For example, results from a randomized intervention for African American men found that use of an educational booklet and video led to significant increases in knowledge about prostate cancer screening compared to wait list controls (39). As we work to reduce the differences in computer and Internet access among racial groups (40), we must also ensure that information resources posted on the Web are suitable for diverse populations.

Our study presents important and original findings. First, Internet resources about prostate cancer screening were age appropriate, that is, most Web pages did mention explicitly that older men were at higher risk for prostate cancer. Previous research showed that older men are often not mentioned as intended readers or as at high risk for cancer even in publications or on Web sites specifically written for senior populations (5,6). Previous work (6) showed that compared with colorectal and breast cancer information, prostate cancer information was more

often written in less technical language, though still at a high school level. This study on 70 prostate cancer Web pages showed that reading level was close to Grade 13, a difficult, college level. According to the most recent NAAL survey (12), more than 65% of African Americans have basic or below basic literacy skills. Therefore, it is important that printed and online prostate cancer screening and prevention information be written in plain language that is understandable by all. In addition to understandable content, computers and Web pages tailored to older adults (e.g., having age-appropriate images, adequate font size, audio options for hearing-impaired) must be considered if we are encouraging seniors to seek health information on the Web. Echt and colleagues (41) stated that age-related changes in cognition (e.g., comprehension, working memory) and perceptual motor skills (e.g., task speed, motor control) can affect computer literacy development in older adults. Computer and Internet anxiety is also common among seniors. In an investigation of psychological barriers to Internet use among older adults, it was found that most seniors who had a positive perception of the usefulness, ease of use, and efficacy of the Internet used the Web more often than did those who reported negative perceptions about the Internet (42).

A surprising (though nonsignificant) finding was that resources on lifestyle behaviors were written at a more difficult level than those on screening. Post hoc analysis was conducted to see whether pages on cancer screening had less text and more images than pages on lifestyle. We found no images on lifestyle-only pages and a total of six images on pages that contained information about screening alone or with information about cancer risk. Comprehension can be affected by the extent to which the information is tailored to readers and the format in which the information is presented (i.e., text vs graphics) (43). Educational videotapes and interactive decision-making tools containing clear and relevant visuals and graphics in addition to plain language explanations have provided prostate cancer patients with greater understanding of their disease and have enabled them to participate more actively in their health decisions (44). Printed or online text alone may not meet the information needs of all consumers or patients, especially those with limited literacy or health literacy skills. The importance of plain language has been examined with respect to decision aids for prostate cancer patients. For example, plain language decision aid resources in three formats (booklet, Internet, and audio tape) were helpful to men in their decisions about localized

prostate cancer treatment (45). Limited research exists, however, on the importance of literacy in understanding and engaging in prevention for prostate cancer.

Our study had several limitations. First, we consulted only 70 Web pages. Although we recognize that numerous Web sites about prostate cancer exist, we are confident that we included sites that consumers and patients find most often using three popular search engines. Second, the readability tools used have limitations. Word processing programs calculate a readability score from an estimate rather than from the actual number of syllables. Furthermore, readability formulas can produce different grade-level scores depending on the passages selected and the criterion of comprehension employed. These instruments also do not consider the influences of graphics, format, and readers' prior knowledge. Third, the CSAT tool was originally intended for printed cancer materials targeting African Americans and has not been validated in the literature. We used it, nonetheless, because it is the only available quantitative measure of the cultural sensitivity of cancer prevention resources. As discussed elsewhere (34) and as seen from our results, a limitation of the CSAT scoring system is that generic cancer articles, untailored to blacks or other minority groups, may still be rated as culturally sensitive. Finally, we did not examine quality of Web site content because it has been assessed in other research (3,4).

Guidelines for prostate cancer screening suggest that the decision to have prostate-specific antigen testing should be a shared one with physicians (46). At the same time, men report more personal control over their final decisions about screening (46). As culturally diverse individuals turn to the Web for prostate cancer information, they must be guided to clear and culturally appropriate resources to assist them with the important decision of whether or not to be screened and to encourage them to engage in healthy lifestyle behaviors that reduce the risk of developing prostate cancer.

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Tables

Table 1. Mean Readability Scores of 70 Web Pages Discussing Prostate Cancer Prevention, by Domain Type

Domain	SMOG ^{a,b} Score (95% CI)	Flesch-Kincaid ^b Score (95% CI)	Flesch Reading Ease ^c Score (95% CI)
.com (n=35)	12.84 (12.09–13.60)	11.10 (10.49–11.71)	45.59 (41.36–49.82)
.org (n=26)	12.99 (11.94–14.03)	11.22 (10.47–11.98)	44.51 (39.01–50.02)
.gov (n=3)	11.25 (6.24–16.25)	9.13 (6.58–12.68) ^d	57.63 (40.20–75.06)
.edu (n=2)	14.88 (10.94–18.82)	14.05 (9.60–18.50) ^d	36.00 (14.40–57.60)
Other (n=4)	12.01 (9.95–16.33)	11.93 (9.22–14.63)	38.78 (14.23–63.32)

CI indicates confidence interval.

^a Simple Measure of Gobbledygook.

^b Scores are presented as school grade level to indicate the education level needed to understand the material.

^c Scale ranges from 0 (very difficult to read) to 100 (very easy to read).

^d $P < .05$.

Table 2. Mean Readability Scores of 70 Web Pages Discussing Prostate Cancer Prevention, by Web Page Focus

Web Page Focus	SMOG ^{a,b} Score (95% CI)	Flesch-Kincaid ^b Score (95% CI)	Flesch Reading Ease ^c Score (95% CI)
Risk factors (n=13)	12.65 (11.22–14.08)	10.68 (9.76–11.60)	47.32 (39.86–54.79)
Screening (n=12)	13.81 (12.09–15.52)	11.60 (10.14–13.06)	40.73 (29.05–52.42)
Lifestyle (n=8)	14.09 (11.28–16.90)	12.13 (9.89–14.36)	39.93 (25.39–54.46)
Risk factors & screening (n=15)	12.40 (11.33–13.46)	11.11 (10.05–12.18)	46.83 (39.94–52.35)
Risk factors & lifestyle (n=17)	12.21 (11.65–12.77)	11.00 (10.30–11.70)	46.83 (42.28–51.38)
Screening & lifestyle (n=2)	13.95 (6.13–21.76)	11.60 (6.52–16.68)	45.75 (6.98–98.48)
Risk factors, screening, & lifestyle (n=3)	13.01 (2.85–23.17)	10.60 (5.81–15.39)	49.97 (34.81–65.13)

CI indicates confidence interval.

^a Simple Measure of Gobbledygook.

^b Scores are presented as school grade level to indicate the education level needed to understand the material.

^c Scale ranges from 0 (very difficult to read) to 100 (very easy to read).

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Table 3. Mean Cultural Sensitivity Assessment Tool (CSAT) Scores^a of 70 Web Pages Discussing Prostate Cancer Prevention, by Racial or Ethnic Group Mentioned on the Web Page

Racial or Ethnic Group Mentioned	CSAT Category 1 — Format Score (95% CI)	CSAT Category 2 — Written Message Score (95% CI)	CSAT Category 3 — Visual Message Score (95% CI)	Overall CSAT Score (95% CI)
General population/white (n=7)	3.76 (3.53–4.00)	3.26 (2.79–3.72)	0.82 (0.51–2.15)	2.63 (2.10–3.15)
Black (n=1)	3.33	3.56	3.36	3.42
Asian (n=1)	3.33	3.00	0.00	2.11
Black & white (n=29)	3.64 (3.52–3.77)	3.29 (3.17–3.41)	1.73 (1.08–2.39)	2.89 (2.66–3.11)
Black, Hispanic, & white (n=1)	3.67	3.56	0.00	2.40
Black, Asian, & white (n=10)	3.77 (3.61–3.93)	3.27 (3.05–3.48)	1.46 (0.11–2.82)	2.84 (2.35–3.32)
>3 groups (n=11)	3.79 (3.64–3.94)	3.47 (3.25–3.69)	1.51 (.32–2.70)	3.02 (2.61–3.44)
None (n=10)	3.33 (3.04–3.63)	3.07 (2.74–3.40)	0.47 (–0.24 to 1.17)	2.29 (2.01–2.57)
Total (n=70)	3.64 (3.56–3.72)	3.28 (3.20–3.37)	1.36 (0.96–1.76)	2.78 (2.64–2.93)

CI indicates confidence interval.

^a The CSAT scale ranges from 4 (strongly agree that the information is culturally sensitive) to 1 (strongly disagree that the information is culturally sensitive) on three format questions (category 1), 11 message questions (category 2), and 16 visual message questions (category 3). Scores calculated for each of the three categories are averaged for the overall CSAT score. Cancer resources with overall scores of ≤ 2.50 are classified as culturally insensitive.

Table 4. Overall Cultural Sensitivity Assessment Tool (CSAT) Scores^a for 70 Web Pages Discussing Prostate Cancer Prevention, by Web Page Focus

Web Page Focus	Overall CSAT Score		
	Mean (95% CI)	Minimum	Maximum
Risk factors (n=13)	2.69 (2.35–3.04)	1.97	3.73
Screening (n=12)	2.54 (2.13–2.94)	1.93	3.52
Lifestyle (n=8)	2.32 (1.98–2.67)	1.81	3.08
Risk factors & screening (n=15)	3.18 (2.83–3.53)	1.88	3.90
Risk factors & lifestyle (n=17)	2.79 (2.53–3.04)	2.37	3.76
Screening & lifestyle (n=2)	2.90 (–3.58 to 9.38)	2.39	3.41
Risk factors, screening, & lifestyle (n=3)	3.26 (1.79–4.72)	2.58	3.66
Total (n=70)	2.78 (2.64–2.93)	1.81	3.90

CI indicates confidence interval.

^a The CSAT scale ranges from 4 (strongly agree that the information is culturally sensitive) to 1 (strongly disagree that the information is culturally sensitive) on three format questions (category 1), 11 message questions (category 2), and 16 visual message questions (category 3). Scores calculated for each of the three categories are averaged for the overall CSAT score. Cancer resources with overall scores of ≤ 2.50 are classified as culturally insensitive.

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Table 5. Frequency of Mention of Emotionally-Charged Terms on 70 Web Pages Discussing Prostate Cancer Prevention

Term	No. Web Pages (%)	No. Times Mentioned
Negative	6 (9)	6
Death/Deadly	20 (29)	28
Fatal	3 (4)	3
Victim	1 (1)	1
Positive	7 (10)	17
Hope/Hopeful	4 (6)	4
Certainty	0 (0)	0
Link	11 (16)	16
Evidence	22 (31)	44
Proof/Proven	9 (13)	11
Uncertainty	2 (3)	2
Unknown	10 (14)	11

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ORIGINAL RESEARCH

Discussions by Elders and Adult Children About End-of-Life Preparation and Preferences

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PEER REVIEWED

Abstract

Introduction

In the United States, 73% of deaths occur among people aged 65 years or older. Although most would prefer to die at home after a short illness, most actually die in institutions after prolonged declines. Despite this discrepancy, elders and their adult children often do not discuss end-of-life preferences. Use of advance directives has not been widespread, and people often avoid the subject until a crisis. This project focused on informal family communication about end-of-life preparation and preferences, about which little is known.

Methods

In May 2006, we conducted in-depth exploratory interviews with 15 older adults about their end-of-life preparation and preferences and with 15 younger adults about their parents' end-of-life preparation and preferences. The interview included an item rating the depth of discussion.

Results

Participants in both groups were primarily female and white. Mean age of older adults was 78.6 years (range: 70–88 years). Mean age of younger adults was 53.1 years (range: 42–63 years); mean age of their parents was 82.6

years (range: 68–99 years). Nine older adults reported discussing end-of-life preparation and preferences with their adult children; six had barely discussed the topic at all. Ten younger adults reported having talked with their parents about end-of-life preparation and preferences; five had not discussed it. Barriers to discussions about end-of-life preparation and preferences were fear of death, trust in others to make decisions, family dynamics, and uncertainty about preferences. Facilitators for discussion were acceptance of the reality of death, prior experience with death, religion or spirituality, and a desire to help the family. Successful strategies included casually approaching the topic and writing down end-of-life preparation and preferences.

Conclusions

Knowing the obstacles to and facilitators for discussion can help health care and public health professionals target approaches to encouraging elders and their families to discuss end-of-life preparation and preferences before a crisis.

Introduction

In the United States, death is increasingly the province of old age, with 73% of deaths occurring among people aged 65 years or older (1). End-of-life care is mediocre at best (2) and therefore is an emerging health concern (3,4). Most people express a desire to die at home after a short illness, but 75% will die in institutions — half in hospitals and 25% in nursing homes — after slow declines caused by chronic disease (2). Twenty-five percent of Medicare expenditures for an average beneficiary occur in the final year of life (5).

People can increase the likelihood that end-of-life care will meet their wishes by communicating in advance those wishes to others. Advance directives (i.e., living will and health care power of attorney) have been advocated since at least 1990 when Congress passed the Patient Self-Determination Act, but they still are not widely used (6,7). Because little is known about the process of informal family discussions regarding end-of-life preparation and preferences (EOLPP), we studied the perspectives of 15 elders about their EOLPP and 15 younger adults about their parents' EOLPP. We sought to answer the following questions: 1) How do elders express their EOLPP to their children? 2) Are their children receptive? 3) What are the barriers to this exchange of information? 4) What facilitates these discussions? and 5) What differences emerge from examining the older and younger adults' responses separately?

Methods

Descriptive Information

Because death remains a taboo subject in modern U.S. society, we chose a qualitative design based on constructivist perspectives (8) for this exploratory pilot project. When little is known about a subject, qualitative research is appropriate to harvest personal perceptions regarding the topic.

In May 2006, after obtaining approval from the University of Georgia Institutional Review Board, we conducted in-depth interviews with 15 community-dwelling persons aged 70 years or older (i.e., older adults [OAs]) who had living children and with 15 persons aged 42 to 63 years (i.e., younger adults [YAs]) who had parents living independently. We identified participants through purposive sampling, using the snowball technique. Seven OAs were recruited through the local council on aging, and four were recruited through acquaintances who then suggested four others, consistent with the snowball approach. YAs were similarly recruited: four were staff or volunteers at the local council on aging; eight were recruited through personal acquaintances; and three others were recruited through snowballing. We did not attempt to pair parents with their own adult children but instead chose OAs and YAs independently. Participants received a \$25 honorarium.

Interview Questions

Our overall goal was to develop and pilot a guide for comprehensive qualitative in-depth interviews for a larger study related to death and dying. The first author conducted all interviews. Using open-ended questions, we inquired about participants' experiences with the deaths of family members and friends; knowledge about and use of hospice; and attitudes and feelings about death, funerals, and related topics. Next we asked OAs about the process and quality of discussions with their adult children about EOLPP and sought the same information from YAs regarding conversations with their parents. Because the interviews queried attitudes about both funerals and end-of-life care, responses varied in addressing one or both topics. We asked participants about their familiarity with *Five Wishes* (9), which incorporates the living will and health care proxy in an easy-to-understand format that is useful for family discussions.

We solicited demographic information about participant age, sex, race/ethnicity, and education; OAs' number and ages of adult children; and the ages of the YAs' and their parents, as well as YAs' number of siblings. Two ratings questions asked OAs to self-report their health and YAs to report their parents' health on a scale of 1 (poor) to 5 (excellent); and participants to rate the depth of discussions about EOLPP with their children (OAs) or parents (YAs) from 1 ("hardly discussed at all") to 7 ("have discussed completely and taken action"). Interviews averaged 60 to 90 minutes.

Analysis

We used several methods for addressing rigor in qualitative research (8,10–12). We kept meticulous records of interviews, which were audio taped and transcribed verbatim. We reviewed the transcripts while listening to the interview tapes to ensure accuracy. Transcripts were entered into the NVivo 7 qualitative analysis software (QSR International, Cambridge, Massachusetts), which was used for coding themes. Two researchers from different disciplines independently coded the transcripts through multiple iterations of coding and constant comparison; an audit trail was maintained documenting how the themes emerged.

Results

OAs were primarily female (13 [87%]) and white (10

[67%]), with four (27%) African Americans and one (7%) Asian. Mean age of OAs was 78.6 years (range: 70–88 years). OAs had a mean of 3.2 adult children ranging in age from 36 to 64 years (mean: 50.1 years). Four OAs had some high school; three others were high school graduates, five had at least some college, and two had attended graduate school; for one OA, education was unknown. OAs' self-rated health averaged 3.50; none reported their health as poor.

YAs also were primarily female (12 [80%]) and white (14 [93%]), with one African American. Mean age was 53.1 years (range: 42–63 years). YAs had a mean of 3.3 siblings. YAs' parents ranged in age from 68 to 99 years (mean: 82.6 years). Two YAs were high school graduates; six had at least some college, and seven had attended graduate school. We did not collect education information about the YAs' parents. YAs rated their parents' health at 2.87; none rated their parents' health as poor.

OAs rated their mean depth of EOLPP discussion with their adult children as 4.21; YAs rated their mean depth of discussion with their parents as 4.73, a nonsignificant difference. Eleven OAs said they wanted no heroic measures to prolong their lives, three said maybe or unsure, and one definitely wanted life-prolonging efforts. Nine YAs believed their parents would not want heroic measures, two believed they would, and four did not know. Three OAs and two YAs were familiar with *Five Wishes*.

From the differences that emerged about family discussions, we conceptually organized the responses (Figure) as follows:

- **Yes/Yes** (n = 9 OAs; n = 10 YAs): Parents are able to share their EOLPP with their children.
- **Yes/Not Yet** (n = 2 OAs; n = 2 YAs): Parents wish to discuss EOLPP (Yes), but their adult children do not (Not Yet).
- **Not Yet/Yes** (n = 0 OAs; n = 1 YA): Parents do not talk about EOLPP (Not Yet), but their adult children are willing to hear their wishes (Yes).
- **Not Yet/Not Yet** (n = 4 OAs; n = 2 YAs): Parents have not discussed EOLPP, and their adult children have not pursued the subject.

Eleven OAs reported being comfortable planning ahead and sharing their thoughts about EOLPP (Appendix A, no. 1). Nine OAs already had talked at length with at least

ELDERS: Willing to Discuss?			
Yes		Not Yet	
Elders talk	Elders try to talk	Elders unwilling or postponing	Elders unwilling or postponing
Planning occurs—information is exchanged	Small exchange of information possible	Small exchange of information possible but unlikely	No planning
Children listen, are receptive	Children cut off conversation	Children instigate discussion; receptive	Children do not instigate discussion
Yes	Not Yet	Yes	Not Yet
ADULT CHILDREN: Willing to Discuss?			

Figure. Likelihood of planning matrix: conceptual organization of responses from interviewed elders and adult children about whether they discuss end-of-life preparation and preferences

one adult child. However, even OAs and their children who discussed EOLPP had not always addressed all issues (Appendix A, no. 2). Six OAs reported trying to talk with their children but being rebuffed or having their children refuse to discuss the OAs' EOLPP (Appendix A, nos. 3–6).

Ten YAs reported talking with their parents about EOLPP (Appendix B). Five YAs either were not yet ready to discuss EOLPP or their parents had not broached the subject with them (Appendix C).

Four OAs and four YAs indicated their openness to discussing EOLPP or their recognition of it as a topic they should discuss but continued to postpone discussing (Appendices D and E). Obstacles to discussing EOLPP fell into five categories:

- **Protection of the children.** OAs believed they needed to shield their adult children from the fact of their parents' death. YAs believed their parents were shielding them.
- **Trust in other people to make the decisions.** OAs expressed trust in the family, God, and the physician. YAs mentioned their parents trusted them (children) and God to make end-of-life preparations but did not mention their parents' trust in the physician.
- **Preferences unknown.** OAs expressed not knowing their preferences. No YAs mentioned this as an issue with their own parents, but some did not know their parents' preferences.
- **Family rarely together.** Both OAs and YAs expressed

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as an impediment to discussing the parents' EOLPP the difficulty of gathering the family and finding an appropriate time to discuss the topic. YAs were more likely than OAs to mention distance and infrequent family visits as obstacles.

- **Fear of death.** OAs expressed fear or a wish to avoid discussing death. One YA indicated her father feared death.

Four facilitators helped OAs talk with their families about EOLPP (Appendix F):

- Acceptance of death,
- Religious faith or spirituality,
- Experience with hospital care (especially in regard to life-prolonging measures), and
- Perception of EOLPP discussion as a way to help the family.

Respondents who reported productive EOLPP discussions identified some successful strategies (Appendix G), as follows:

- **A casual approach.** At least four OAs reported mentioning their EOLPP casually to at least one or two children at a time and on an ongoing basis as a primary strategy for discussing the topic. Although not identified as such, YAs' descriptions also sometimes indicated a casual approach (Appendix B).
- **Discussion with one child.** Both OAs and YAs reported differences among children's willingness to discuss EOLPP. Willingness to listen by at least one adult child with whom the elder could comfortably talk helped the elder express EOLPP. Three OAs indicated daughters were easier than sons to talk with about EOLPP, but seven OAs could discuss EOLPP with their sons or found no difference between their sons and daughters. YAs reported observing differences in their siblings' abilities to discuss EOLPP with their parents.
- **Written EOLPP (Table).** Six OAs reported having spoken with their families about an advance directive but had not written their EOLPP. Seven OAs had written, signed, and shared their powers of attorney with their children: four had signed and shared their advance directives. Eight YAs reported their parents had written, signed, and shared their powers of attorney; eight reported their parents had signed and shared advance directives. Additionally, some OAs had given their children detailed instructions about their after-death arrangements.

Discussion

America has a death-denying culture (13), and people who cannot face death are not likely to be able to discuss EOLPP. The need for education and communication is evident (6,14–18). Only 18% of Americans have living wills (6). People sometimes trust, even prefer, others to make end-of-life decisions for them (16). Although 95% of elders in one study (19) said they “trusted” someone — more often children than spouses — to make decisions for them, fewer than half actually had spoken with the person they expected to make the decision. However, research suggests that discussing EOLPP lightens a family's decision-making burden (20).

Surrogate decisions are problematic (16). In one study, surrogates' decisions were wrong 30% of the time (5), erring mostly toward over-treatment. In reflecting on the hospital as the primary site of death for elders and on the fact that only 22% allow time to plan for death, Kaufman (20) noted, “It is ironic that, in the hospital setting, families are the players with the least knowledge . . . yet they are burdened with what seems to them untenable responsibility” (p. 38). Kaufman observes many families believe they must make life-or-death decisions and “the fact that patients rarely articulate to family or physicians their desires either for life prolongation by technological means or for the cessation of treatment” (p. 36) is a primary difficulty in determining appropriate treatment.

Thus, understanding the process of family EOLPP discussions is important. Our findings contribute to this understanding but are subject to limitations. First, study participants have not yet provided feedback about the validity of our findings (11,21). Second, our participants might differ from the general public in their willingness to discuss EOLPP, as evidenced by their consenting to an interview. Our small sample presumably would not include people who fear death to the extent they would not consent to an interview. Thus our matrix (Figure 1) assumes that, given the right time and right intervention, all elders and their adult children eventually will discuss EOLPP. However, further research is needed to determine whether an additional category, in fact, exists: a parent/child dyad that might never discuss EOLPP. A revised matrix would need to include this group. Finally, because our sample was primarily female and white, our results might not be generalizable to men or to people of other races/ethnicities; we are targeting additional interviews

to men and African Americans. Our recruitment of study participants from the local community council on aging counterbalanced any limitations inherent in the snowball selection technique.

In our study, a casual approach to EOLPP and writing down EOLPP were reported as effective. Both options overcome the obstacles of talking with one child at a time — which potentially could result in family conflicts about the parents' actual EOLPP — and the difficulties of gathering the family at one time and place. Writing EOLPP in some form and giving them to all their children ensures all family members will receive the same message. Even if the children do not read the information when it is written, they will have the parents' preferences when they need them.

Study participants showed interest in learning more about EOLPP. Health care and public health professionals could design interventions targeted toward people in each category of the matrix that would facilitate discussions about EOLPP. Another strategy to facilitate EOLPP discussions is to offer educational sessions that would, for example, explain *Five Wishes*, perhaps even as parent/adult child events, to encourage the dyads to address advance planning. Furthermore, the act of engaging in this interview seemed to spur some participants to begin thinking about their need to address EOLPP; a follow-up of our sample would reveal whether they later discussed EOLPP with their families after participating in our study.

As the older population has increased in the United States, the way elders die has become a public health issue. Our pilot study sheds light on the little-understood process by which elders do or do not discuss their EOLPP with their children. Despite its limitations, the study provided valuable insights from the perspectives of OAs regarding individual barriers and facilitators to discussing the topic. Future research is needed to identify interventions at the interpersonal and societal levels.

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Tables

Table. Actions Regarding Advance Directives Reported by Older Adults (N = 15) and by Younger Adults (N = 15) about their Parents, Study on End-of-Life Preparation and Preferences, May 2006

Action	Shared and Signed		Discussed, Not Written		No Action/Don't Know	
	OA	YA	OA	YA	OA	YA
Advance directive document	4	8	6	1	5	6
Health care power of attorney/ Health care decision maker	7	8	4	3	4	4

OA indicates older adults (aged ≥70 years); YA, younger adults (aged 42–63 years).

Appendices

Appendix A. Selected Comments From Older Adults (OAs) Who Had Discussed Their End-of-Life Preparation and Preferences With Their Adult Children, Regardless of Whether the Children Wanted to Discuss the Topic

1. One OA rated her discussion a 7, saying, "My kids know me. They know what I like and what I don't like."
2. Another OA rated her discussion a 3 "because there's lots I would still like to communicate with [my son] about."
3. One OA said, "I gave my daughter an envelope with directives, etc., and she said, 'I don't want to talk about this.' Every time I try to broach the subject, she doesn't want to talk about it. I said, 'Well, when will you talk about it?' She said, 'Well, I am gonna wait until something awful happens.' The envelope is still sealed in her desk."
4. The interviewer asked, "Have you had discussions with your son about what your wishes would be?" The OA replied, "To a degree, but he doesn't wanna talk about it. I am hoping to talk more. I kept some of [my husband's] ashes, and I said to my son one time, 'Well, honey, when I am gone, sprinkle daddy's ashes on top of mine and give it a little shake,' and he said, 'Mother!'"
5. One OA said, "I say anything to them about it and they want me to stop talking about it: 'Don't be talking about it, I don't want to hear it.'"
6. One OA told the interviewer, "I said I don't want to be kept alive . . . but I don't remember which one I told that. It was one of my sons. He just turned it off, so we will see. . . ."

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Appendix B. Selected Comments From Younger Adults Who Had Discussed End-of-Life Preparation and Preferences With Their Parents

1. "[My mother] doesn't like to discuss it head on; she takes a bit of an angle to get to it, but the content was there."
2. "We have talked about it, but we really haven't written anything down. We just have it mentally."
3. "We are starting to talk about what their services should be like, and Mother periodically drops the stuff on me, like, 'Boy, that's always been one of your dad's favorites.' So I write the stuff down real quick."

Appendix C. Selected Comments From Younger Adults Who Had Not Discussed End-of-Life Preparation and Preferences With Their Parents

1. "They never really said much . . . they did have a living will, but they did that without any real discussions with the rest of us . . . so nobody knew where they were or what they said."
2. "My dad discussed a lot about insurance. . . . But as far as making decisions about end of life, 'if I'm in the hospital, do you disconnect?' or whatever, none of that."
3. "[In] my husband's family . . . there was zero [discussion]. There was nothing,"
4. "You don't want to go there. You don't want to approach that in a conversation."

Appendix D. Selected Comments of Interviewed Older Adults Who Postponed Discussing End-of-Life Preparation and Preferences With Their Adult Children

General comments

1. "I realize I gotta do that. That's one thing I keep putting off."
2. "No action. I haven't really wanted to talk about it, but I know I need to."
3. "I haven't taken action, and every time I try, I haven't spoken to my son, but I have a feeling he'll say, 'Oh Mom, let's not worry about that.'"

Barriers to discussing end-of-life preparation and preferences

Protection of the children

1. "[My children] don't comprehend anything bad pertaining to me or their dad, but sometimes you have to face it. . . . As far as they are concerned, it's 20 years down the road or more, but it's not, but they think it is."
2. "I don't talk to my children about me dying because they are so protective of me. It would hurt them, and I know they don't want to hear anything like that. . . . They don't even want to think about it, so I don't bring up the subject. . . ."

Trust in family, God, or the physician to make the decisions for them

1. "I am not saying that when this happens do this, and when this hap-

pens do this. I trust my kids; they will make the right decision."

2. "I don't want to be kept alive. If God wants me to go, let Him let me go."
3. "I am gonna tell my doctor that I want a living will and let him put it in his file, and the only way that I want to be put on life support is for him to make decisions that I would come back to some kind of a good way of living."

Not knowing their preferences

"That part I haven't said too much. I want them to put me on life support sometimes I think, and then other times I don't."

Family rarely together

"I haven't talked to my children about it. I keep saying I am going to, but it's hard to get both of them here at the same time. They are in and out, and about the only time we get together is where we have a lunch or dinner or Christmas, Thanksgiving, or something."

Fear of death

1. "I haven't completely got over that fear. . . . Every once in a while, my medications get to a certain point and it seems like I have a different feeling inside, and I think well, you are just gonna die. Now this don't happen often, and then I begin to think, am I ready? So, I still have a little bit, I haven't got to that point yet where it's completely gone. It might not ever be gone on this earth."
2. "I think I live in a little bit of a dream world in that I really avoid unpleasant or sad things."

Appendix E. Selected Comments From Younger Adults Who Will Not Discuss End-of-Life Preparation and Preferences With Their Parents Who Want to Discuss the Topic

1. "Last Christmas, my mother brought out casket information . . . she was very serious about it . . . she was trying to show us what she had, and my siblings started joking with her. I was afraid she was going to get really upset because she was serious . . . but my siblings didn't want to talk about it, you could obviously tell that they didn't want her thinking and talking about that."
2. "I've actually talked with my siblings about it when the Terri Schiavo case came about, and I had the forms, and I wanted to bring them out too, but the only time we're all together is at the holiday time, so it just sort of seemed like it was a weird time."

Appendix F. Selected Comments From Interviewed Older Adults About Four Facilitators to Discussing End-of-Life Preparation and Preferences

Acceptance of death as a part of life

1. "It does not scare me in any way to talk about death because it's just something that if we live long enough we are going to die, but we don't want to. . . . Sometimes if you are lucky you get to where you can feel

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more at peace about it.”

2. “I was in denial. I am not in denial anymore, having gone through two in the last year. I do not have a negative feeling about death.”
3. “I am not morbid by any means and God and Heaven knows I would rather be here. I don’t wanna die, but the whole thing about it is, one of these days we’re all going to, and why not make the preparations?”
4. “I think when you are dead, you are dead. And I think if you don’t have nice memories, that would be terrible, but I am not a religious person anymore.”

Religious faith or spirituality

1. “When you have faith yourself, it don’t supposed to be upsetting to you because we are all born to die, and if you die with Christ, you are gonna live again. So I never think about dying . . . but I hope I be ready when God calls me. I have never seen anybody that still wanted to stay here when time come to go.”
2. “You are supposed to be ready and to prepare yourself for this and that’s the way I look at it, but it’s not easy, unless you are a Christian and you live right, you know there’s no problem, you are just as peaceful as that next person.”
3. “I am a strong believer in Christ. . . . Death is not with me a sad situation. It’s joy. When you see people suffer, you know they are better off gone than to keep suffering.”

Past experience with deaths of friends and family

“I don’t want all of that poked down my nose because you know when I had this surgery, they put all them things in my nose. . . . I really, if it would do any good, I would say it, but with my husband, I saw that [it] didn’t do any good.”

A way to help the family

1. “I have got to help my family. I have got to make some kind of decision when that time comes. I told him I didn’t want to be kept alive if I had cancer or something. . . . I’ve just gotta do it. I need to do it for their sake.”
2. “I know that one of these days I am gonna die, and I sure don’t wanna be laying there knowing that I am gonna be dying, and them worrying about this, that, and the other.”
3. “My son said, ‘I am sure glad you made that decision [to have his father cremated] because I would have had a lot of trouble making that decision.’ I said, ‘Well, Daddy and I talked about it a lot, and we were of the same opinion.’”

Appendix G. Selected Comments From Interviewed Older Adults and Younger Adults About Successful Strategies for Discussing End-of-Life Preparation and Preferences

Taking a casual approach

1. “All along I have mentioned it all the time. It’s not just a sit down decision . . . and they have taken it in.”

2. “It’s just kind of casually. . . . It’s casual, but I think they all know exactly what I want.”
3. “It’s been very casual . . . the fact that we want cremation and no heroics . . . very casual . . . It’s never been, ‘Let’s sit down and talk about this.’”

Discussing EOLPP with at least one child

1. “One of my sons would be a one because it makes him nervous, but then the other one that I put in charge of my affairs, I could tell him anything.”
2. “My older sister and my brother are open to talking about it. My youngest sister is really not willing to discuss it very much.”

Writing it down

1. “He had . . . everything printed out, written out. . . . He had already set aside, you know, the power of attorney for the living will and all of that had been done.”
2. “She just wrote it and gave it to me. ‘Read this and if you have any questions, let me know because this is what you are doing.’ I know what she would want. Like if there was some sort of crisis, I wouldn’t be wringing my hands wondering, what should I do? I mean, I know exactly.”

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ORIGINAL RESEARCH

Managed-Medicare Health Club Benefit and Reduced Health Care Costs Among Older Adults

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PEER REVIEWED

Abstract

Introduction

Our study was undertaken to determine the association between use of a health plan-sponsored health club benefit by older adults and total health care costs over 2 years.

Methods

This retrospective cohort study used administrative and claims data from a Medicare Advantage plan. Participants (n = 4766) were enrolled in the plan for at least 1 year before participating in the plan-sponsored health club benefit (Silver Sneakers). Controls (n = 9035) were matched to participants by age and sex according to the index date of Silver Sneakers enrollment. Multivariate regression models were used to estimate health care use and costs and to make subgroup comparisons according to frequency of health club visits.

Results

Compared with controls, Silver Sneakers participants were older, more likely to be male, used more preventive services, and had higher total health care costs at baseline. Adjusted total health care costs for Silver Sneakers

participants and controls did not differ significantly in year 1. By year 2, compared with controls, Silver Sneakers participants had significantly fewer inpatient admissions (-2.3%, 95% confidence interval, -3.3% to -1.2%; $P < .001$) and lower total health care costs (-\$500; 95% confidence interval, -\$892 to -\$106; $P = .01$). Silver Sneakers participants who averaged at least two health club visits per week over 2 years incurred at least \$1252 (95% confidence interval, -\$1937 to -\$567; $P < .001$) less in health care costs in year 2 than did those who visited on average less than once per week.

Conclusion

Regular use of a health club benefit was associated with slower growth in total health care costs in the long term but not in the short term. These findings warrant additional prospective investigations to determine whether policies to offer health club benefits and promote physical activity among older adults can reduce increases in health care costs.

Introduction

Despite the many benefits of physical activity, including better health, improved functioning, increased quality of life, and reduced mortality (1-4), approximately 25% of U.S. adults aged 65 or older engage in less than 10 minutes of moderate- or vigorous-intensity activities per week (5). Physical inactivity places an economic burden on the health care system and society as a whole (6-8). A longitudinal cohort study of people aged 54 to 69 showed that 2-year total health care expenditures were 7% lower for those who engaged in regular vigorous activity than

for their sedentary counterparts (9). Another study estimated that health care costs for a previously sedentary adult aged older than 50 who engages in moderate physical activity at least 3 days per week can be reduced by \$2200 over 2 years (10). As health care costs related to inactivity increase, more data are needed to assess the use of health policy and environmental change to promote health and reduce the impact of behavioral risks and chronic conditions (11-13).

Health plan promotion and support of physical activity via exercise programs as a coverage benefit has the potential to reach many people; 61% of Americans younger than 65 had employment-based health insurance in 2004 (14), and nearly 100% of Americans aged 65 or older had Medicare coverage. Two previous studies of a health plan-sponsored community-based group exercise program (EnhanceFitness) for Medicare Advantage plan enrollees found that adjusted 1-year health care costs were similar for participants and matched controls in a general population (15) and for a subgroup of members with diabetes (16).

The primary objective of this study was to determine whether the use of a health club benefit targeted to older adults was associated with a reduction in total health care costs. Our study extends the prior work in two ways. First, this study examines a different physical activity benefit (Silver Sneakers [SS]) in a larger population over a longer time frame, which enables us to determine whether participation is associated with change in health care use and costs over a 2-year period. Second, we used a larger sample to explore more fully the dose-response relationship between participation and total costs. Results from this study may provide evidence of the economic benefits of collaborations between health plans and health clubs to reduce physical inactivity by older adults.

Methods

Subject selection and eligibility

Our study was based at Group Health Cooperative of Puget Sound (GHC), a consumer-governed, mixed-model health maintenance organization with more than 500,000 members. We received administrative and claims data on 8473 members aged 65 or older who enrolled in the GHC Medicare Advantage (MA) plan, were continuously

enrolled at GHC for at least 1 year before joining the program, and participated in SS between January 1, 1998, and December 30, 2003. Up to three GHC MA enrollees ($n = 24,331$) who never used the program were matched by age and sex to serve as controls for each SS participant. Participants and their matched controls were each assigned an index date representing the month that the participant first enrolled in SS. We excluded members who had less than 2 years of continuous enrollment after their index date, had missing cost data in any of the 3 years, had long-term care costs at baseline, or were unmatched SS participants or controls, which left 4766 SS participants and 9035 matched controls in our study for analysis.

The SS program provided the GHC MA enrollees access to selected local fitness centers in an unstructured format. Participants had access to conditioning classes designed for older adults, exercise equipment, a pool, sauna, and other amenities that varied across facilities. A subcontractor administered the program and worked with the fitness centers. The GHC MA enrollees learned about the SS program from targeted mailings, a member benefits Web site, or their health care providers during routine preventive visits.

Data sources

GHC administrative data, which have been used extensively in prior research (17,18), were the source of all utilization, cost, patient demographics, and other covariates. Cost variables were derived from the GHC cost accounting system, which integrates clinical information, units of service, and actual costs from the general ledger for 15 separate feeder systems. GHC identified all costs as either direct patient care costs or overhead costs. All overhead costs are fully allocated to individual patient care departments. Departments captured in the database included medical staff, nursing, pharmacy, laboratory, radiology, hospital inpatient, and community health services. Units of service were weighted by relative value units for ancillary departments, by technical relative value units for radiology, by College of Anatomical Pathology units for laboratory, and by visit length for outpatient visits. From this process, the precise cost for each unit of service delivered was then calculated, and costs were assigned to patients on the basis of units of service used. For example, primary care costs included all direct and indirect costs associated with visits or telephone calls

by primary care or preventive medicine personnel that were related to direct patient care, preventive services, or risk factor reduction counseling.

The utilization outcomes we examined were for inpatient admissions, primary care visits, and specialty care visits (defined as obstetrics and gynecology services, cardiac diagnostics, diagnostic pathology, alternative medicine, and rehabilitative services). The cost outcomes we examined were for primary and specialty care costs, inpatient admission costs, and total health care costs. We selected primary care visits and costs because a more general outpatient cost summary was not available. Total health care costs were examined to provide an overall summary of the impact of SS participation on costs.

In the analysis, we controlled for covariates that might influence the economic outcomes that were available in GHC administrative data. These covariates included age, sex, baseline utilization or cost (as appropriate), inclusion on the GHC diabetes or heart registries, indication of arthritis on the outpatient visit problem list, patient risk, and a preventive services index. Comorbid conditions (arthritis, coronary artery disease, congestive heart failure, hypertension, depression, and diabetes) were ascertained from problem lists for outpatient visits according to *International Classification of Diseases, Ninth Edition, Clinical Modification* diagnostic codes (19). Patient risk was measured using RxRisk (20), a measure of chronic disease burden and comorbidity that was previously shown to have good predictive power for explaining odds of hospitalization (21) and total health care costs (15,16,22). RxRisk was calculated for each member on the basis of age, sex, and pharmacy utilization data for a 6-month period before the index date (20). Because members who use other preventive services may be more likely to participate in SS than are members who do not, we calculated a preventive services index to adjust for self-selection of health-oriented individuals into SS participation. The preventive services index was derived from the sum of the number of times a person received a fecal occult blood test, a flexible sigmoidoscopy, a screening mammogram, prostate cancer screening, an influenza vaccine, or a pneumococcal vaccine during the 2 years preceding the index date.

Statistical analysis

We included all SS participants in the main analyses regardless of whether they made any visits to a health club

over 2 years. We used two-tailed *t* tests and chi-square tests for unadjusted comparisons between SS participants and controls. We used multivariate ordinary least squares (OLS) regressions to determine differences in health care costs between SS participants and controls for 1 and 2 years after the index date while adjusting for age, sex, RxRisk, preventive services index, arthritis visits, inclusion in the health plan's heart or diabetes registries, and baseline use and costs. The results were similar to those obtained using generalized linear models with a gamma distribution and log-link function (23), so we present OLS results. Previous work suggests that using OLS regressions and large samples (≥ 500 observations) would yield unbiased estimates of absolute differences in use and cost data even when assumptions about normality and homoscedasticity are not met (24).

We performed exploratory dose-response analyses using OLS on the basis of the average number of health club visits during 2 years to determine incremental differences in total health care costs in members whose visits averaged less than 1 visit per week, 1 to less than 2 visits per week, 2 to less than 3 visits per week, and 3 or more visits per week. Average attendance was calculated by adding all health club visits during the 2 years and dividing by 104 weeks. SS participants who persisted with their visits to the health clubs for 2 years were compared with those who stopped using their physical activity benefit after the first year of SS enrollment. Because this study was interested primarily in differences in total health care costs between SS participants and controls and because subgroup analyses were purely exploratory, statistical tests were not adjusted for multiple comparisons.

To improve balance in observed covariates, we used propensity score (PS) adjustments in a sensitivity analysis (25,26) We estimated a logit model to generate each member's propensity of joining SS and entered PS as an additional covariate in our models. The inclusion of PS did not change the results of any of the models, so we present results from the simpler multivariate models.

All cost data were adjusted to 2003 dollars. Robust standard errors were used in all regressions. All statistical procedures were performed with Stata 9.0 (Stata Corporation, College Station, Texas). Institutional review boards at GHC and the University of Washington approved the study protocol.

Results

Unadjusted comparisons between SS participants and controls

Compared with controls, SS participants were slightly older, more likely to be male, had a lower chronic disease burden, used more preventive services, and had higher total health expenditures at baseline (Tables 1 and 2). A small percentage of members (2%) who signed up for the SS program never made a visit to a health club during the 2 years; another 2% did not visit a health club until the second year. The number of health club visits made by SS participants was 75 visits (median, 49; interquartile range, 11–120) in year 1 and 55 visits (median, 12; interquartile range, 0–89) in year 2.

The follow-up interval for all SS participants and controls was 2 years. In year 1, unadjusted total, inpatient admission, and specialty care costs were not different between SS participants and controls (Table 2). However, SS participants had more primary and specialty care visits (both, $P < .05$) and slightly fewer inpatient admissions than did controls ($P = .02$) in year 1. In year 2, SS participants had lower unadjusted total health care costs and fewer inpatient admissions than did controls (both, $P < .01$); unadjusted outpatient primary and specialty care utilization and costs were higher among SS participants (all, $P < .01$).

Adjusted comparisons between SS participants and controls

In year 1, adjusted total health care costs were similar for SS participants and controls (+\$2; 95% confidence interval [CI], -\$341 to \$344; $P = .99$) (Table 2). We observed a modest difference between SS participants and controls in inpatient admissions in the adjusted model (-1.0%; 95% CI, -2.1% to -0.1%; $P = .05$). SS participants made more primary and specialty care visits than did controls (both, $P < .001$).

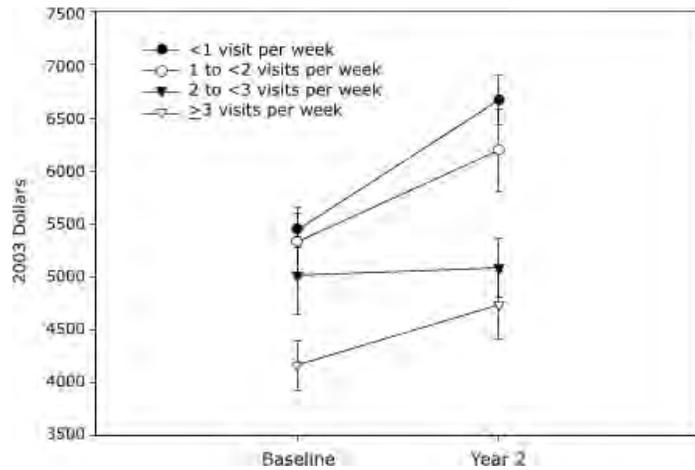
By year 2, total health care costs were significantly lower for SS participants compared with controls (-\$500; 95% CI, -\$892 to -\$106; $P = .01$). This difference in costs was mainly due to the fewer inpatient admissions among SS participants compared with controls (-2.3%, 95% confidence interval, -3.3% to -1.2%; $P < .001$) and the slightly lower inpatient costs (-\$270; 95% CI, -\$533 to -\$6; $P =$

.05). SS participants made more primary and specialty care visits and incurred greater costs associated with primary care than did controls (all, $P < .001$).

Exploratory adjusted dose-response analysis of health club use

SS participants were categorized according to the mean number of health club visits per week over 2 years: less than 1 visit per week, 1 to less than 2 visits per week, 2 to less than 3 visits per week, and 3 or more visits per week. We observed graded baseline differences in the proportion of women, RxRisk, mean preventive services index, and health care costs across the visit categories (results not shown). Adjusted models showed a significant threshold dose effect on total health care costs at year 2 (Figure). Compared with SS participants who averaged less than one visit per week, those who averaged 2 to less than 3 visits per week or 3 or more visits per week had similar reductions in total health care costs at year 2 (2 to <3 visits, -\$1252; ≥ 3 visits, -\$1309).

Approximately 61% ($n = 2902$) of the SS participants continued to use their health club membership in the second year. The regular attendance of these *continuers* is reflected in their total number (SD) of health club visits. In year 1, continuers made 109 (84) visits, and in year 2, they made 89 (86) visits, higher than the average number of health club visits for the SS group as a whole. Although total health care costs at baseline were similar for both subgroups, members who did *not* continue health club attendance in year 2 ($n = 1659$), or *noncontinuers*, had significantly greater health service use in year 1. For example, more noncontinuers (11%) had an inpatient admission for all causes than did continuers (8%). In addition, noncontinuers had a mean (SD) of 5.7 (4.5) primary care visits and 3.5 (3.4) specialty care visits in year 1, compared with continuers, who had 5.1 (4.2) primary care visits and 3.2 (3.3) specialty care visits during the same year. Because we did not have access to data on whether disease burden increased in year 1, we compared the proportion of outpatient visits with new diagnostic codes between these two subgroups. In year 1, noncontinuers were more likely to receive new diagnostic codes on their problem list for arthritis (12.5%, noncontinuers vs 10.3%, continuers), cardiovascular disease (13.6%, noncontinuers vs 12.0%, continuers), diabetes (2.6%, noncontinuers vs 2.0%, continuers), and depression (8.1%, noncontinuers vs 5.6%, continuers).



Visits per Week	Comparison Group Visits per Week	Year 2 Cost Difference, \$ (95% CI)	P Value
<1	1 to <2	-300 (-1166 to 566)	.50
	2 to <3	-1252 (-1937 to -567)	<.001
	≥3	-1309 (-2061 to -558)	.001
1 to <2	2 to <3	-952 (-1872 to -33)	.04
	≥3	-1009 (-1985 to -34)	.04
2 to <3	≥3	-57 (-880 to 766)	.89

Figure. Adjusted total health care costs of Silver Sneakers (SS) participants in 2003 dollars, by mean number of health club visits per week for 2 years (top) and year 2 cost differences between categories of visits per week (bottom). SS participants (n = 4766) were categorized according to the mean number of health club visits per week over 2 years: less than 1 visit per week (n = 2778), 1 to less than 2 visits per week (n = 819), 2 to less than 3 visits per week (n = 593), and 3 or more visits per week (n = 576). Error bars indicate standard errors.

Discussion

We found that older Medicare beneficiaries who elected to use a health plan–sponsored physical activity benefit had significantly lower total adjusted health care costs (–\$500) 2 years after the index start date compared with similar members who did not participate in the program. This cost difference is primarily a result of a lower number of SS members who had any inpatient admission combined with slightly lower inpatient care costs. We also found that greater use of the health club membership was associated with smaller increases in total health care costs from baseline to year 2. These results extend previous work suggesting that increased physical activity is associ-

ated with positive health outcomes, reduced mortality, and lower health care costs (2,9,10,27,28). Our estimates of cost reductions as a result of participation in the physical activity benefit were generally lower than those reported in other published studies that examined health care costs in relation to self-reported physical activity in older adults aged 59 to 69 (9) and older adults with a mean age of 63 (10). To our knowledge, this is the first study to examine the longitudinal effects of a health plan–sponsored physical activity benefit on health care costs and utilization for a large sample of older adults.

Notably, the cost of the health club benefit was included in the overall cost allocations in this study. Therefore, in constructing such benefits, payers will need to ensure that the benefit cost does not exceed savings and potential resources required to build incentives for regular participation. For older adults, greater access to fitness facilities may not necessarily encourage greater exercise participation. Recent figures from the health plan indicate that 25% of the eligible plan members were enrolled in the SS program in 2006. In any given month on average, however, only 28% of these enrollees actually visited the facilities at least once; that is, approximately 7% of the total plan membership actively used their benefit.

Many factors may influence a member’s decision to make use of such benefits, such as awareness of the benefit, perceived accessibility to the fitness center or other exercise programs, and favorable attitudes and beliefs about exercise. Although a health care provider may mention the SS program to an older adult member during biennial preventive health visits, the health plan currently does not have formal follow-up processes in place to ensure that members are regularly encouraged to either continue with SS or other community-based exercise programs. Although efforts to increase physical activity in sedentary older adults can be resource-intensive and challenging, the financial returns for health plans that offer such physical activity benefits could be maximized with targeted efforts (29). Modest investments in improving the structure of SS to encourage consistent use of the physical activity benefit (e.g., 2 to 3 visits per week) could result in greater cost savings for the health plan.

Although a full economic analysis of the SS program that simultaneously accounts for costs and effects would be useful for health plans and decision makers (30), we did not have health status data for the GHC member population

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during this period. Insights can be gleaned from one recent cost-effectiveness analysis from the United Kingdom, which showed that a large-scale community-based program of exercise classes for older adults was effective in producing improvements in physical and mental health at an incremental cost of \$33,637 per quality-adjusted life year gained (31). This cost estimate is remarkable, given that only 26% of the eligible study sample actually attended one or more class sessions — a factor that would have blunted estimates of health benefit, thereby making the cost-effectiveness ratio less favorable. More trials of such magnitude with rigorous cost-evaluations are clearly needed in the United States.

As is the case with all observational studies, we cannot completely exclude residual confounding or selection bias as an alternative explanation for our findings. SS participants engaged in more preventive screenings and had fewer illnesses than did controls. These differences may account for the lower health care costs regardless of participation in an exercise program. In addition, SS participants who were no longer using their health club benefit in year 2 had greater health service use in year 1 and indeed appeared to have developed new health problems that could have interfered with their continued participation. We did not have data on the types of exercise SS participants engaged in at the health clubs, nor did we have information on non-SS physical activity for all subjects. However, participation in other physical activity by controls would only have underestimated the differences in cost savings between the groups.

We attempted to control for both health status and health-seeking behavior by including a measure of chronic disease burden and a preventive services index in our regression models. We also included cost and utilization values before the index dates. By including these values as covariates in models with the same outcome at follow-up as the dependent variable, we addressed both potential confounding and differences between the groups at baseline. Participation in the SS program over time may have helped to increase older adults' functional capacity and self-efficacy to engage in other physical or social activities outside the program. This could partially explain why health care costs for participants did not differ from those for controls in year 1 but were significantly reduced in year 2, despite declines in the total number of SS visits over that time.

We showed that elective participation in a health club benefit, which had no impact on health care costs for older adults in the first year, was associated with lower total health care costs in the second year. Moreover, greater use of such benefits resulted in smaller increases in health care costs over 2 years. Given the limitations of the study design and methods, these findings need to be confirmed with randomized controlled trials to rule out the influence of self-selection and thereby provide more definitive evidence about the health and economic outcomes that result from health plans providing a health club benefit. These early results are encouraging, and if confirmed, may point to an effective strategy to increase physical activity among older adults.

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Dr. Nguyen had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. Other contributions include study concept and design: Nguyen, LoGerfo, Ackermann, Maciejewski; acquisition of data: Williams; analysis and interpretation of data: Nguyen, Ackermann, Maciejewski, Berke, Williams, LoGerfo; drafting of the manuscript: Nguyen, Ackermann, Maciejewski; critical revision of the manuscript for important intellec-

tual content: Nguyen, Ackermann, Maciejewski, Berke, Patrick, Williams, LoGerfo; statistical analysis: Nguyen, Maciejewski, Williams.

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Tables

Table 1. Demographic and Health Characteristics of Participants and Controls, Silver Sneakers (SS) Program, Group Health Cooperative of Puget Sound, Seattle, Washington, 1998–2003

Characteristic	Controls (n = 9035)	SS Participants (n = 4766)	P Value ^a
Demographics			
Age, y, mean (SD)	72 (5)	73 (5)	.09
Women, n (%)	5987 (66)	3012 (63)	<.001
Comorbidities,^b n (%)			
Arthritis	1450 (16.1)	990 (20.8)	<.001
Coronary artery disease	1087 (12.0)	593 (12.4)	.48
Inclusion in health plan's heart registry	1681 (18.6)	917 (19.2)	.36
Congestive heart failure	412 (4.6)	145 (3.0)	<.001
Hypertension	2233 (24.7)	1129 (23.7)	.18
Depression	816 (9.0)	458 (9.6)	.27
Diabetes	1427 (15.8)	620 (13.0)	<.001
Inclusion in health plan's diabetes registry	1413 (15.6)	618 (13.0)	<.001
RxRisk, ^c \$, mean (SD)	2557 (1676)	2416 (1443)	<.001
Preventive services index, ^d mean (SD)	1.8 (1.7)	2.4 (1.8)	<.001

^a Unadjusted comparisons were made using t test for unequal variance (continuous variables) or chi-square test (dichotomous variables).

^b Comorbid conditions (arthritis, coronary artery disease, congestive heart failure, hypertension, depression, and diabetes) were ascertained from problem lists for outpatient visits according to *International Classification of Diseases, Ninth Edition* diagnostic codes (19).

^c RxRisk is a measure of chronic disease burden and comorbidity (20) and is expressed as predicted 6-month costs in 2003 dollars. Higher costs represent higher comorbidity.

^d Preventive services index is the sum of the number of times a person received preventive services in the 2 years preceding the index date. The following services were counted: fecal occult blood test, flexible sigmoidoscopy, screening mammogram, prostate cancer screening, influenza vaccine, and pneumococcal vaccine. Counts ranged from 0 to 8.

Table 2. Health Care Use and Health Care Costs 1 and 2 Years After Index Start Date, Silver Sneakers (SS) Program, Group Health Cooperative of Puget Sound, Seattle, Washington, 1998–2003

Use or Cost Measure per Year	Controls (n = 9035)	SS Participants (n = 4766)	Adjusted Mean Difference ^a (95% Confidence Interval)	P Value
Health Care Use				
No. (%) of people with an inpatient admission				
Baseline	825 (9.1)	432 (9.1)	NA	NA
Year 1	984 (10.9)	454 (9.5)	-1.0% (-2.1% to -0.1%)	.05
Year 2	1129 (12.5)	471 (9.9)	-2.3% (-3.3% to -1.2%)	<.001
No. of primary care visits per person				
Baseline ^b	4.5 (5.0)	5.1 (4.3)	NA	NA
Year 1	4.7 (4.6-4.8)	5.3 (5.2-5.5)	0.40 (0.27-0.53)	<.001
Year 2	4.8 (4.7-4.9)	5.3 (5.2-5.4)	0.26 (0.13-0.40)	<.001
No. of specialty care visits per person				
Baseline ^b	2.7 (3.2)	3.2 (3.3)	NA	NA
Year 1	2.9 (2.8-3.0)	3.3 (3.2-3.4)	0.22 (0.11-0.33)	<.001
Year 2	3.0 (2.9 to 3.1)	3.4 (3.3-3.5)	0.25 (0.14-0.36)	<.001
Health Care Costs per Person, \$				
Total health care costs				
Baseline ^b	4693 (7288)	5212 (8530)	NA	NA
Year 1	5687 (5486-5888)	5677 (5388-5966)	2 (-341 to 344)	.99
Year 2	6742 (6480-7003)	6155 (5843-6466)	-500 (-892 to -106)	.01
Inpatient admission costs				
Baseline ^b	1000 (4381)	1248 (6182)	NA	NA
Year 1	1391 (1268-1515)	1346 (1130-1561)	-32 (-279 to 214)	.80
Year 2	1803 (1644-1963)	1497 (1283-1711)	-270 (-533 to -6)	.05
Primary care costs				
Baseline ^b	788 (876)	911 (871)	NA	NA
Year 1	829 (810-849)	962 (937-988)	101 (70-133)	<.001
Year 2	875 (854-896)	983 (956-1010)	80 (46-113)	<.001
Specialty care costs				
Baseline ^b	716 (1254)	793 (1213)	NA	NA
Year 1	813 (783-843)	825 (792-857)	-14 (-58 to 29)	.51
Year 2	890 (860-922)	935 (895-975)	37 (-12 to 86)	.14

Values are expressed as either mean (SD) or mean (95% confidence interval). NA indicates not applicable.

^a Adjusted mean difference is defined as the change from baseline in participants minus the change from baseline in controls. Differences were calculated using multivariate linear regression models with robust standard error estimates that controlled for age, sex, preventive services index, RxRisk (a measure of chronic disease burden and comorbidity [20]), indication of arthritis on the outpatient visit problem list, inclusion in the health plan's diabetes or heart registries, and baseline measures of health care utilization and cost.

^b Two-tailed *t* tests and chi-square tests were used for unadjusted comparisons between controls and SS participants at baseline, *P* < .05.

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COMMUNITY CASE STUDY

Translating a Community-Based Motivational Support Program to Increase Physical Activity Among Older Adults With Diabetes at Community Clinics: A Pilot Study of Physical Activity for a Lifetime of Success (PALS)

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PEER REVIEWED

Abstract

Background

Regular physical activity is an important goal for elders with chronic health conditions.

Context

This report describes Physical Activity for a Lifetime of Success (PALS), an attempt to translate a motivational support program for physical activity, Active Choices, for use by a group of diverse, low-income, community-dwelling elders with diabetes.

Methods

PALS linked physical activity assessment and brief counseling by primary care providers with a structured referral to a community-based motivational telephone support program delivered by older adult volunteers. People with diabetes aged 65 years or older who were receiving

care at two community clinics were randomized to receive either immediate or delayed intervention. The main intended outcome measure was physical activity level; the secondary outcome measure was mean hemoglobin A1c.

Consequences

One-third of those offered referral to the PALS program in the clinic setting declined. Another 44% subsequently declined enrollment or were unreachable by the support center. Only 14 (21%) of those offered referral enrolled in the program. Among these 14, the percentage who were sufficiently active was higher at follow-up than at enrollment, though not significantly so. Using an intent-to-treat analysis, which included all randomized clinic patients, we found no significant change in mean hemoglobin A1c for the intervention group compared with controls.

Interpretation

A community-based referral and support program to increase physical activity among elderly, ethnically diverse, low-income people with diabetes, many of whom are not English-speaking, may be thwarted by unforeseen barriers. Those who enroll and participate in the PALS program appear to increase their level of physical activity.

Background

Despite the significant benefits of regular physical activity for older adults (1-3), the majority are not optimally active (4). Although older adults with diabetes have even

more reason to be active than younger adults, their levels of activity also are low (5). Thus, encouragement and monitoring of physical activity by primary care providers has been recognized as a key indicator of quality of care for patients with diabetes (6).

Lack of adequate physical activity among people with diabetes raises the question of how clinicians can best improve the activity levels of their patients. Although it is not clear whether physician counseling is effective in increasing physical activity levels (7), such counseling with trained educators providing in-person follow-up or telephone support has shown promise (3,7).

These observations formed the background for the project described here, Physical Activity for a Lifetime of Success (PALS). The PALS program links clinics to a senior center-based program modeled after the Active Choices program (8). The Active Choices model is a 6-month program in which community agencies assist individuals in engaging in a physical activity program. This model has been shown to increase caloric expenditure in young and middle-aged adults. However, it has not been evaluated in a diverse or low-income population of older adults with diabetes (8). Thus, the goal of our study was to attempt to translate a variant of the Active Choices program to older, low-income, ethnically diverse people with diabetes in partnership with community clinics.

Context

Setting

We conducted our study in the Southeast Seattle neighborhood from March 1, 2005, through July 31, 2006. This neighborhood is largely below the median income for the city and the surrounding county (King County), and when the study began, most of the population aged 65 years or older was from races other than white. An earlier study had demonstrated that the neighborhood had sufficient resources (i.e., older adult-oriented physical activity programs, exercise facilities) to support physical activity for older adults, but demand for such programs was relatively low (9). Before this intervention, the University of Washington's (UW's) Health Promotion Research Center had also been promoting opportunities for seniors to be active (10). While the PALS study was in progress, the research center undertook a related effort to reduce

common barriers to physical activity (11).

We decided that developing a program that enhanced existing efforts to improve care of people with diabetes would be most sustainable. After reviewing evidence-based support programs, we chose to import the Active Choices program (8) in a modified format and rename it Physical Activity for a Lifetime of Success, or PALS. The organizations involved were two community clinics, the neighborhood senior center, a community social services provider, and the UW's Health Promotion Research Center. PALS was made available for referral through primary care providers (PCPs). The community clinics had an ongoing quality assurance program, including participation in a collaborative care model to monitor their patients with diabetes (6). An electronic registry had been in place for several years to provide reminders, including a record field addressing physical activity (6). In July 2004, the community clinics adopted the Seattle Rapid Assessment of Physical Activity (RAPA) program (12) to assess physical activity levels for all their older patients with diabetes.

All community partners contributed to the PALS project design. We obtained institutional review board approval from UW. Before the start of the study, participating community clinics mailed a letter to all eligible participants to inform them of the project.

Participants

All patients with diabetes aged 65 years or older who had visited a clinic within the previous 18 months were eligible to participate. No a priori clinical reasons for exclusion were defined, but PCPs eliminated any patients who they determined would not be medically suitable because of comorbidities. Comorbidities that precluded participation were profound dementia, severe congestive heart failure, decompensated psychiatric illness, and terminal malignancy. Some patients were excluded because of a lack of interpreter services. Lack of telephone access was also a reason for exclusion.

Recruitment

The PCP referred patients to the PALS program during routine appointments. Patients completed the RAPA questionnaire at their first visit following the start of the study period. This prompted the PCP to review the patient's physical activity level and discuss the benefits

of physical activity. The PCP then developed a prescription for physical activity (sample prescription available at <http://depts.washington.edu/hprc/docs/parx.pdf> *) in collaboration with the patient. To avoid making the process overly complex, we did not formally assess motivational readiness to exercise.

After developing the physical activity prescription, the PCP asked the patient if he or she would be receptive to contact by the PALS community support program. Patients who expressed interest signed a consent form permitting the sharing of their name, contact information, and exercise prescription with community partners. A referral was then faxed to the PALS project coordinator, who arranged an intake interview. If a person decided to participate, additional consent was obtained on the first visit to the senior center.

Delayed intervention group

All clinic patients, regardless of group assignment and interest in participating in the PALS program, received a guide to local activity resources, as well as handouts about the benefits of exercise, tips on safety, and strength and balance exercises.

Methods

Physical activity intervention

The PALS program was a motivational support program delivered by older adult volunteers over the telephone. The theoretical framework underlying the program on which PALS is modeled, Active Choices (8), is behavioral, incorporating principles of self-efficacy and tailoring support to an individual's readiness to change. We adapted the Active Choices program in several ways. First, we streamlined volunteer training materials and reduced the literacy level of participant materials. Second, we focused on increasing physical activity levels rather than on heart-rate goals. Third, we hired a PALS coordinator who conducted intake interviews. Fourth, the staff of the neighborhood senior center recruited telephone volunteers from among active older adults already engaged in senior center programs. Training for telephone volunteers was conducted by Active Choices staff who consulted on the PALS project and, later, by the senior center program coordinator.

We made ongoing telephone support available to participants. Except for an initial interview and intake conducted at the senior center, the client participant chose the site to carry out his or her physical activity plan and could include any combination of home- and community-based programs. Participants were encouraged to continue with the PALS program for a minimum of 6 months. Certain barriers to increasing activity were reduced: fees were waived for EnhanceFitness classes (a community-based group exercise program for older adults that originated in the Seattle area) (13), and transportation was offered to group walking sites.

PALS program staffing

The PALS program was staffed by a half-time project coordinator employed by Senior Services of Seattle/King County and was based at the senior center. Primary skills sought in the coordinator were an ability to communicate effectively, a genuine interest in working with older adults, experience in engaging and motivating volunteers, and a personal commitment to being physically active.

Randomization

Clinic patients with diabetes were offered the program in a staggered manner, with one set of patients randomly allocated to a group offered PALS participation early, and another to one offered PALS 1 year later. Eligible participants were identified from the diabetes registries of each of the participating community clinics and randomly assigned to the immediate intervention group or to the 1-year, delayed intervention group. People with diabetes who reached age 65 or who newly established care at the beginning of the study were also randomized to the immediate or delayed intervention groups. Those who became newly eligible later in the study period were added to the delayed intervention group. Both these groups of patients are referred to here as "late-added participants."

Outcome measurements

The primary outcome measure for the PALS study was the participant's level of physical activity, as measured by the RAPA questionnaire (12). RAPA scores of 1–3 correspond to minimal physical activity, scores of 4 and 5 are suboptimal but consistent with some potential health benefit (4), and scores of 6 and 7 are consistent with the U.S. Surgeon General's recommendations (14) for optimal

physical activity. RAPA assessments were completed upon enrollment and again at 6 or more months following enrollment.

Our secondary outcome measure was average hemoglobin A1c (HbA1c), which was assessed within 6 months of commencement of the study and at follow-up clinic visits 6 months or more after the study began.

Data analysis

We assessed differences between the two study groups at baseline with two sample *t* tests for continuous variables and chi-square tests for dichotomous variables. We used the McNemar test for matched pairs to assess differences between RAPA scores at enrollment and at follow-up.

Consequences

Characteristics of participants randomized to immediate and delayed intervention groups

Table 1 shows baseline characteristics of eligible participants, by intervention group. Those randomized to the immediate intervention group were significantly older than those in the delayed intervention group, because many of those who “aged in” on turning age 65 (late-added participants) were added to the delayed intervention group. The groups were otherwise well balanced with respect to sex, race, and language, as well as baseline RAPA scores and HbA1c values. Age, blood pressure, body mass index, or HbA1c did not differ significantly between those who enrolled in PALS and those who did not.

Success of attempt to recruit community-based, sedentary older adults

Fourteen of sixty-five persons who were offered the program enrolled (Figure).

Impact of PALS on physical activity levels and HbA1c results

Among the 14 PALS participants, the percentage who were sufficiently active increased, although not significantly (Table 2).

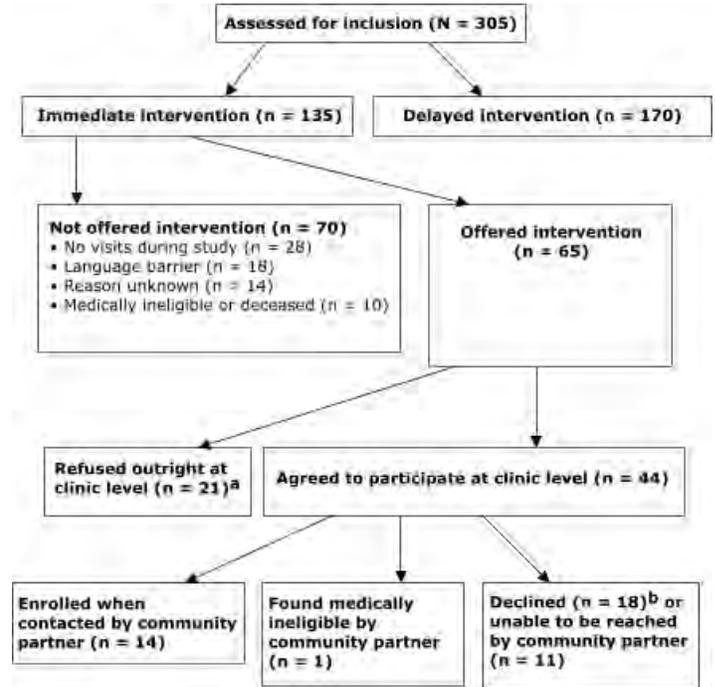


Figure. Participant flow, PALS study, 2005 – 2006.
^a Reasons for outright refusal were lack of interest, feeling at an age for rest rather than physical activity, feeling already active enough, perceived ill health and consequent inability to be more active, depression, unfamiliarity with the senior center, and uneasiness about having a telephone call from a stranger.
^b Reasons for declining after initially agreeing to participate were lack of interest, too busy, other issues of higher priority, and difficulty comprehending English.

Change of HbA1c levels did not differ significantly between immediate intervention participants (average HbA1c decline, 0.1%) and delayed intervention participants (average HbA1c decline, 0.3%).

Barriers and facilitators encountered

Time constraints inherent in the outpatient visit were a probable barrier to providers’ offering the intervention. This factor may have been responsible for the 20% of potential participants who were never offered the intervention. Opportunities to discuss physical activity during a visit to a health care provider were frequently limited by a more acute medical issue.

Lessons learned

Clinic visits may not be an ideal environment in which to engage participants. In addition, motivating seniors to begin exercising is a major challenge.

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Subsequent steps

Because clinic visits may not be ideal settings for engaging participants, UW researchers and community clinics discontinued recruiting during clinic visits. The community clinics' health educator became responsible for contacting patients with diabetes to invite them to participate in PALS. The clinics also lowered the eligibility age for PALS to 50 years.

We are considering conducting focus groups with patients who did not enroll in PALS to understand barriers that prevented them from enrolling and to solicit their ideas about delivering such a program. In addition, we are considering obtaining feedback from PCPs on their perceptions of PALS and perspectives on offering it to patients.

Feedback to community

We have shared the findings from this study with key physician providers at each of the community clinics. We also have discussed the findings with the director of the senior center.

Interpretation

This analysis of an attempt to engage low-income, ethnically diverse older adults in a community-based, motivational physical activity support program yielded two main findings: 1) participation rates among those eligible were low overall and 2) the program had some impact on physical activity levels among those who did enroll.

Participation rates for PALS appear to be similar to those of a comparable program. An Active Choices intervention had 45%–53% participation after clients expressed interest in the program (15). In our study, 14 (44%) of 32 clients who were willing to discuss the program and whom we were able to contact agreed to participate.

The low participation rates in PALS may have several explanations. First, of the half of those assigned to the intervention group who were never offered the intervention, 40% were not offered it because they did not visit the clinic during the study period. Another 25% lacked needed interpreter services, and 14% were medically unable to participate. In efficacy studies of physical activity (3), people who did not speak fluent English or who had

medical limitations are excluded at the outset; however, our goal in this evaluation was to use a real-world approach that could be replicated in clinical settings. That is, we attempted to offer the program broadly with as few a priori exclusions as possible.

A second major reason for low participation rates was that 30% of those offered the intervention declined participation outright. They offered several reasons for declining (Figure): lack of interest, feeling at an age for rest rather than physical activity, feeling already active enough, perceived ill health and consequent inability to be more active, depression, unfamiliarity with the senior center, and uneasiness about having a telephone call from a stranger. Low participation also may have been related to cultural issues.

The third major reason for low participation was the 70% of those who agreed to participate were never reached by the study coordinator or declined participation when reached. Reasons may have included moving from the area or a desire to please their PCP by agreeing to participate when they had no intention of doing so. Specific reasons offered for declining when contacted by the PALS coordinator (Figure) were lack of interest, too busy, other higher priorities, and difficulty understanding English.

Participants who enrolled in PALS appeared to improve their level of physical activity. However, our numbers are small, so this finding should be interpreted with caution. Further study of the PALS model involving larger numbers of older adults is warranted.

In addition to the small number of participants, our study has several other limitations, the most important of which derive from grafting a translational research project such as PALS onto a community clinics' ongoing quality improvement effort. We were dependent on the PCPs' routine clinical behavior. For this reason we did not have completed RAPA questionnaire scores on all eligible clients and so were unable to conduct an intent-to-treat analysis of our physical activity measure. This contrasts with traditional research studies in which baseline levels of physical activity are assessed for all who agree to participate. Although the RAPA questionnaire was designed to be a simple, self-administered form, many patients needed assistance to complete it because of low literacy or lack of fluency in English. Clinic staff were often unable to assist because of other demands on their time.

These results indicate that a community-based program designed to increase physical activity may confront substantial challenges when offered to ethnically diverse, low-income, elderly adults with diabetes, even when some identified barriers, such as fees for the EnhanceFitness program and lack of transportation, have been minimized. The impact of an ongoing quality assurance program to assess physical activity in a primary care clinic population remains to be determined.

Other recent practice-based studies attempting similar translational research for other aspects of diabetes care have found little or no differences in outcomes, despite monitoring of key measures of quality of diabetes care with feedback to providers and patients and improvement in care processes. The lack of impact of these studies on key health outcomes may be related to the usual attempt in translational research to reach a representative sample of the population under study rather than (as in efficacy trials) a carefully selected subgroup that meets a clear set of inclusion and exclusion criteria (16).

Over time, as the importance of physical activity is repeatedly discussed, participation among people who initially were uninterested in increasing physical activity may improve. If the goal of enhancing physical activity among the elderly is to be achieved, exploration of the barriers to activity among those who declined to participate in our program would be valuable information for improving future programs.

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Tables

Table 1. Baseline Characteristics of Study Participants, Physical Activity for a Lifetime of Success (PALS), 2005-2006

Characteristic	Immediate Intervention (n = 135)	Delayed Intervention (n = 170)	Group Test P value ^a
Age (y, mean [SD])	73.6 (7.9)	71.9 (6.3)	.04
Female (%)	71.9	65.9	.23
Races other than white (%)	80.6 (n = 134)	85.9 (n = 170)	1.14
Non-English speaking (%)	38.6 (n = 132)	43.2 (n = 169)	.64
Preintervention HbA1c, mean (SD)	7.0 (1.5)	7.2 (1.6)	.36
Preintervention RAPA score distribution:			.72
1-3	51.0%	50.5%	
4 or 5	23.0%	27.3%	
6 or 7	26.0%	22.2%	

SD = standard deviation, HbA1c = hemoglobin A1c.
^a For continuous variables, two sample t-test. For dichotomous variables, chi-square.

Table 2. Distribution of Rapid Assessment of Physical Activity (RAPA) Scores for PALS Participants (N=14) at Enrollment and at 6 or More Months Following Enrollment, 2005 - 2006 ^a

RAPA Score	At Enrollment (%)	≥6 Months Following Enrollment (%) ^b
1-3	42.9	28.6
4 or 5	35.7	28.6
6 or 7	21.4	42.9

^a P = .25 for RAPA scores dichotomized to sufficiently active (yes/no).
^b One participant had no RAPA measurement at 6 months but did have a RAPA measurement at 12 months; the 12-month RAPA score was used here.

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Depression as a Major Component of Public Health for Older Adults

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PEER REVIEWED

Abstract

Although public health is often conceptualized only as the prevention of physical illness, recent data suggest that mental illnesses are increasingly relevant to the mission of disease prevention and health promotion. Projections are that by 2020, depression will be second only to heart disease in its contribution to the global burden of disease as measured by disability-adjusted life years. Also, as the population ages, successive cohorts of older adults will account for increasingly larger segments of the U.S. population. We present the diagnostic criteria, prevalence, and risk factors for depressive disorders among older adults; the challenges of recognizing and treating depression in this population; the cost-effectiveness of relevant public health interventions; and the public health implications of these disorders.

Introduction

Depressive disorders, which are syndromes characterized by the impairment of mood regulation, most commonly include major depression and dysthymia, a disorder characterized by chronic low mood (1,2). In older adults (generally defined as aged 65 years or older), these disorders may also be characterized by impairment in cognition, a syndrome sometimes referred to as *pseudodementia* (2), and by psychomotor agitation or retardation (1). As

a result, symptoms of depressive disorder are frequently masked in older adults and may initially appear to be cognitive impairment or an early sign of neuroendocrine and related chronic disorders, making physical and laboratory examination of older adults with symptoms of depressive disorders important to their care.

Although research shows that the prevalence of major depression is generally lower among older adults than among young adults (3), understanding depressive disorders among older adults remains vital to public health. Rates of major depression rose markedly over the past decade (4), suggesting that future cohorts of older adults will have increasing numbers of people who have experienced or are contending with depressive disorders. Projections suggest that by 2020, depression will become the second leading cause of disease worldwide, as measured by disability-adjusted life years (5). Furthermore, depression characteristically complicates the course and outcome of other illnesses among older adults.

Perhaps more compelling, depressive disorders are strong predictors of suicide for older adults, and the majority of those who committed suicide had seen their health care providers within the month before their deaths (6). Despite the lower rates of depression among older people (3), suicide rates are higher in this age group than in any other (7), suggesting that significant depressive symptoms may indicate a serious threat to the health and survival of older adults.

Tragically, both older adults and their health care providers may be misguided by the belief that depression is an expected part of aging (8). Also, depressed older adults may have multiple complaints (9), making the diagnosis and treatment of depressive disorders particularly difficult (8,9). These findings suggest the need for public health

interventions to destigmatize the diagnosis and treatment of depression and to better enable older adults and their health care providers to recognize this condition. To help better address these issues, we describe recent developments in understanding the characteristics of depressive disorders in older adults and provide an overview of the diagnostic criteria, prevalence, risk factors, and public health impact of these disorders.

Methods

We searched PubMed (National Center for Biotechnology Information, Bethesda, Maryland) using the keywords *depression* and *dysthymia* crossed with the search terms *public health* and *older adults* and found 51 articles relevant to our study. We limited our review to articles that were published in the past 10 years and that provided definitional or diagnostic criteria for depressive disorders, indicated a specified observation interval, and for the most part, reported on empirical investigations. Subject matter experts suggested additional articles. Table 1 describes the 19 articles retained for comprehensive review.

Diagnostic Criteria for Depression and Dysthymia

According to the *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition (1), the diagnosis of major depression can be made if a patient has five or more of the following symptoms during the same 2-week interval with at least one of the symptoms being either depressed mood or loss of interest or pleasure in activities that were previously pleasurable:

- Depressed mood
- Loss of interest or pleasure in previously pleasurable activities
- Significant weight gain or loss
- Insomnia or hypersomnia
- Psychomotor agitation or retardation
- Fatigue
- Feelings of worthlessness or inappropriate guilt
- Impaired concentration
- Recurrent thoughts of death

Although some empirical investigations use these criteria to determine eligibility for inclusion as study subjects,

these investigations must be distinguished from studies using clinically significant depressive symptoms, because the latter may include some study subjects who meet diagnostic criteria for major depression. For these study subjects, the existing symptoms are generally viewed as significantly impairing quality of life and performance of the activities of daily living.

Although similar to a diagnosis of depression, a diagnosis of dysthymia requires only two or more of the following symptoms:

- Poor appetite or overeating
- Insomnia or hypersomnia
- Fatigue
- Low self-esteem
- Impaired concentration
- Feelings of hopelessness

A diagnosis of dysthymia also requires that the person experience depressed mood for most of the day, more days than not, across an interval of at least 2 years, and not be asymptomatic for longer than 2 months during the 2-year course of illness (1). Thus, dysthymia follows a more chronic course than that of depression but comprises fewer disabling symptoms.

Although generally construed as less severe than major depression, dysthymia is by no means a benign illness. In an investigation of older outpatients with a diagnoses of “double depression” (i.e., major depression combined with dysthymia), Joiner et al found that these people had sharply higher rates of hopelessness than did people with a diagnosis of just one of these illnesses (29).

Prevalence, Comorbidity, and Risk Factors

Major depression has been found to be less prevalent among older adults living in communities than among younger community residents. This finding may appear counterintuitive to notions of depression as an expected facet of aging and may reflect, at least among women, the influence of cohort effects (10). Using the diagnostic criteria for major depression, the Epidemiologic Catchment Area (ECA) Study reported a 1-year prevalence of this disorder of 0.9% among people aged 65 years or older, compared with 2.3% for people aged 45 to 64 years and 3.9% for people aged 30 to 44 years (3). Although the ECA Study

began in 1980, its results on major depression remain noteworthy because, unlike other studies, the findings of the ECA Study are based on diagnostic criteria for depressive disorder. Moreover, the ECA Study has the strength of having assessed a large sample of adults aged 65 years or older ($N = 187,161$) in five geographically distinct sites (New Haven, Connecticut; Baltimore, Maryland; St. Louis, Missouri; Durham, North Carolina; Los Angeles, California) (11).

The Established Populations for Epidemiologic Studies of the Elderly, a longitudinal study of data from three communities (East Boston, Massachusetts; New Haven, Connecticut; and two counties in Iowa), compared over a 6-year interval 5751 older adults who were not depressed with 496 who were depressed. The depressed group had a relative risk of 1.67 (95% CI, 1.44–1.95) for inability to perform activities of daily living and of 1.73 (95% CI, 1.54–1.94) for mobility impairment (12). These results suggest that although depressive disorders may not be highly prevalent among older adults, they pose serious consequences to health and functioning.

The living environment of older adults appears highly relevant to the prevalence of depressive disorders. One study of 539 older adults receiving health care in their homes found that about 13.5% were depressed according to diagnostic criteria (13), and a study of the medical records of 3710 nursing home patients found a 20.3% prevalence of depression (14). A study of 562 residents in 65 nursing homes in the Netherlands is particularly telling: symptoms of depressive disorder were pronounced among newly admitted nursing home residents (26.9%), especially among those admitted from their own homes (34.3%) rather than from a hospital (19.7%) (15). Similarly, an epidemiologic study of the prevalence of dysthymia revealed a lifetime prevalence of 1.7% among older adults residing in their home community (3), whereas a study of 224 consecutively diagnosed older outpatients in a late-life depression clinic found a 17.9% prevalence of dysthymia (16).

Given the high rates of depression among older adults receiving home care or living in institutions, it is not surprising that comorbidity in people in these groups may be risk factors for depression. Analyzing data obtained from 2611 Asian adults aged 55 years or older, Niti et al (17) found the prevalence of symptoms of depressive disorder to be much higher for respondents with chronic disease (13.7%–24.2%) than for those without chronic disease

(7.5%). Multivariate analyses by these investigators found that after adjustment for comorbidity and functional status, asthma and chronic obstructive pulmonary disease, gastric problems, arthritis, and heart failure remained independently associated with symptoms of depressive disorder. Thus, the chronic diseases frequently reported by older adults may increase the likelihood of depressive disorder.

On the other hand, depressive disorders are themselves associated with risk factors for chronic disease in older adults. In one study, older adults with elevated scores on a test of psychological distress were found to be more likely than their peers not experiencing such distress to smoke, to be obese, to be impoverished, and to have received a diagnosis of diabetes, heart disease, or stroke (18). Older adults who reported a decline in self-reported physical activity over a 3-year interval were significantly more likely to be depressed than were those who did not (19). Likewise, another study found that older adults who were depressed at baseline were less likely than those who were not depressed to report substantial improvement in self-rated health and more likely to report a substantial decline across the 2-year follow-up interval (20). Longitudinal research has established that long-term symptoms of depressive disorder are inversely related to health among older residents of communities (21), corroborating cross-sectional findings that depression is associated with disability in the cognitive and physical activities of daily living (22).

Serebruany et al (30) note that the diagnosis of depression is an independent risk factor for mortality among patients with acute coronary syndromes (ACS). One class of antidepressant medications, serotonin-specific reuptake inhibitors (SSRIs), is thought to inhibit platelet activity, which may protect the heart independent of its use as an antidepressant (30). This property may be particularly valuable because depression, which commonly follows ACS, is associated with an increased risk of mortality (23). In a randomized, double-blind, placebo-controlled study of 369 patients with ACS and depression, Glassman et al (23) found that 53% of depressive episodes began before hospitalization for the index episode of ACS. Over a 4-year study period, the following groups of patients benefited from administration of an SSRI agent: patients with episodes of depression preceding their ACS, patients with a history of depression, and patients whose episodes were severe. The investigators further noted that these

three predictors of response to an SSRI medication are independent and specified that the presence of more than one of them considerably increases the benefits of an SSRI but also reduces the probability of spontaneous recovery. These data point to the importance of considering both somatic and psychiatric factors in attempting to optimize the care of older adults with cardiovascular disease, and more broadly, they indicate the interrelatedness of the pathophysiology of organ systems.

Public Health Impact and Impediments to Intervention

The importance to public health of the finding that depressive disorders may often lead to chronic disease cannot be overstated. We also need to appreciate the tendency of depressive disorders to complicate the course and treatment of chronic disease. Moreover, as chronic disease and depressive disorder are increasingly recognized as contributing to the challenges of providing quality health care, understanding the connection between the two becomes more vital.

Unfortunately, detecting depressive disorders in older adults may be difficult because symptoms may be masked as physical complaints, particularly among frail older adults. Brief assessment tools, such as the Psychological Distress Inventory (PDI-29), may be useful in identifying undiagnosed psychological disorders among frail adults receiving home care services (24) and thereby decrease the likelihood that depressed older adults will not receive treatment. Other risk factors for nontreatment or inadequate treatment of depression in older adults include being male, being African American or Latino, experiencing fewer than two or more previous depressive episodes, and expressing a preference for counseling instead of antidepressant medication (25).

Because older adults are usually no longer employed, the cost of depression and the efficacy of its treatment often receive little consideration. Depression in older adults is costly, however, because it results in more visits to doctors' offices and emergency rooms (31). Older adults with chronic disease and depressive disorder may experience increased symptoms of disease (26), and depression is an independent risk factor for mortality (27). Whether alone or with physical chronic diseases, depression is a major source of disability among older adults (32), and

older adults with increased symptoms of depressive disorder are less mobile and report fewer social contacts than do their peers who are not depressed (12).

In truth, public health interventions need not be costly and may result in reduced expenditures. The IMPACT (Improving Mood — Promoting Access to Collaborative Training) program, a collaborative-care approach to the management of depression and diabetes in older adults, is a stepped-care program that demonstrates this point (28). Older adults are assigned depression care managers who provide structured activities, including exercise. Participants may choose either problem-solving treatment or antidepressant treatment, both from a primary care provider. The problem-solving treatment is a structured 6- to 8-session psychotherapy intervention with efficacy comparable to that of antidepressants. In the IMPACT Study (recruitment, 1999–2001), 418 of 1801 patients at 18 primary care clinics from 8 health care organizations in 5 unspecified states were randomly assigned to receive either the IMPACT intervention ($n = 204$) or usual care ($n = 214$). During a 24-month period, participants in the IMPACT program had a mean of 115 more depression-free days than did participants receiving usual care (28).

The broad costs of depression in older adults — premature mortality, morbidity, and diminished quality of life — are incalculable. Unfortunately, the stigmatization of mental illness and the cost of medication keep many older people from adhering to treatment for depression (33). By integrating depression and other mental illnesses into research and interventions, the public health community will likely increase recognition of depression and lessen needless suffering. At the same time, we need to work to enhance the prevention and management of depression and to address policy and resource considerations necessary to support these endeavors.

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Tables

Table. Studies of Depressive Disorders in Older Adults, 1975–2007

First Author, Study Type	Year	Data Source and Sample Size	Findings
Prevalence, Comorbidity, and Risk Factors			
Kasen (10), cohort study	1975, 1983	Mothers in two counties participating in a study of childhood behaviors, New York N = 701	Revealed a cohort effect on the relationship between age and depression, with depression decreasing with age in the cohort born after 1944 ($\beta = -0.26, P = .03$), compared with the cohort born before 1944 ($\beta = .09, P = .18$).
Leaf (11), multi-site cross-sectional study	1980	Epidemiologic Catchment Area Study, United States N = 187,161	Prevalence of major depression was lower among adults aged 65 years or older than among adults aged 30-44 years and 45-64 years (3).
Penninx (12), multisite longitudinal survey	1982-1983 (baseline)	Established Populations for Epidemiologic Studies of the Elderly, United States N = 6247	Over a 6-year follow-up period, older adults who were depressed at baseline were more likely than those who were not to develop an incident disability in daily living activities (36.1% vs 23.9%, $P < 0.001$) and in mobility (67.1% vs 48.3%, $P < 0.001$).
Bruce (13), cross-sectional study	1997-1999	Visiting Nurses Service of Westchester County, New York N = 539	Among patients receiving in-home care, 13.5% had major depression, which was significantly associated with morbidity, a past history of depression, and reported pain.
Jones (14), cross-sectional study	1996	Medical Expenditure Panel Survey, Nursing Home Component, United States N = 3710	About 20.3% (95% CI, 18.9%-21.7%) of nursing home residents were depressed. Prevalence was highest among white non-Latino, younger residents, women, and residents with marital status other than never married, better cognition, comorbidities such as heart disease or Parkinson disease, or a 1-2 year stay in a nursing home.
Achterberg (15), observational study	1997	65 nursing homes in the Netherlands N = 562	26.9% of newly admitted patients had depressive symptoms, with a higher prevalence among those admitted from their homes (34.3%) than those admitted from a hospital (19.7%) but not among those admitted from a shelter.
Devanand (16), cross-sectional study	1994	Late-life depression clinic, United States N = 224	Prevalence of dysthymia was 17.9% among 224 consecutively diagnosed depressed older patients; mean age of onset, 55.2 years. Dysthymia appeared to be preceded by major life stressors such as divorce (22.5%), bereavement (17.5%), retirement (12.5%), family problems (10%), financial problems (7.5%), and major medical illnesses (5.0%).
Niti (17), prospective cohort study	2007 (publication)	Singapore Longitudinal Ageing Study, China N = 2611	Older adults without chronic illnesses were less likely to have depressive symptoms (7.5%) than were those with various chronic medical conditions (stroke, 24.2%; gastric problems, 23.7%; heart failure, 22.3%; asthma and chronic obstructive pulmonary disease, 22.3%; osteoporosis, 15.8%; and hypertension, 13.7%), which were independently associated with depressive disorders even after adjusting for comorbidity and functional status.
Pratt (18), cross-sectional survey	2001-2004	National Health Interview Survey, Family Core and Sample Adults component, United States N = 123,610	The prevalence of serious psychological distress (SPD) was lower for adults aged 65 years or older (2.3%-2.5%) than for other age groups (2.6%-4.0%). People with SPD were significantly more likely than people without SPD to smoke, to be obese, to be impoverished, and to have received a diagnosis of diabetes, heart disease, or stroke.

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Table. (continued) Studies of Depressive Disorders in Older Adults, 1975–2007

First Author, Study Type	Year	Data Source and Sample Size	Findings
Prevalence, Comorbidity, and Risk Factors (continued)			
Penninx (19), prospective cohort study	1992-1993 (baseline); 1995-1996 (follow-up)	Longitudinal Aging Study, Amsterdam N = 2121	Over the 3-year study period, decline in self-reported physical ability was significantly greater for participants who were depressed at baseline than for those who were not ($P < .001$).
Han (20), prospective cohort study	1993 (baseline); 1995 (follow-up)	Assets and Health Dynamics Among Oldest-Old National Survey, United States N = 6714	Older adults who were depressed at baseline were less likely than those who were not depressed to report substantial improvement in self-rated health and more likely to report a substantial decline across the 2-year follow-up interval.
Meeks (21), prospective cohort study	2000 (publication); conducted in 5 waves across 6-month intervals	Probability sample of community residents aged 55 years or older, Kentucky N = 1479	Chronic depressive symptoms were a strong predictor of decline in daily functioning and of having more health problems at follow-up.
Patrick (22), cross-sectional study	1998-1999	Community-based rural Medicaid long-term care service recipients, West Virginia N = 221	Depression was predictive of disability in cognitive and physical activities of daily living, which in turn were predictive of disability in basic activities of daily living. The number of chronic conditions were significantly correlated with depression.
Glassman (23), multicenter randomized control trial	1997-2001	Sertraline Antidepressant Heart Attack Randomized Trial, United States N = 369	53% of patients had an episode of major depressive disorder before hospitalization for the index episode of acute coronary syndrome, with the majority (94%) of the disorders occurring 30 days before hospitalization.
Public Health Impact			
Preville (24), cross-sectional study	Data obtained from older adults registering in two community services centers during 1/15/1997-3/31/1998	Study of Frail Elderly Receiving Home Care Services, United States N = 177	Psychological Distress Inventory (PDI-29) was found superior to the Primary Care Evaluation of Mental Disorders (PRIME-MD) in detecting depression and anxiety in older patients who were not cognitively impaired but who reported a stressful life event during the previous 6 weeks.
Unützer (25), cross-sectional study	1999-2001	Analysis of baseline data from Improving Mood — Promoting Access to Collaborative Trial (IMPACT), United States N = 1801	The groups most likely to report nontreatment or inadequate treatment for depression were males, African Americans, Latinos, people who had fewer than two prior depressive episodes, and people with a preference for counseling instead of antidepressant medication.

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Table. (continued) Studies of Depressive Disorders in Older Adults, 1975–2007

First Author, Study Type	Year	Data Source and Sample Size	Findings
Public Health Impact (continued)			
Ruo (26), cross-sectional study	9/2000-12/2002	Patient Health Questionnaire and assessment of cardiac function parameters (Heart and Soul Study), United States N = 1024	Patients with coronary artery disease and depressive symptoms reported more significant impairments in physical activity, quality of life, and overall health than did patients with coronary artery disease without depressive symptoms.
Schulz (27), longitudinal study	1989-1995	Assessment of association between baseline depressive symptoms and 6-year mortality among men and women in four counties (Cardiovascular Health Study), United States N = 5201 n = 984 decedents	18.9% of baseline participants died within 6 years. Mortality rate was positively associated with strong baseline depressive symptoms. Even when controlling for other relevant predictors, increased depressive symptoms remained a strong, independent predictor of mortality.
Katon (28), randomized controlled trial	7/1999-8/2001 (recruitment); 2006 (publication)	Subgroup analysis of patients with diabetes from IMPACT, United States N = 418	Patients receiving the IMPACT intervention (structured exercise and problem-solving treatment or antidepressant medication) had a mean of 115 more depression-free days than did participants receiving usual care.

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SPECIAL TOPIC

Developing a Telephone Assessment of Physical Activity (TAPA) Questionnaire for Older Adults

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Abstract

Introduction

We report on development and preliminary validation of a brief, telephone-based measurement tool for assessing physical activity in older adults. The Telephone Assessment of Physical Activity (TAPA) questionnaire is based on the University of Washington Health Promotion Research Center's Rapid Assessment of Physical Activity (RAPA), a written questionnaire.

Methods

The Rapid Assessment of Physical Activity questionnaire was modified to permit interviewers to administer it as a telephone interview. We retained its scoring levels and interpretation. The pilot test of the telephone version assessed the questionnaire's ease of administration and construct validity in a community-based sample of older adults. Spearman rho and kappa statistics were computed for comparison with the Rapid Assessment of Physical Activity questionnaire and the Community Healthy Activities Model Program for Seniors questionnaire.

Results

Thirty-four older adults completed the telephone assessment. A Spearman rho of 0.74 and a kappa statistic of .48 were found between TAPA and the written RAPA.

Conclusion

The pilot test demonstrated that the TAPA questionnaire is a promising instrument for use as a brief, telephone-based questionnaire for assessing physical activity in older adults.

Introduction

Physical activity has been shown to assist older adults in managing chronic conditions and to delay decline in their physical and mental health (1). Currently, however, reports show that fewer than 20% of U.S. adults aged 64 or older engage in the U.S. Surgeon General's recommended levels of physical activity (2), and only 11% engage in strength training (3).

The Rapid Assessment of Physical Activity (RAPA) questionnaire was designed to provide clinicians with a tool for quickly assessing the level of physical activity of their older adult patients (4). It was developed following an extensive review and evaluation of existing written questionnaires, which were found to be either too long or to lack sufficient sensitivity for measuring physical activity in older adults. RAPA was found to be reliable and valid compared with the longer, validated Community Healthy Activities Model Program for Seniors (CHAMPS) questionnaire (4,5). However, one drawback to RAPA's use outside the clinical setting is its highly visual format, which is not amenable to a telephone-based assessment of physical activity. This study was designed to address this limitation of RAPA by adapting it for use in telephone-based surveys of physical activity.

Other telephone-based physical activity surveys have been used and validated for general use; however, these surveys were not designed to address specific aspects of physical activity among older adults, for example, capturing lighter activities, such as walking leisurely, light vacuuming, light yard work, or light exercise such as stretching (5-7). Telephone-based surveys could be an ideal means of assessing physical activity in older adults, given the many challenges that prevent researchers from evaluating and monitoring this population group, such as the dependence of seniors on others for transportation to a research site. Disabilities often preclude travel to appointments with health care providers and to research sites. Furthermore, evaluating physical activity during visits to health care providers is often difficult because of the large number of competing health issues to be addressed.

We will discuss the process by which we adapted and developed a new telephone-based physical activity survey for older adults and our preliminary findings from a pilot test of the survey. We compare the Telephone Assessment of Physical Activity (TAPA) with RAPA, the system on which it was modeled, and to CHAMPS for criterion validity. Because scoring for both TAPA and RAPA are the same, we hypothesized that if both compare equally well with the CHAMPS instrument, an argument for using TAPA and RAPA interchangeably could be made. Our goal is to help researchers, clinicians, and public health practitioners quickly assess and monitor levels of physical activity in older adults.

Methods

Study design, sample, and setting

In our study's cross-sectional design, we recruited older adults from the greater Seattle area using advertisements at senior centers, congregate meal sites, and senior public housing. We distributed flyers and used senior services representatives to recruit participants. Criteria for inclusion were being aged 50 years or older, English-speaking, and having the ability to answer questions regarding physical activity on both a written questionnaire mailed to participants and in a telephone survey. Assistance in filling out the written survey was offered to anyone who needed help because of physical disability (e.g., poor vision, arthritic pain in the hands). We excluded from the study those who were unable to answer questions because

of significant cognitive impairment (e.g., Alzheimer's disease) or severe acute illnesses (e.g., active heart failure).

The CDC-funded Health Promotion Research Center (HPRC) at the University of Washington in Seattle oversaw development and adherence to the study protocol. A research assistant with a master's degree in public health mailed and received all the written questionnaires and administered all the telephone physical activity questionnaires. An effort was made to include underrepresented participants, including men, people of color, and less active seniors.

Questionnaire development

HPRC researchers, along with members of the RAPA development team, began by adapting the RAPA questions to a telephone survey format. Participants who met the eligibility criteria and gave oral consent during a screening telephone call were then administered the TAPA. After finishing the survey, the research assistant gained qualitative tool performance information by asking the following questions: "We are developing this survey to use with health care and social service providers who work with older adults. Do you have any comments about the survey (probe about satisfaction, ease of use, acceptability, comprehension)? What did you like about the survey? What could be improved?" One week after TAPA administration, the written versions of RAPA and CHAMPS were either mailed to the participant's home or arrangements were made to meet the participant in person to administer the questionnaires orally. Information gathered by the research assistant was used in an iterative process to allow successive improvements to the questionnaire.

We tested two earlier versions of TAPA to improve its ease of use and understandability. The earlier versions had more complicated sentence structure. We found that participants understood and more easily responded to questions with fewer concepts to consider, leading us to subdivide some of our questions. For example, in version 2, question 4 reads "I do moderate physical activities every week, but less than 30 minutes per day, 5 days per week. Does this describe you?" In the final version, we separated this question into two questions, 4a and 4b (see Appendix); "I do some moderate physical activities every week, but less than 30 minutes per day. Does this describe you?" and "I do some moderate physical activities every week, but less than 5 days per week. Does this describe you?" A

total of two pilot versions were administered during this iterative process. The questionnaire was administered between August 2005 and March 2007. The University of Washington Human Subjects Division approved all procedures, and participants received a nominal gratuity of \$15 to thank them for participating.

Scoring of RAPA and TAPA was based on physical activity criteria derived from the Surgeon General's recommendations (2). One point is given for "sedentary level of activity," two for "underactive," three for "active but does not meet standard recommendations," four for "meets standard recommendations." CHAMPS scoring is based on caloric energy expended in moderate-intensity physical activities having a metabolic equivalent value of ≥ 3.0 (4).

Analysis

To assess how well TAPA captured the physical activity level of older adults, we compared it with the two written questionnaires, RAPA and CHAMPS. In initial analyses we looked at the agreement in levels of physical activity (sedentary to active), from TAPA and RAPA. We then analyzed the participants' answers to TAPA and RAPA for their relationship to CHAMPS both in calories scored as a continuous variable and in meeting or exceeding the Surgeon General's physical activity recommendations. CHAMPS activities were scored as a continuous variable by determining moderate physical activity calories per week. Participants met the physical activity recommendation if they reported in CHAMPS that they engaged in moderate physical activities at least 5 days per week for a total of 3 or more hours per week or engaged in vigorous physical activities at least 3 days per week for a total of 1 or more hours per week. We assessed criterion validity by calculating a Spearman rho. Scoring instructions are described in the Appendix. Stata 9 software (StataCorp LP, College Station, Texas) was used for this analysis.

Results

Thirty-six participants completed the TAPA telephone survey. Of those who completed TAPA, 34 also completed RAPA and CHAMPS. Participants were aged 63 to 92 years (mean age 75), were mostly female (62%), and represented a diverse sample of minority groups (Table 1). TAPA and RAPA each took 5 to 10 minutes to administer compared with 30 to 40 minutes for CHAMPS.

Table 2 shows the percentage of participants for each level of activity and compares responses from the TAPA and RAPA questionnaires. For both questionnaires, the four activity levels were fairly well distributed with a slightly greater percentage of participants meeting the Surgeon General's physical activities criteria for being sedentary or underactive (2).

The Spearman rho showed a moderately strong correlation of 0.74 ($P = .001$) between TAPA and RAPA (Table 3). A kappa statistic of .46 ($P = .001$) showed moderate agreement above chance between the same two questionnaires. TAPA, with a Spearman rho of .672 ($P = .001$) and a kappa statistic of .526 ($P = .001$), did not perform as well as CHAMPS. RAPA also did not perform as well as CHAMPS, with a Spearman rho of .663 ($P = .001$) and a kappa statistic of .398 ($P = .001$).

Discussion

Our study begins to address the existing need among researchers, clinicians, and public health practitioners for a telephone-based physical activity assessment tool for older adults that is brief and effective. TAPA was developed using the strengths of the written RAPA questionnaire and going through two piloted versions in order to improve instrument quality. We designed the TAPA survey to err on the side of participants not meeting physical activity criteria when they actually met criteria; that is, to overestimate the false negative. Like RAPA, TAPA was designed to assess light activity that does not meet the CDC guidelines of 30 minutes or more of moderate physical activity on every or most days of the week (2).

TAPA is an easy-to-administer instrument that has demonstrated acceptability to a wide range of older adults. Though TAPA was not validated by a physical measurement, our study shows good agreement with RAPA. The TAPA and CHAMPS Spearman rho and kappa statistic were consistent with the RAPA and CHAMPS findings. This suggests that TAPA and RAPA may be equally effective in assessing physical activity of older adults in clinical practice.

There are several limitations to this study. The order of question iteration was not changed during the course of our study. This design flaw did not allow us to determine whether the order of the questions affected the strength

of the comparisons. TAPA was not validated using an observable measure of physical activity. A sample size of 34, though diverse in both ethnicity and activity level, was not reflective of the Seattle population as a whole and may not be large enough to make any conclusive statements about TAPA. TAPA's generalizability may also be limited because our sample of seniors engaged in relatively high levels of physical activity compared with seniors in other published reports, which estimate that over 40% of the older U.S. adult population is completely sedentary (8). In addition, TAPA's effectiveness as a monitoring tool was not ascertained. This tool was used only in a cross-sectional analysis, and further research will be required to determine whether it is a competent resource for measuring change over time.

Conclusion

TAPA is a brief, easy-to-administer, telephone-based survey developed in a diverse community setting. It has the same scoring and interpretive characteristics as RAPA; however, neither has been tested against a gold standard physical measurement.

TAPA represents a good start at developing a physical activity assessment tool for older adults that is brief, easy to administer, and telephone-based. Such a tool will play an increasingly important role as the geriatric population increases and greater clinical and public health emphasis is placed on physical activity and on physical activity research.

TAPA needs further validation, including validation in a larger sample that includes a more sedentary group and assessment of its ability to detect change over time. The next steps in development of TAPA include a larger study with similar outcome measures and a validation study with a physical measurement instrument (e.g., pedometer, accelerometer, gas exchange measurement device).

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Tables

Table 1. Demographic Characteristics of Study Participants, TAPA, RAPA, and CHAMPS (N=34), August 2005 - March 2007

Characteristics	Value
Age, mean (range) years	75 (63-92)
Female sex	62%
BMI, mean (range)	24 (19-33)
Race/ethnicity	
White	12%
Asian/Native Hawaiian or other Pacific Islander	35%
Black/African American	26%
Hispanic or Latino	14%
American Indian/Alaska Native	0%
Other or unknown	12%

Table 2. Percentage of Participants at All Physical Activity Levels, TAPA and RAPA, August 2005 - March 2007 (N=34)

Activity Level	TAPA (%)	RAPA (%)
Sedentary	26	26
Underactive	35	32
Active, does not meet standard	21	18
Active, meets standard	18	24

TAPA indicates Telephone Assessment of Physical Activity questionnaire; RAPA, Rapid Assessment of Physical Activity questionnaire.

Table 3. Comparison of TAPA, RAPA, and CHAMPS for All Physical Activity Levels and for Meeting U.S. Surgeon General's Physical Activity Recommendations, August 2005 - March 2007

Comparison (N = 34)	Spearman rho for Physical Activity ^a	Kappa Statistic for Relationship to Surgeon General's Physical Activity Recommendations ^b
TAPA vs RAPA	0.738 (P = .001)	.463 (P = .001)
TAPA vs CHAMPS	0.672 (P = .001)	.526 (P = .001)
RAPA vs CHAMPS	0.663 (P = .001)	.398 (P = .001)

TAPA indicates Telephone Assessment of Physical Activity questionnaire, RAPA, Rapid Assessment of Physical Activity questionnaire, CHAMPS, Community Healthy Activities Model Program for Seniors.

^a Comparisons between TAPA and RAPA in this column have a range of 1-4 (1 indicates sedentary, 2, underactive 3, active but does not meet standard, and 4 = active, meets standard). Comparisons between TAPA and CHAMPS and RAPA and CHAMPS are based on calories expended per week of moderate activities (range 0-7809).

^b Comparisons for meeting Surgeon General's physical active recommendations (7) based on questionnaire responses.

Appendix: Telephone Assessment of Physical Activity (TAPA) Questionnaire

TAPA 1: Aerobic

I am going to ask you about the amount and level of physical activity you usually do. In this survey, we define physical activities as activities where you move and increase your breathing or heart rate. These are activities you do for pleasure, work, or for getting around.

I will read a statement about activities, and you can tell me whether the statement describes you by answering yes or no. For example,

SAMPLE	I am over 50 years old. Does this describe you?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Sure <input type="checkbox"/>
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Do the best you can to answer using the yes/no format; at the end of the survey we can talk about specific activities.

The first statement is

1	I rarely or never do any physical activities. Does this describe you?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Sure <input type="checkbox"/>
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The next statements are about three types of activities: light, moderate, and vigorous. Light activities are activities when your heart beats only slight-

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ly faster than normal and you can still talk and sing during them. Some examples of light activities are walking leisurely, light vacuuming, light yard work, or light exercise such as stretching. Here are two statements about light activity.

2a	I do some light physical activities, but not every week. Does this describe you?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Sure <input type="checkbox"/>
3	I do some light physical activity every week. Does this describe you?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Sure <input type="checkbox"/>

Next are moderate activities. Moderate activities are activities when your heart beats faster than normal. You can still talk but not sing during such activities. Some examples of moderate activities are fast walking, aerobics class, strength training, or swimming gently. I have four statements about moderate activities. The first one is

2b	I do some moderate physical activities, but not every week. Does this describe you?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Sure <input type="checkbox"/>
4a	I do some moderate physical activities every week, BUT less than 30 minutes per day. Does this describe you?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Sure <input type="checkbox"/>
4b	I do some moderate physical activities every week, BUT less than 5 days per week. Does this describe you?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Sure <input type="checkbox"/>
6	I do 30 minutes or more per day of moderate physical activities, 5 or more days per week. Does this describe you?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Sure <input type="checkbox"/>

The next three statements are about vigorous activities. Vigorous activities are activities when your heart rate increases a lot. You typically can't talk or your talking is broken up by large breaths. Some examples of vigorous activities are jogging, running, using a stair machine, or playing tennis, racquetball, badminton, or pickleball. The first statement is

5a	I do some vigorous physical activities every week, BUT less than 20 minutes per day. Does this describe you?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Sure <input type="checkbox"/>
5b	I do some vigorous physical activities every week, BUT less than 3 days per week. Does this describe you?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Sure <input type="checkbox"/>
7	I do 20 minutes or more per day of vigorous physical activities, 3 or more days per week. Does this describe you?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Sure <input type="checkbox"/>

TAPA 2: Strength & Flexibility

And finally, I have two statements about strengthening and stretching activities. First,

TAPA 2	1	I do activities to increase muscle strength , such as lifting weights or calisthenics, once a week or more. Does this describe you?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Sure <input type="checkbox"/>
	2	I do activities to improve flexibility , such as stretching or yoga, once a week or more. Does this describe you?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Sure <input type="checkbox"/>

Are there activities that you do that reflect physical activity that we may have not captured in this survey?

(Write in response)

This concludes my questions. Thank you.

TAPA 1: Aerobic, Scoring Instructions

To score, choose the question with the highest score with an affirmative response. Any number less than 6 is suboptimal.

For scoring or summarizing categorically:

Score as sedentary:

I rarely or never do any physical activities.

Score as underactive:

I do some light physical activities, but not every week, or I do some moderate physical activities, but not every week.

I do some light physical activity every week.

Score as underactive regular:

I do moderate physical activities every week, but less than 5 days per week or less than 30 minutes at a time.

I do vigorous physical activities every week, but less than 3 days per week or less than 20 minutes at a time.

Score as active:

I do 30 minutes or more per day of moderate physical activities, 5 or

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more days per week.

I do 20 minutes or more per day of vigorous physical activities, 3 or more days per week.

TAPA 2: Strength & Flexibility, Scoring Instructions

(Note: The authors made no analysis of TAPA 2, the original of which is reprinted below with scoring instructions in parentheses in order to make the complete TAPA questionnaire available to readers.)

I do activities to increase muscle strength, such as lifting weights or calisthenics, once a week or more. (1)

I do activities to improve flexibility, such as stretching or yoga, once a week or more. (2)

Both. (3)

None (0)

Treating Depression in Older Adults: Challenges to Implementing the Recommendations of an Expert Panel

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PEER REVIEWED

Abstract

Depression is increasingly recognized as a significant public health problem among older adults. Because the condition is highly treatable and currently undertreated among community-based older adults, late-life depression is an appropriate focus for disease prevention programs. We report findings from a recent project to review the scientific literature for published reports about treatment for depression among community-dwelling older adults and to recommend the interventions with proven effectiveness. We also summarize the research findings related to each recommended intervention and describe the elements of each. To show the difficulties involved in translating research into practice, we describe real-world experiences in implementing these evidence-based interventions in various community settings. Because depression among older people is viewed more and more as a public health problem, we suggest that partnerships of providers, patients, and policy makers be forged to overcome challenges related to funding, training, and implementing treatments for this condition.

Introduction

About 5% to 15% of community-dwelling older adults

(i.e., adults aged 60 years or older) suffer from depression (1), which is associated with functional impairment (2-5), high health care costs (6,7), and possibly increased mortality rates through suicide and complications of cardiac disease (2-5,8,9). Recent data suggest that treatment can reduce not only depression but also the secondary symptoms such as pain and improve health-related quality of life (7-10). Whether treatment also reduces health care costs is unclear.

In light of the increasing burden of, and suboptimal treatment for, depression and the extensive scientific literature on treating and preventing depression (1,11), several major public health organizations designated depression as a major public health concern. For example, a key objective of *Healthy People 2010* is to reduce the proportion of adults with disabilities who report symptoms of depression and are less active because of those symptoms (12). In addition, the Task Force on Community Preventive Services endorsed depression as a topic for a systematic literature review to identify effective treatments (13). In this article, we report on a recent special interest project called Defining the Public Health Role in Depression in Older Adults (Depression in Older Adults project), which was supported by the Centers for Disease Control and Prevention (CDC) through the Prevention Research Centers' Healthy Aging Network (PRC-HAN).

Methods

During the first stage of this project, an expert panel of 14 academics in public health or geriatrics (including two of the authors: MS, JF) systematically reviewed published, peer-reviewed studies to learn about successful interven-

tions for depression among noninstitutionalized older adults. Panel members (who were recommended by CDC or PRC–HAN) reviewed all studies of interventions with the primary objective of reducing depression and interventions that had other primary objectives but evaluated depression as a secondary outcome (e.g., a study of participants in an aquatics class for elderly people with arthritis, after which researchers measured not only changes in participants' mobility but also changes in symptoms of depression).

The panel established the following eligibility criteria for studies to be included in our review: 1) the mean age of study subjects should be 60 years or older; 2) the number of subjects should be 25 or more; 3) subjects should not be institutionalized; 4) study criteria for determining whether participants were depressed were based either on a clinical diagnosis (e.g., major depression, dysthymia) or on a symptom-severity score from a standardized assessment instrument, and 5) the study report must clearly describe replicable interventions.

After the review was complete, the panel determined whether the study data were adequate to rate the intervention's effectiveness. When the data were adequate, panel members rated each intervention as effective, of mixed effectiveness, or ineffective. These determinations were based on the quality of the studies. Quality was based on, for example, dropout rates, adequacy of statistical analyses, and magnitude of study participants' response to the interventions. Full details about the criteria used to determine the adequacy of the data, effectiveness of the intervention, and quality of the studies are published elsewhere (14).

For the second stage of the Depression in Older Adults project, the panel was restructured: six of the original members left, and six community health care providers were added. This stage of the project is unique because the panel reviewing the literature and recommending interventions included not only researchers but practitioners familiar with the challenges of planning and implementing interventions. This second panel reviewed the list of interventions found through the literature review and recommended or strongly recommended certain of those interventions for treating late-life depression among community-dwelling older adults to healthy-aging experts and public health professionals. In selecting which interventions to recommend or strongly recommend, the panel

considered not only their effectiveness but the feasibility and appropriateness of implementing them at the community level. The panel also suggested further research on promising interventions. The study methods and citations for reviewed studies are published elsewhere (14,15).

Results

A total of 97 intervention studies met the panel's criteria for inclusion and were grouped into 24 intervention categories (Table). At the end of this two-stage project, the researcher-practitioner expert panel *strongly recommended* interventions based on the depression care management (DCM) model and *recommended* cognitive behavioral therapy (CBT) as treatment for depression in older adults. DCM was supported by eight randomized clinical trials (RCTs) with more than 3000 study subjects. These subjects experienced greater reductions in symptoms of depression, higher remission rates, and more improvement in health-related quality of life than did people in the control groups who were given whatever care their physicians deemed appropriate. In addition, the DCM subjects often reported greater satisfaction with their care than did subjects given usual care. The review also found six RCT studies involving CBT. Typically researchers found that those given CBT treatment had significant improvement in their depression symptoms after less than 1 year. Further details on the reviewed studies and on interventions that are not recommended or that provided insufficient evidence are in the Table.

Depression Care Management

The DCM model is a systematic team approach to treating depression in older adults, which is based on the model for treating chronic diseases (16). Common elements of DCM include diagnosing depression through a validated screening instrument and providing psychotherapy or antidepressants according to evidence-based guidelines. Treatment is reassessed periodically through a validated severity instrument to determine how well patients are responding and to adjust treatment if appropriate. A trained social worker, nurse, or other practitioner (sometimes called a "depression care manager" or "care manager") educates patients, tracks outcomes, facilitates psychotherapy, and monitors antidepressants prescribed by a primary care provider. The care manager works in consultation with a psychiatrist who supervises care but

typically does not see the patients. The goal is to improve rates of adherence to treatment and to improve recognition of, and treatment for, patients not responsive to their initial treatment.

Managing depression in primary care clinics is effective: elderly people already visit these facilities regularly (17-19), and one study of depressed older adults found that DCM was delivered at a mean cost of \$580 per patient (19), compared with total health care cost per patient of about \$8000 (20). At-home interventions involve home visits by the depression care manager, who coordinates with other members of the collaborative care team outside the patient's home. One study of home-based management of depression found that costs averaged \$630 per patient for an average of six visits (9).

Cognitive Behavioral Therapy

CBT is psychotherapy that focuses on the clients' patterns of thoughts and behaviors that induce a depressed mood (21). The therapist teaches clients to recognize and modify these thoughts and behaviors in order to reduce symptoms of depression. CBT usually consists of weekly therapy sessions and daily exercises to help older adults apply CBT skills every day. Studies generally use trained therapists with master's degrees to deliver the intervention. The therapists are supervised by, and may consult with, professionals with a PhD or an MD.

Real-World Experience

Several groups of experts recognize DCM and CBT as proven treatments for depression in many older adults (22,23), yet numerous obstacles prevent these interventions from being used by public health and healthy aging programs. Next we describe several efforts to implement the recommended evidence-based depression interventions in various communities.

Depression Care Management

The Program to Encourage Active and Rewarding Lives for Seniors (PEARLS) is an example of a home-based program to manage depression (9). PEARLS began as a 5-year study of 138 subjects, during which research funds and administrative support were available for selecting and training interventionists, recruiting and funding a super-

vising psychiatrist, recruiting research subjects, collecting data, and assessing outcomes. After the study ended, community agencies began funding and supporting the program. The researchers continued their support through regular meetings with the agency staff and administrators to solve problems and to provide education and training.

As of April 2007, 35 community-dwelling older adults had completed treatment through a social service agency that serves homebound and frail older adults. These 35 were the first to complete treatment after the 5-year study ended. Their depression was diagnosed through the Patient Health Questionnaire (PHQ-9) (a nine-item, validated instrument for screening and diagnosing depression), and their initial average score (10.9) was similar to the initial average score of the participants in the 5-year study. A score of 10.9 indicates an intermediate level of depression (24). After treatment, the average PHQ-9 score of the 35 had decreased to 4.8 and 30 (87%) of the 35 were in remission. Unfortunately, the number of community-dwelling older adults treated (35) is small in comparison with the number of older adults enrolled in the social services program (2033) and the number of enrollees who have mild depression (at least 400). This situation shows that implementing the PEARLS intervention in a real-world setting (rather than a research setting) is difficult even when the obstacles of screening, funding, training, and staffing are overcome.

During a discussion among the researchers, administrators, and staff involved in PEARLS about the barriers to implementing the program more widely, several factors became evident. First, without research staff to recruit older adults with depression, the in-home case managers must identify older adults with depression and refer them to the PEARLS counselors. The case managers are responsible for many other aspects of a client's care, and most clients have needs in areas other than depression. Therefore, referring people with mild depression to PEARLS competes with many other case manager responsibilities. In addition, many clients, because of stigma or other reasons, do not see the need for treatment or are not interested in receiving treatment. Lastly, the research intervention protocol excluded people with moderate or high levels of cognitive impairment and people who did not speak English. The current PEARLS program has many such clients but does not have a blueprint for modifying and adapting the program to meet the needs of these diverse, real-world patients.

The Improving Mood—Promoting Access to Collaborative Treatment (IMPACT) study (<http://impact-uw.org/>*) is an example of primary care, clinic-based DCM. The IMPACT study is the largest geriatric DCM trial conducted to date, involving 1801 older adults from 18 clinics in 5 states (19). The program trained nurses and psychologists to teach their patients problem-solving techniques, and the patients' primary care providers administered antidepressants as needed. Since the study's report was published in 2002, efforts to disseminate and implement the program have continued through a combination of in-person trainings, Web-based information and training modules, and grant-funded efforts to adapt the program to other settings or other populations (20). Although the number of people who received the intervention outside the research study is unclear, several states are collaborating with the study team to implement the program on a large scale.

IMPACT faces challenges similar to those that face PEARLS and other DCM programs. First, although primary care providers are comfortable using measurement-based care, primary care clinics do not usually screen for depression. Therefore, getting primary care providers to incorporate instruments such as PHQ-9 into routine care can be challenging. Second, although evidence clearly shows that nurses who are not health care specialists or nurse practitioners can function as care managers, most third-party insurance providers, including Medicare and Medicaid, do not reimburse expenses when registered nurses serve as care managers. Similarly, Medicare and Medicaid do not pay for a supervising psychiatrist. Finally, although the Internet has greatly reduced the challenges of training diverse audiences all across the country, it is unclear how much actual training is delivered through this mode of communication.

Cognitive Behavioral Therapy

Cognitive behavior therapy is the oldest of the interventions recommended by the expert panel. Although some studies have been done on CBT (25), none were done in primary care settings or as part of community-based geriatric programs. However, since CBT is a single intervention technique, it does not face some of the challenges of multifaceted programs, which require several people to implement. CBT is usually taught during the intern and residency programs for psychiatrists, psychologists, and licensed clinical social workers. Because numerous self-help texts (26) are available detailing the theory and

practice of CBT, many other mental health providers are familiar with its use. However, most of these practitioners work in specialty mental health settings removed physically from primary care or community-based programs that serve older adults. Therefore, linking the patient and the provider is a challenge because many older adults are reluctant to go to mental health specialists. In addition, the interventions that we determined were effective through the literature review were based on depression screening with quantitative instruments to guide and evaluate the therapy. This quantitative-based approach to delivering psychotherapy is not common in many mental health settings.

Discussion

Two points from the review warrant further discussion. First, the panel did not find sufficient evidence from community-based studies to make any recommendations for therapies to deal with grief or prevent suicide. By excluding articles on studies that were based in academic settings, we may have amplified the problem of insufficient evidence. However, excluding these articles was consistent with the community-based focus of our review. Given the multiple losses experienced by older adults and the high suicide rate for older adults in the United States (27), more research is needed in these areas. Second, many of the reviewed interventions targeted primarily other conditions or outcomes (e.g., increases in physical therapy, training in certain skills) and measured depression levels only as a secondary outcome. These interventions did improve the targeted outcomes but did not alleviate depression. Therefore, although depression is a comorbid condition in many patients, it is an independent contributor to suffering and requires direct treatment.

Many real-world challenges to implementing the recommended depression interventions are also challenges for other areas of public health. These are acquiring adequate funds to set up and manage programs well, overcoming barriers to training staff in the intervention techniques, ensuring that people who need the service have access to it, ensuring staff fidelity to established protocols, and having adequate support to evaluate outcomes. Reducing the stigma attached to having mental health problems is one means of improving access to care, especially for older adults with depression. One advantage of the models for managing depression that we reviewed is that they can

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be made available in primary care clinics or in the home, places without any stigma attached to them.

In summary, several interventions are effective for treating depression in older adults and were deemed appropriate by an expert panel for community-based implementation. Many challenges remain, but overcoming these is an important public health priority. Partnerships among researchers, health care providers, and policy makers will be necessary to overcome the funding and training obstacles that block implementation of treatment programs for older adults. As shown by research studies (7-10) and stated by the President's New Freedom Commission on Mental Health, good emotional health is necessary for good physical health (28).

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Table

Table. Intervention Categories, Data Adequacy, Effectiveness Rating, and Recommendations with Regard to Studies Reviewed for the Project: Defining the Public Health Role in Depression in Older Adults, 2004-2007

Intervention Category	Studies Reviewed (N) ^a	Adequate Data?	Effectiveness Rating	Recommendation
Depression care management (home)	8 (1119)	Yes	Effective	Strongly recommended
Depression care management (clinic)	2 (2399)	Yes	Effective	Strongly recommended
Group psychotherapy targeting depression	6 (292)	Yes	Ineffective	Insufficient evidence
Individual psychotherapies targeting depression: CBT	6 (432)	Yes	Effective	Recommended
Individual psychotherapies targeting depression: other therapies ^b (except CBT)	6 (490)	Yes	Mixed effectiveness	Insufficient evidence
Psychotherapy targeting mental health	5 (574)	Yes	Mixed effectiveness	Insufficient evidence
Psychotherapy for caregivers	2 (394)	Yes	Mixed effectiveness	Not applicable ^c
Education and skills training: targeting older adults	10 (2803)	Yes	Ineffective	Not recommended
Education and skills training: targeting caregivers	11 (2026)	Yes	Mixed effectiveness	Not recommended
Geriatric health evaluation and management (home)	7 (708)	Yes	Mixed effectiveness	Not recommended
Geriatric health evaluation and management (clinic)	4 (2157)	Yes	Ineffective	Not recommended
Exercise: primary target depression	1 (1828)	Yes	Not eligible ^d	Not eligible ^d
Exercise: other primary targets	9 (1796)	No	Mixed effectiveness	Not recommended
Bereavement: group therapy	2 (367)	Yes	Not eligible ^d	Not eligible ^d
Bereavement: hospice	1 (96)	No	Not eligible ^d	Not eligible ^d
Bereavement: individual treatment	1 (33)	No	Not eligible ^d	Not eligible ^d
Community-based suicide prevention	3 (18,641)	No	Not eligible ^d	Not eligible ^d
Suicide prevention: depression care management	1 (598)	No	Not eligible ^d	Not eligible ^d
Nutrition	1 (81)	No	Not eligible ^d	Not eligible ^d
Peer support	1 (291)	No	Not eligible ^d	Not eligible ^d
Adult day health	1 (44)	No	Not eligible ^d	Not eligible ^d
Incontinence	1 (30)	No	Not eligible ^d	Not eligible ^d
In-home respite for caregivers	1 (55)	No	Not eligible ^d	Not eligible ^d
Physical rehabilitation and occupational therapy	7 (822)	Yes	Ineffective	Not recommended

CBT indicates cognitive behavior therapy.

^a The total number of participants in all studies reviewed in the category is given in parentheses.

^b Other therapies include brief relational/insight therapy, brief psychodynamic therapy, self-management, reminiscence, bibliotherapy, and problem-solving.

^c The second panel of reviewers moved studies originally categorized as “Psychotherapy for Caregivers” to the “Education and Skills Training Targeting Caregivers” category; therefore, no recommendation was made for interventions in the “Psychotherapy for Caregivers” category.

^d Intervention categories for which data were inadequate were not eligible for an effectiveness rating or recommendation.

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Disaster Preparedness and the Chronic Disease Needs of Vulnerable Older Adults

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Abstract

About 80% of older adults have at least one chronic condition that makes them more vulnerable than healthy people during a disaster. These chronic conditions — combined with the physiological, sensory, and cognitive changes experienced as part of aging — result in frail older adults having special needs during emergencies. Planning and coordination among public health and emergency preparedness professionals and professionals who provide services for the aging are essential to meet these special needs. Several tools and strategies already exist to help prepare these professionals to protect and assist older adults during a disaster. These include having professionals from diverse fields work and train in coalitions, ensuring that advocates for older adults participate in communitywide emergency preparedness, and using community mapping data to identify areas where many older adults live.

Introduction

An estimated 14 million people aged 65 or older living outside an institution reported in Census 2000 that they had some level of disability, mostly linked to chronic conditions such as heart disease or arthritis (1). Frail older adults — defined as those with serious, chronic health problems — are more likely than the healthier or younger population to need extra assistance to evacuate, survive,

and recover from a disaster (2). In fact, at least 13 million older adults (aged 50 years or older) in the United States have said they would need help to evacuate during a disaster, and about half of these would require help from someone outside their household (3).

Disasters disproportionately affect frail older adults. Before hurricanes Katrina and Rita in 2005, adults aged 60 or older made up only 15% of the population of New Orleans, Louisiana (4,5). However, 71% of those who died because of the hurricane were over age 65 (6). During the 1995 heat wave in the Midwest, the median age of the 465 people in Chicago whose deaths were heat-related was 75 (7).

The sheer numbers of the aging population give an even greater urgency to addressing the needs of older adults following a disaster. The U.S. population aged 65 or older is expected to almost double in size within the next 25 years (8). By 2030, some 72 million people — almost one of every five Americans — will be aged 65 or older (1). Persons aged 85 or older are the fastest growing segment of the U.S. population (1).

Chronic Disease and Disability

Arthritis, hypertension, heart disease, diabetes, and respiratory disorders are some of the leading causes of activity limitations among adults aged 65 or older (1). These conditions can impair an older adult's ability to prepare, respond, or recover from a disaster. Treating chronic disease following a natural disaster must therefore become a public health and medical priority (9). Emergency managers who work with public health and providers of services for the aging (aging services) need to place a priority on special planning for frail older adults who encounter severe weather-related events, earthquakes, large-scale

attacks on civilian populations, technological catastrophes, influenza pandemics, or other disasters.

Consider the following statistics:

- About 80% of adults aged 65 or older have at least one chronic health condition (1).
- About 50% of older adults have at least two chronic conditions (1).
- Nearly 50% of adults aged 65 or older have hypertension, 36% have arthritis, 20% have coronary heart disease, 20% have cancer, 15% have diabetes, and 9% have had a stroke (10).

Chronic conditions often lead to disabilities and the inability to perform basic activities of daily living (ADLs) such as bathing, dressing, eating, and moving around the house. In 2002, 52% of older adults reported that they had some type of disability, including 37% who reported a severe disability and 16% who reported that they needed some type of assistance as a result of their disability (11). In 2004, another study found that about 27% of community-dwelling Medicare beneficiaries over age 65 reported that they had difficulty in performing one or more ADLs, and an additional 13.7% reported difficulties with other activities such as preparing meals or shopping (11).

After a disaster, conditions such as stress, the lack of food or water, extremes of heat or cold, and exposure to infection can contribute to rapid worsening of a chronic illness that was under control before the event (12). Interruptions in medication regimens and needed medical technologies also can exacerbate underlying conditions and increase the risk of morbidity or mortality (12,13). Older adults with chronic conditions also may face health risks from either inadequate nutrition or from too much sodium, fat, and calories contained in the Meal, Ready-to-Eat (MRE) packages often offered to evacuees.

Following Hurricane Katrina, a survey of 680 evacuees living in Houston shelters in September 2005 showed that 41% reported having chronic health conditions such as heart disease, hypertension, diabetes, and asthma; 43% indicated that they were supposed to be taking a prescription medication; and 29% of those who were supposed to take prescription drugs said they had problems getting prescriptions filled (14). Most of those surveyed did not give their age, but many of the people who were in shelters were older adults (14).

Special Characteristics of Older Adults

Certain characteristics of older adults may prevent them from adequately preparing for disasters and hinder their adaptability during disasters. In addition to chronic health conditions, older adults may have impaired physical mobility or cognitive ability, diminished sensory awareness, and social and economic limitations (2). For example, declining vision or hearing can make it difficult for an older adult to communicate. Older adults with cognitive problems may become agitated during a crisis or feel overwhelmed by the crowding, noise, and lack of privacy in a shelter. They may need assistance to ensure that they have their medications, adequate nutrition and water, and assistive devices. Older adults also may be more vulnerable to emotional trauma during a disaster (15). Because older adults are often reluctant to seek or accept mental health services, they may not obtain the counseling they need, even if it is available (13,16).

Lessons Learned

The public health role following disasters traditionally has focused on preserving lives; ensuring safe food, water, and sewage disposal; and controlling infectious disease, environmental risks, and pests. Only rarely was there a need to take any special action for older adults with chronic conditions, because people generally were quickly able to return to normal after a short-duration disaster. In these circumstances, chronic disease did not seem to be a public health or medical priority (9). The September 11, 2001, terrorist attack in New York City created a greater awareness of the needs of the chronically ill population, but it was not until the catastrophic hurricanes that struck the Gulf Coast in 2005 that public health and other professionals fully grasped the urgency of addressing the chronic health needs of vulnerable populations during disasters. The destruction of the medical infrastructure, the displacement of residents from their homes, and the inability to access pharmacies or medical care all contributed to the emergence of chronic diseases as a critical concern (9).

On September 11th, about 6,300 seniors lived around the World Trade Center's Twin Towers in New York City, and nearly 19,000 older adults lived within a three-block radius (17). Many frail older adults and persons with disabilities were confined for days to their high-rise apartments near the World Trade Center without electricity,

fresh supplies, a way to refill their medications, or any way to communicate with the outside world (18). Home care workers could not get in to visit their clients (17), and community service providers could not get to their offices or access computers with client information. In addition, many frail adults were unknown to community workers because they had never applied for services (18).

Along the Gulf Coast in 2005, hurricanes Katrina and Rita and the accompanying flooding resulted in 1,330 deaths, many of which were among older adults (3). In addition, an estimated 200,000 people with chronic medical conditions, who were evacuated or isolated after Hurricane Katrina, lacked access to their medications and usual sources of care (6). As the recovery effort continued, even those evacuees who had the recommended three-day supply of prescriptions ran out.

Since Hurricane Katrina, public health personnel, emergency responders, and aging services professionals have begun working together to plan for protecting frail older adults who may need assistance following a disaster. The goal is to create an emergency response system that can rescue and shelter vulnerable populations and then ensure that they continue to receive routine health care, such as prescription medications, as recommended by the Chronic Diseases and Vulnerable Populations in Natural Disasters Working Group, part of the Coordinating Center for Health Promotion, Centers for Disease Control and Prevention (CDC) (12).

Recommendations

In response to September 11th and to the Gulf Coast hurricanes of 2005, experts have made recommendations to communities on preparing for disaster:

- Develop strong relationships and partnerships among public health agencies, services for the aging, emergency responders, and other entities before disaster strikes to improve coordination, communication, and response in emergency situations (3).
- Have backup communications systems, and maintain a copy of essential information in two locations (18).
- Use mapping systems to identify areas with high concentrations of older adults (18).
- Create a citywide emergency plan for older adults and persons with disabilities (18) that includes a separate

shelter area for them (19), an evacuation system that includes transporting their medications and supplies with them, a network of emergency pharmaceutical services (17), and a system for evacuating pets (6).

- Provide appropriate public information on emergency preparedness in appropriate formats to older adults and persons with disabilities (3).
- Establish a secure system of photo identification and permits for professional health care and senior service workers that will enable them to reach their homebound clients in an emergency (17,18).
- Develop an emergency support system for in-home services, including emergency respite care and communications systems for in-home caregivers (17).
- Create a list of volunteers willing to help in an emergency (17).
- Arrange with local restaurants to provide food to older adults during an emergency (17).
- Improve identification and tracking methods for older adults and their health information (3).

Resources to aid communities in addressing these recommendations and Internet addresses for these resources are listed in the Table.

Working With the Aging Services Network

Public health professionals can create the most effective disaster preparedness plans for vulnerable adults by working with the network of aging services professionals (known as the “aging services network”), which includes state and local departments on aging, local service providers, and Indian tribal organizations that provide services to older adults. The network, operating under the auspices of the federal Older Americans Act, already plays a vital role in delivering meals and providing transportation, information, and other services to older adults. During a disaster, this network reaches out to its clients and identifies those who need assistance obtaining food, water, shelter, or medications (20).

Tools for Preparedness Planning

Surveillance and assessment

Community assessments following disasters can identify health-related needs and support public health interven-

tions (21). CDC can help state and local public health agencies use existing health surveillance systems to estimate the need for emergency responders who can address chronic health conditions and disabilities following a disaster.

Following the events of September 11th, Connecticut, New Jersey, and New York added a mental health module to their ongoing Behavioral Risk Factor Surveillance System (BRFSS) surveys to help public health professionals understand the importance of addressing the physical and emotional needs of older adults living in the area (22). BRFSS data and data from other information systems provide information on the prevalence of diabetes, heart disease, stroke, hypertension, or asthma before a disaster, giving planners better knowledge about the needs of their population with chronic disease (9).

Geographic mapping systems

A geographic information system can map the residences of older adults and persons with special needs who will require assistance during an emergency evacuation. After Hurricane Charley crossed Florida in 2004, CDC provided population maps for the three most damaged counties to enable workers to identify and interview someone from almost 600 households with an older adult (23). In one county, workers found that in one-third of the households with a chronically ill older adult, at least one of the older person's conditions had worsened because of the hurricane; 28% of the households reported that an older adult was unable to receive routine care for a chronic disease. In another county, 9% of households with older adults did not have access to prescription drugs. Local health care providers used this information to accelerate restoration of medical services and access to medications in the affected areas (23).

Handbooks

The U.S. Administration on Aging's *Emergency Assistance Guide 2006* helps professionals plan for emergencies (Table). In addition, the American Red Cross has materials that focus on special populations, including *Disaster Preparedness for Seniors by Seniors* and *Disaster Preparedness for People with Disabilities* (Table). The Florida International University and University of South Florida, with funding from the U.S. Administration on Aging, have developed a planning tool for aging services professionals. The tool, titled *Designing a Model All-*

Hazards Plan for Older Adults: The Role of the Aging Services Network in Assuring Community All-Hazards Readiness for Elders and in Providing Assistance to Elders when Disasters Occur (Table), contains detailed recommendations on addressing the needs of vulnerable older adults in all areas of the country during disasters. CDC's Coordinating Office for Terrorism Preparedness and Emergency Response has drafted *Public Health Workbook to Define, Locate and Reach Special, Vulnerable, and At-Risk Populations in an Emergency* (Table).

Conclusion

Planning for assisting populations with chronic diseases, especially vulnerable older adults, during a disaster is essential to meeting their special needs. Public health professionals should link with professionals in aging services, emergency planning, and other groups to create a comprehensive system for addressing the needs of older adults during a disaster. Planning, coalition building, and using mapping systems are among the numerous tools and strategies available to creating an emergency response system that can rescue and shelter vulnerable populations in disaster situations.

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Tables

Table. Resources Available to Help Communities Prepare for Disasters

Resource	Responsible Agency or Organization	Web link
Behavioral Risk Factor Surveillance System	Centers for Disease Control and Prevention (CDC)	http://www.cdc.gov/brfss/
<i>CDC's Disaster Planning Goal: Protect Vulnerable Older Adults</i>	CDC (through a contract with Health Benefits ABCs)	http://www.cdc.gov/aging/pdf/disaster_planning_goal.pdf
<i>Designing a Model All-Hazards Plan for Older Adults: The Role of the Aging Services Network in Assuring Community All-Hazards Readiness for Elders and in Providing Assistance to Elders when Disasters Occur</i>	Florida International University and University of South Florida (Administration on Aging contract)	http://www.allianceforaging.org/pdfs/DisasterPlan.pdf
Disaster assistance Web site	Administration on Aging	http://www.aoa.gov/ELDFAM/Disaster_Assistance/Disaster_Assistance.asp
<i>Disaster Planning Tips for Older Adults and Their Families</i>	CDC (contract with Health Benefits ABCs)	http://www.cdc.gov/aging/pdf/disaster_planning_tips.pdf
<i>Disaster Preparedness for People with Disabilities</i>	American Red Cross	http://www.prepare.org/disabilities/disabilities.htm
<i>Disaster Preparedness for Seniors by Seniors</i>	American Red Cross	http://www.redcross.org/services/disaster/0,1082,0_9_,00.html
<i>Eldercare Locator</i> (provides links to aging network resources)	Administration on Aging	http://www.eldercare.gov
<i>Emergency Assistance Guide 2006</i>	Administration on Aging	http://www.aoa.gov/PRESS/preparedness/preparedness.asp#guide
<i>Emergency Preparedness Tips for Older Adults</i>	Foundation for Health in Aging, American Geriatrics Society	http://www.healthinaging.org/public_education/disaster_tips.pdf
<i>Just in Case: Emergency Readiness for Older Adults and Caregivers</i>	Administration on Aging	http://www.aoa.gov/PROF/aoaprogram/caregiver/overview/Just_in_Case030706_links.pdf
<i>Pandemic Flu Operational Plan</i>	Administration on Aging	http://www.aoa.gov/press/preparedness/pdf/AoA_Flu_Pandemic_Draft_Plan_7-20-06a.doc
<i>Preparing for Disaster for People with Disabilities and Other Special Needs</i>	Federal Emergency Management Agency / American Red Cross	http://www.fema.gov/pdf/library/pfd_all.pdf
<i>Public Health Workbook to Define, Locate and Reach Special, Vulnerable, and At-Risk Populations in an Emergency</i> (draft)	CDC	http://www.bt.cdc.gov/workbook/
Ready America Web site	U.S. Department of Homeland Security	http://www.ready.gov/america/getakit/seniors.html
<i>Resources for Planning How to Protect Your Pets in an Emergency</i>	CDC	http://www.bt.cdc.gov/disasters/petprotect.asp

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ORIGINAL RESEARCH

Factors Related to Cardiovascular Disease Risk Reduction in Midlife and Older Women: A Qualitative Study

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PEER REVIEWED

Abstract

Introduction

Cardiovascular disease (CVD) is the leading cause of death for women in the United States. A healthy diet and appropriate physical activity can help reduce the risk for CVD. However, many women do not follow recommendations for these behaviors. In this study, we used qualitative methods to better understand knowledge and awareness about CVD in women, perceived threat of CVD, barriers to heart-healthy eating and physical activity, and intervention strategies for behavior change.

Methods

We conducted four focus groups with 38 white women aged 40 years or older in Kansas and Arkansas. We also interviewed 25 Cooperative State Research, Education, and Extension Service agents in those states. Environmental audits of grocery stores and the physical environment were done in three communities.

Results

Most women were aware of the modifiable risk factors for CVD. Although they realized they were susceptible, they

felt CVD was something they could overcome. Common barriers to achieving a heart-healthy diet included time and concern about wasting food. Most women had positive attitudes toward physical activity and reported exercising in the past, but found it difficult to resume when their routine was disrupted. The environmental audits suggested that there are opportunities to be physically active and that with the exception of fresh fish in Kansas, healthful foods are readily available in local food stores.

Conclusion

Interventions to change behavior should be hands-on, have a goal-setting component, and include opportunities for social interaction. It is especially important to offer interventions as awareness increases and women seek opportunities to build skills to change behavior.

Introduction

Heart disease is still considered a disease that affects men, although every year since 1984, it has affected more women than men in the United States (1). In 2004, approximately 500,000 women died of cardiovascular disease (CVD), making it the leading cause of death for women in this country (2).

A lifestyle that includes a healthy diet, weight control, and appropriate physical activity can dramatically reduce the risk of heart disease in women (3-9). A dietary pattern that focuses on vegetables, fruits, low and nonfat dairy foods, whole grains, legumes, fish, and lean meats helps to reduce cholesterol levels and lower blood pressure, leading to an overall reduction in CVD risk (1,10-12). Increasing

physical activity similarly helps to improve weight control and reduce risk of developing CVD in women (13). Yet few women are leading heart-healthy lifestyles. According to the 1999–2000 National Health and Nutrition Examination Survey data, half of women aged 51–70 years fail to eat at least 5 servings of fruits and vegetables per day (14). Nearly 40% of women do not engage in any type of leisure-time physical activity (15), and nearly 70% of women aged 40 or older are overweight or obese (16).

Strategic tactics to reduce CVD risk involve the development and evaluation of educational and behavioral programs that can be implemented by organizations in communities where many women at high risk can be reached. To develop effective interventions, it is important to understand the target population in relation to the behaviors. Qualitative methods are ideal for gathering in-depth information to help develop this understanding (17). By using several different qualitative methods, the findings of each may be confirmed and extended (18).

Several previous studies have used qualitative methods to examine women's perceptions and awareness of CVD risk. Focus groups have been conducted with low-income African American women (19–22) as well as young and middle-aged white, Latina, and American Indian women (21–23). The results of these studies suggest that awareness of personal risk varies in different populations. Common barriers to behavioral change to reduce risk include a lack of support, food preferences, time, and cultural factors. Women in these studies said they wanted interventions that taught them skills, were tailored to their needs and situations, and included social support.

CVD develops over several decades, and efforts to prevent it that begin earlier in life are likely to have greater benefit. However, lifestyle modifications may still reduce risk, even in older adults (24). These efforts may become especially important as the United States faces a growing number of older citizens (25).

In this study, focus groups were conducted with midlife and older (aged 40 or older) sedentary women who would be appropriate candidates to target with an intervention. The objectives of this study were to use qualitative methods to determine the knowledge and awareness of CVD risk in midlife and older women, identify barriers to heart-healthy eating and physical activity, and develop intervention strategies that are likely to be feasible and effective.

Methods

Focus groups

We conducted four focus groups in Kansas and Arkansas in June 2006. Two groups were conducted in each state: one in a rural community (population of less than 7000) and one in a small city (population of approximately 40,000). Cooperative State Research, Education, and Extension Service (CSREES) agents, who serve as leaders on health issues in rural communities, recruited a purposive, nonrandom sample of sedentary women aged 40 or older. Women were recruited through CSREES agents' community networks and through listings at community events. Focus groups took place at CSREES sites within the communities and were led by a trained focus group facilitator. In total, 38 women participated, with group sizes ranging from 8 to 11 participants. Sessions typically lasted 90 minutes. A \$50 incentive was given to each participant to improve attendance. Each session was recorded on a digital audio recorder for subsequent transcription. Participants signed informed consent forms in accordance with the requirements of the Tufts University Institutional Review Board.

The discussion guide for the focus groups was designed to address four key topic areas: 1) awareness and knowledge about CVD risk factors; 2) attitudes, perceptions, and barriers regarding physical activity; 3) attitudes, perceptions, and barriers regarding a heart-healthy diet; and 4) opinions about nutrition and physical activity interventions. We conducted a pilot focus group using the guide to ensure good discussion flow and question comprehension. No changes were made to the guide after the pilot.

The NVivo program (version 2.0 for Windows, QSR International Pty Ltd, Doncaster, Victoria, Australia) was used to help code the data. One person coded key phrases into a framework that was based on the questioning structure. During this initial coding process, additional themes emerged from the data and were added to the framework. Data were then recoded using the revised framework.

Interviews with CSREES agents

CSREES, part of the U.S. Department of Agriculture, has as its mission the advancement of knowledge for agriculture, the environment, and human health and well-being (26). The food, nutrition, and health programs within

CSREES are designed to strengthen the nation's capacity to address issues related to diet, health, food safety, food security, and food science and technology (27). Because of their role, CSREES agents have in-depth knowledge of the communities they serve and are in an ideal position to deliver interventions related to heart health.

Two members of the research team conducted structured interviews with 15 CSREES agents in Arkansas and with 10 CSREES agents in Kansas. The discussion guide for these interviews was designed to determine their perceptions of the target population regarding nutrition, physical activity, and heart health, and to obtain their opinions on interventions to address these issues. All of the agents were women. They represented a wide range of geographic locations within each state. However, in accordance with the CSREES mission, most were in rural communities.

Interviews with each agent were conducted by telephone and lasted 15 to 30 minutes. The responses were compiled in a word processing program, and the NVivo program was then used to assist with coding. As with the focus group data, the data from these interviews were coded in a two-step process: key phrases were coded into a framework that was based on the questioning structure, and additional themes that emerged from the data were added to the framework and coded. CSREES agents signed informed consent statements approved by the Tufts University Institutional Review Board.

Community observation

The research project manager used community observation to confirm and extend the information gathered through the focus groups and interviews and to assess the availability of specific food items. Three of the four communities represented in the focus groups, the two in Kansas and the larger in Arkansas, were observed. An unforeseen transportation issue prevented observation of the fourth community. Observation included an audit of the major supermarkets in the community as well as health food stores, if there were any. We identified stores through online business directories and by asking the county CSREES agents, all of whom had resided in the communities for many years. To guide the audit, we developed a list of foods that might be considered "heart healthy." It included whole grain pasta, bread products and flours, and brown rice; a variety of fresh and frozen produce; dried and canned beans; canned, fresh, and non-breaded frozen

fish (any type); and low-fat dairy (how much 1% or nonfat milk was available in proportion to 2% or whole milk). The research project manager visited all stores and checked whether the items on the list were available in the store. In addition, digital photographs were taken to document how these foods were presented in the stores.

The research project manager also observed the physical environment. This part of the audit was based on the Irvine Minnesota Inventory for Observation of Physical Environment Features Linked to Physical Activity (28). The project manager used the coding instrument from this inventory as a guide to determine accessibility (e.g., easy to get to, no locked gates or other barriers), pleasurable, perceived safety from traffic, and perceived safety from crime in the main downtown area and in major residential sections of the communities. The information gathered included the availability a public recreation area, the condition of sidewalks, and the presence of crosswalks, curb cuts, and pedestrian crossing signals. However, it was not a formal, quantitative audit, because a single data collector made observations and systematic sampling was not used. The goal was to use a set of standard questions to form qualitative impressions of the physical environment.

Results

The recruitment criteria for the focus groups were sex, age, and physical activity level. Women were required to be at least 40 years old and sedentary. The participants who met those criteria and responded ranged in age from early 40s to late 80s. Reflecting the demographics of the communities, all women were white.

Knowledge and awareness about CVD risk in women

CSREES agents described the women in the target population as having a variable level of awareness about heart disease risk in women, and focus group data supported this. Most women in the focus groups were aware that heart disease is the leading cause of death for women in the United States, although several believed that it was breast cancer. They were generally aware that heart attack symptoms for a woman are often more subtle than for men. One group talked about women having smaller veins. They were aware of both modifiable risk factors and the genetic component for CVD.

Participants in all focus groups identified a number of foods as being part of a heart-healthy diet, including low-fat foods. Whole grains (oatmeal in particular) and fruits and vegetables were named in all four groups. Nuts, beans, and fish that is not fried were also mentioned.

CSREES agents reported that the women were more likely to have misconceptions about diet than about physical activity. The agents' perceptions were that misconceptions were likely to be around the role of *trans* fats and about fad dieting. However, focus group participants were aware that *trans* fats should be avoided, and no misconceptions about them emerged. Participants did have some food-related misconceptions, though. Cheese, garlic, and spices were incorrectly named as foods that would promote heart health. Coffee and caffeine were incorrectly named as things that should be avoided.

The women talked about several types of physical activity that would be good for their hearts, including walking, running, or things that "get your heart rate up." CSREES agents confirmed that for the most part, women in the target population have a moderately high level of understanding about the role of physical activity in reducing risk and the types of activity that are most beneficial, but they have difficulty in putting their knowledge into practice.

Perceived threat of CVD

Many women in the four groups said that their greatest concern about their own health was not a specific illness, but developing any condition that would incapacitate them.

I think it would be horrible to be incapacitated where you couldn't do for yourself . . . you couldn't drive, you couldn't walk to the mailbox, or whatever, you had to depend on someone else to do it for you. (larger community, Arkansas)

Many saw CVD as something that could be overcome, and they were not concerned about it despite their awareness that heart disease is the leading cause of death among women.

We have a lot of heart history in our family, too, but they've survived it. And they've had stents and bypasses and all of this, but they've survived it and are doing very well — cancer just seems to be one

of those things that you can't get stopped . . . (larger community, Kansas)

I've been there, and done that, been through two major heart surgeries, and I'm invincible. (larger community, Arkansas)

CSREES agents confirmed that heart disease was not perceived as a major threat to women, despite their high levels of awareness. Agents added that some women are more concerned about breast cancer, and other women believe that heart disease will not happen to them.

Some focus group participants expressed a certain amount of fatalism regarding their risk, because of strong family history. In each group, at least one woman talked about how diet and physical activity had not made an impact on her cholesterol levels. These women still thought it was a good idea to eat healthfully, exercise, and get checked by a doctor, so that they would not have to worry about it as much.

My goal for myself is just to make changes that are healthy and become so much a part of my life that I'm not focused on that. (Several agree). I'd rather be focused on a lot of other things. (smaller community, Kansas)

Barriers to healthy eating

Only one community (in Kansas) had a health food store. However, the results from the audit suggest that most heart-healthy foods are readily available in the communities, and access is not a major barrier. The major supermarkets had a good selection of whole grain products. They also had a good selection of fresh and frozen vegetables, fresh and frozen fruits, and dried and canned beans. Although the stores devoted more space to 2% and whole milk, all had an ample supply of 1% and nonfat milk. All stores had a good selection of canned fish. Fresh fish was readily available in Arkansas, but in Kansas, only the one large store in the larger city had fresh fish. Stores in both states carried frozen fish, but breaded fish dominated the freezer section and the selection of plain filets was extremely limited.

Data from the CSREES agent interviews and focus groups corroborated the results of the environmental audit, although a few women added that fresh produce is

not as readily available in the winter months. Although heart-healthy foods are readily available, women said that they find it difficult to avoid less healthful foods.

And the healthy foods are always there. You know, you can lead a horse to water but can't make him drink. I try to cook healthy and try to have healthy things . . . but I like fried foods too, so it's hard. (larger community, Kansas)

Many women reported that avoiding high-calorie snacks was especially difficult. They saw snacking as their main downfall. Even when they were able to eat more healthfully at meals, they reported having difficulty choosing healthy snacks.

Time emerged as a major barrier to healthy eating, for different reasons. Women with children still in the home said that they had very busy schedules and did not have time to cook. Retired women said that they were tired of cooking after doing it for so many years and did not want to spend the time.

Women who lived with husbands and children thought that it would be easier for single women to eat a more healthful diet.

I think when you have kids, there's a snack problem. We still have a child at home, and he will eat salads and vegetables, but he really likes to have other things in the house, too. (smaller community, Kansas)

Conversely, women who lived alone thought it would be easier for those with husbands and families to eat better.

I think I'm one of the oldest ones here, so I can say as a younger mother and younger, I did that [cooked healthfully] for my family. Trying to have them have a healthy diet. But now, it's a lot harder. (larger community, Kansas)

Wasting food came up as a barrier to change in three of the four groups. Women reported eating more than they want because they do not want to throw food away.

And we're in a generation, our kids now are not that way, but we're in a generation that don't waste food. I mean, my kids were — when they went to

the table and they ate what was on the table and they cleaned their plates out. But now, they're not that way. So I think that's an example, because we've been taught not to waste food and we eat instead of throwing it out. (larger community, Arkansas)

Other barriers included being pressured to eat at social events, confusion over what they perceive as conflicting health messages, hunger when they try to cut down on portion sizes, lack of menu planning that leads to eating out, not liking fruits and vegetables, and difficulty in changing eating patterns they had developed in childhood.

Barriers to physical activity

In the communities in both states, the overall qualitative impression from the environmental audit was that there were readily accessible, pleasant places to walk that were reasonably safe in terms of both traffic and crime. In Arkansas, there were very few sidewalks in rural areas, but it was still possible to walk safely. CSREES agents confirmed these observations.

Weather did arise as a barrier to physical activity in both the focus groups and the key informant interviews. In terms of indoor physical activity, the three communities that were observed all had gyms. Some focus group participants said that feeling self-conscious at the gym was also a barrier. There were other options for indoor walking in all communities.

Most CSREES agents felt that most women would be willing to increase their physical activity levels. Many of the focus group participants had engaged in regular physical activity in the past but found it difficult to resume after something disrupted their routine.

[A]nd then I changed jobs, and it took so long to get down to the Y to work out . . . I just stopped doing it, and then gradually I just started eating bad again and whatnot . . . I don't really have an excuse now. I have lots of time, I could do it, I just got out of the habit. (larger community, Arkansas)

A few women said that physical activity could be boring, but they would be willing to do it if it could be made fun. Only a couple of women said that they do not exercise because they are lazy or dislike it. Even those women

seemed somewhat willing to try it if they could find something that they would enjoy. A few women did not want yet another commitment, and they mentioned strategies for incorporating physical activity into their regular schedule, such as parking further away from the store or taking the stairs rather than the elevator.

Intervention strategies

Overall, the women felt that they already knew a fair amount about what they need to do to reduce their risk of CVD in terms of diet and physical activity; they just need help putting that knowledge into practice. They said that to motivate them to keep coming, an intervention program should be hands-on. CSREES agents confirmed that programs with a hands-on component are most popular with their constituency. Hands-on nutrition intervention programs that had worked best for them in the past had included tastings and cooking exercises.

Focus group participants also wanted a program to include goal-setting, where they set reasonable, realistic goals so that they can see results, even small ones. They want to receive recognition that they had met those goals. CSREES agents felt comfortable in helping women set goals and in giving them recognition for meeting goals.

CSREES agents and focus group participants both reported that walking is a preferred form of physical activity. Most women expressed a positive attitude about both walking and dancing, especially when they could be done with other people. CSREES agents confirmed that their most successful programs for midlife or older women include a social component, and that if participants have opportunities to build relationships, they will be highly motivated to keep coming back.

Discussion

There was a high level of awareness of CVD among the women in the focus groups in this study. Two large national campaigns, the National Heart, Lung, and Blood Institute's Heart Truth campaign (29) and the American Heart Association's Go Red for Women campaign (30), have put substantial resources toward increasing awareness in recent years. Awareness has increased significantly since the Go Red for Women campaign began in 1997 (31). Although women were not specifically asked how

they had heard about the problem, these campaigns could have contributed, either directly or indirectly, to the level of awareness in this population.

Both the focus groups and the interviews with CSREES agents indicate that the women are knowledgeable about CVD risk factors. Although there were some misconceptions, especially concerning diet, they were few. The women's belief that low-fat foods are inherently protective against CVD probably reflects older messages about CVD, which focused on total fat rather than saturated fat. It is uncertain why cheese was mentioned as a heart-healthy food. Several women believed that coffee or caffeine should be avoided. Although a study done in 1957 demonstrated a relationship between drinking coffee and CVD and was influential for many years, the current evidence is mixed and inconclusive (32).

Although the women recognized that they had a high level of susceptibility to CVD, they perceived the severity of CVD to be low. They saw CVD as something that they could either live with or overcome. At the same time, their biggest concern regarding their health was if they were to become disabled in some way. This suggests that health messages that focus on CVD as a potentially disabling condition may help persuade women to take action by increasing their perception of the potential severity of CVD.

Waste emerged as a major barrier to dietary behavior change. Women said that they would eat more than they wanted because they felt strongly about not letting food go to waste. This did not come up as an issue in previous studies with younger women and could reflect the age demographic in the groups. This should be taken into account when designing interventions targeted at older people.

In other qualitative studies, family responsibilities and preferences emerged as major barriers to physical activity and heart-healthy eating (22,23). These themes were not prominent in our results, perhaps because the women were older and either lived alone or had older children with less influence on their time and on the family meal. However, the time necessary to purchase and prepare food did emerge as a barrier. In our study, retired women reported having the time, but not wanting to take it. Food preference, a barrier for women in previous studies, also surfaced in our groups. This is not surprising, since taste is a major determinant of food choice (33).

Overall, the results suggest that many of the women were in the contemplation stage according to Prochaska's Transtheoretical Model (34). According to the model, people in this stage intend to change in the next 6 months. They are aware of the benefits of change but are also acutely aware of the costs and are in the process of balancing the two. Most women in the focus groups were aware of the problem of CVD and knowledgeable about diet and exercise, suggesting that they had actively sought out information. Many had exercised in the past and had had positive experiences, but had fallen out of the habit. CSREES agents described them as being willing to increase their physical activity levels. However, both CSREES agents and the women themselves spoke of the many barriers to making a change. The women had difficulty putting their knowledge into action. This finding may reflect the way participants were recruited. Although it was specified that they must be sedentary to participate, women with an interest in diet, physical activity, and CVD and who were willing to discuss these issues without taking part in an action-oriented program were probably more likely to respond.

Self-reevaluation strategies may be appropriate and effective for women in this stage (34). These have been effective in moving people from the contemplation stage to the preparation stage, in which a person intends to take action in the next month and has taken some significant action in the past year (34). Self-reevaluation techniques may help a woman see how the benefits outweigh the costs by causing her to evaluate her self-image when she is doing the changed behavior ("I feel like a strong person when I exercise") or when she is not ("I feel lazy and unhappy when I don't exercise"). Self-reevaluation techniques include the provision of healthy role models, imagery, and value clarification (35).

Both the focus group and the interview results suggest that a viable intervention should include hands-on strategies such as taste testing and food preparation, allow space for social interaction, and include a goal-setting component. The community observations indicate that the environment will support positive behavior change. Foods that fit into a heart-healthy eating pattern are readily available, with the exception of fish in Kansas. Walking is a preferred form of physical activity, and there are safe and pleasant places to walk. Dancing may be a good alternative when exercise must be done indoors.

These results contribute to a growing body of evidence about women's knowledge and perceptions regarding CVD risk. They also provide some guidance for preferred strategies for behavior change. This is especially important as awareness increases and women look for opportunities to develop the skills necessary to help reduce their risk of this serious disease.

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SPECIAL TOPIC

Design and National Dissemination of the StrongWomen Community Strength Training Program

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PEER REVIEWED

Abstract

Background

Physical activity is essential for maintaining health and function with age, especially among women. Strength training exercises combat weakness and frailty and mitigate the development of chronic disease. Community-based programs offer accessible opportunities for strength training.

Program Design

The StrongWomen Program is an evidence-informed, community-based strength training program developed and disseminated to enable women aged 40 or older to maintain their strength, function, and independence. The StrongWomen Workshop and StrongWomen Tool Kit are the training and implementation tools for the StrongWomen Program. Program leaders are trained at the StrongWomen Workshop. They receive the StrongWomen Tool Kit and subsequent support to implement the program in their communities.

Dissemination

Program dissemination began in May 2003 with a

three-part approach: recruiting leaders and forming key partnerships, soliciting participant interest and supporting implementation, and promoting growth and sustainability.

Assessment

We conducted site visits during the first year to assess curriculum adherence. We conducted a telephone survey to collect data on program leaders, participants, locations, and logistics. We used a database to track workshop locations and program leaders. As of July 2006, 881 leaders in 43 states were trained; leaders from 35 states had implemented programs.

Conclusion

Evidence-informed strength training programs can be successful when dissemination occurs at the community level using trained leaders. This research demonstrates that hands-on training, a written manual, partnerships with key organizations, and leader support contributed to the successful dissemination of the StrongWomen Program. Results presented provide a model that may aid the dissemination of other community-based exercise programs.

Background

Aging and the value of strength training

Physical inactivity and poor nutrition are leading contributors to chronic disease and premature death throughout the United States and abroad (1-3). As the average lifespan of Americans increases, older adults are becoming

ing vulnerable to the effects of chronic disease, weakness, and functional decline. During aging, people often lose strength, muscle mass, and bone mass and decrease their levels of physical activity and dietary quality (4-6). The age-related loss of muscle and bone mass and their effects are more pronounced in women because women naturally have less muscle and bone mass than men and because the loss of lean tissue is accelerated during menopause (7-9). That loss of muscle mass may compromise a woman's ability and confidence to participate in regular exercise and to perform common daily activities, such as household chores (10-12).

Research has shown that many age-related physiologic declines are not inevitable. Laboratory and home-based studies have demonstrated that strength training — also referred to as progressive resistance training or weight lifting — confers numerous health benefits, particularly for women as they age. Strength training is an activity in which muscles move dynamically against weight (or other resistance) with small but consistent increases in the amount of weight being lifted over time. Done regularly, these exercises build bone and muscle and help to preserve strength, independence, and vitality (13-16). For instance, postmenopausal women aged 50 to 70 years increased bone and muscle mass, as well as strength, during 1 year of progressive strength training exercises while their age-matched counterparts, who did not strength train, experienced declines in these measures (17). In addition to reducing the risk of osteoporosis, strength training reduces risk for falls, lessens morbidity from diabetes and osteoarthritis in older adults, reduces depression, and improves sleep and self-confidence, according to randomized, controlled trials (13,16-22).

Despite compelling scientific research and recommendations from the government and the American College of Sports Medicine (ACSM), only 17% of adult women and approximately 12% of all adults aged 65 or older participate in strength training exercises (23-25). One objective of the U.S. Department of Health and Human Service's *Healthy People 2010* guidelines is to increase to 30% the proportion of adults who perform physical activities that enhance and maintain muscular strength and endurance (25).

Community-based programming and community leaders

Exercise programs can be executed in a variety of settings. People may choose to exercise at home, with a group

at their faith-based organization, or at a sport and fitness facility. Home-based programs, for instance, involve an individual acquiring materials — including instructions and illustrations as well as background and motivational information — and then following the program at home. One example is the widely disseminated *Exercise: A Guide from the National Institute on Aging* (4). Home-based programs offer convenience and affordability but little opportunity for feedback or socializing. Other common venues for exercise are fitness clubs, where individuals purchase memberships that provide access to a range of equipment, instructors, and classes. Although this setting allows for feedback and social opportunities that are unavailable in home-based programs, it may present barriers such as cost, accessibility (i.e., location and transportation issues), and individuals' lack of confidence in using equipment or participating in classes.

Community-based exercise programs are similar to programs operated in fitness clubs in that they bring groups of participants together to exercise. In contrast, community-based exercise classes are held in public venues, such as local community or recreational centers, churches, county 4-H buildings, or public housing facilities; also, "membership" is simply being a member of that local community. Community-based programs often have a host organization that supports programs by providing equipment and generating publicity. Community-based exercise programs offer many advantages: they are typically more accessible, less expensive, and less intimidating than programs in fitness clubs, and they provide opportunities for feedback and social and peer support, which have a positive impact on long-term behavior change (26-35). Community-based programs have also been shown to increase knowledge and awareness of health-related behaviors (e.g., making healthy food choices) and to promote and support long-term behavior change (26-28). Because of these advantages, community-based exercise programs may be more feasible and sustainable than home-based programs or those requiring membership (29,30).

The StrongWomen Program is a community-based exercise program that focuses on increasing women's access to regular strength training opportunities and increasing knowledge about the importance of regular strength training (35-37). Community leaders assist in executing community-based programs in the following areas: administrative tasks (e.g., registration), program promotion (e.g., fliers, informational meetings), class organization, sched-

uling, set up, conducting the classes, and responding to program participants' questions, needs, and feedback. The formal title for a community leader who has been trained to implement the StrongWomen Program is StrongWomen Program Leader, hereafter referred to as program leader.

Research, demographics, and the social environment

Several factors converged in the 1990s to create a fertile environment for the dissemination of a community-based strength training program targeted to women. During this period, research was published that demonstrated the importance of lifting weights as age increases, particularly for women (13,16-19). The publication of the *Strong Women* books and similar publications translated much of the research into practical strategies for individual use (38-40). In addition, several other communication and media elements — ranging from television and radio to print and online publications — supported the message of the importance of strength training for women.

Concurrently, the absolute numbers of middle-aged and older women (aged 40 or older) was growing, increasing the number of potential program participants. From 1990 to 2000, the number of women aged 40 or older grew by 23.3%, compared with a 13.2% growth in the total population (41,42). Women were also increasingly engaged in their own health, becoming more educated about their options for maintaining good health as they approached midlife and becoming more empowered to engage actively in making healthful decisions (43-45).

An increased awareness and promotion of exercise at the local, state, and national levels fueled the interest in making healthier choices. In particular, the ACSM and the Centers for Disease Control and Prevention were publishing clear, discernible messages about the importance of physical activity in general and strength training in particular (14,46). Chapter 22 of the *Healthy People 2010* report presented data on strength training practices in the late 1990s and goals for 2010, including goals for the proportion of older adults to participate in strength training exercises (25,35,36).

This environment prompted the development of the StrongWomen Program. The goal of the program was to translate the strength training research into a practical application that program leaders could implement in their communities for a broad audience of women. With the

growing interest and demand from the target population of women and the support of recent research, the timing was optimal for women to gather and work toward the goals of improved health and wellness. The StrongWomen Program was designed to meet these goals and to provide the additional benefit of a supportive social community of “strong women” program participants and leaders.

The combination of a strong and growing research base, demographic changes in the target population, and the recognition that social support is an important element of participation in exercise programs made the development and dissemination of the StrongWomen Program timely (Figure 1).

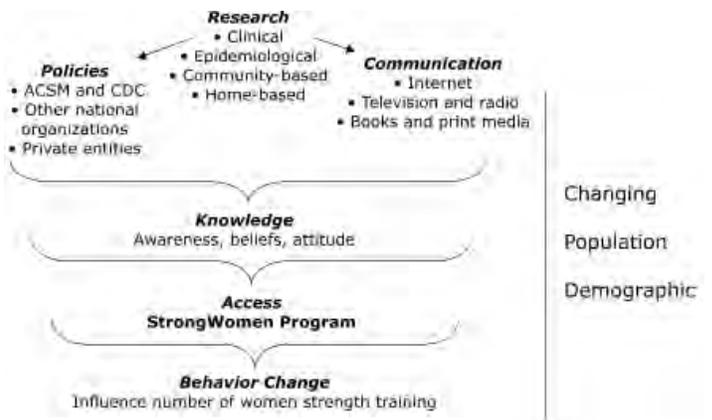


Figure 1. Contextual concept for development and dissemination of the StrongWomen Program, a community-based strength training program targeted to women aged 40 or older. ACSM indicates American College of Sports Medicine; CDC, Centers for Disease Control and Prevention.

Program Design

The mission of the StrongWomen Program was to increase the health and vitality of middle-aged and older women across the country. To achieve this mission, the principal objective was to disseminate an easily sustainable, evidence-informed, community-based strength training program targeted to middle-aged and older women.

Overcoming barriers to program implementation

Barriers to implementing safe and effective exercise programs, particularly for older individuals, are common. They include program fees, physical accessibility, scheduling, equipment purchase, and identifying qualified leaders. One goal of the StrongWomen Program was to review

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existing research and publications to address potential barriers proactively during the development phase and, therefore, create a curriculum, training, and support system for leaders that would address and minimize potential obstacles to implementation and sustainability. A discussion of barriers and how to overcome them follows.

Evidence-informed programming

Many academic institutions contribute to the growing body of literature about the benefits of exercise for older adults. Unfortunately, little of this research reaches the public, and when it does, it is rarely translated into practical and accessible exercise programs. We based the StrongWomen Program on scientific research and public health recommendations that advise older adults to perform strength training exercises at least twice weekly; this foundation provides the essential element of credibility for the program (17,23-25,46-52).

Community-based programming

We designed the StrongWomen Program as a community-based program to be implemented in nonprofit community settings and organizations. We aimed to make the program as affordable, accessible, and approachable as possible and to use the social support of program participants and leaders to promote sustained behavior change. We encourage program leaders and their organizations to facilitate communication and networking among program participants.

Educating health care providers

Another barrier to exercise programs for older adults is the lack of knowledge among physicians and other health care providers about evidence-informed exercise programs that are available to their patients. The StrongWomen Program Tool Kit (described below) includes an easy-to-read information sheet that participants can give to their health care provider, along with a packet of peer-reviewed research articles detailing the scientific basis for the program. We distribute contact information for our staff and each site's leader to foster communication between health care providers and program administration and leaders (4-6,10-13,16-22).

Experience of the StrongWomen Program participants

StrongWomen Program classes last approximately

1 hour and consist of 5 minutes of warm up (e.g., walking, marching in place), 40 minutes of strength training, 5 minutes of balance training, and 5 minutes of cool down (i.e., stretching and flexibility exercises). The StrongWomen Program is a 12-week session with two 1-hour classes per week on nonconsecutive days. Generally, eight to 15 participants per class participate in the 12-week session as a group. Most program leaders operate subsequent sessions as a maintenance program for a group that has completed a 12-week session while initiating separate sessions for new groups. We encourage participants to perform the strength training exercises on their own on a third nonconsecutive day of the week. To assist them, leaders distribute copies of the exercise descriptions and illustrations as well as a list of local resources for other physical activity opportunities (e.g., walking clubs). Program leaders may choose to make minor adjustments to the recommended program. For example, they may schedule a 10-week class instead of a 12-week class.

The greatest variation in program logistics is in participant cost and equipment. The out-of-pocket cost to participants ranges from none (when no class fee is charged and equipment is provided by the program) to \$120 for 12 weeks of classes (\$5 per class twice per week), plus the need to bring their own equipment. A typical fee for a session in which all equipment is provided by the program is \$48 to \$96 for 12 weeks of classes (or \$2-\$4 per class). Ultimately, the program leader or the organization implementing the program determines the fees and how the equipment is acquired and paid for. The equipment per participant includes at least two sets of dumbbells (i.e., a 5-lb and an 8-lb pair), an adjustable ankle weight (10-20 lb per cuff), and an exercise mat or towel for floor exercises.

When participants must purchase their own equipment, it costs approximately \$50 to \$80 (\$10-\$15 for dumbbells, \$30-\$50 for a 20-lb ankle weight, and \$10-\$15 for an exercise mat). This estimate is for new equipment and includes shipping and handling fees. Obtaining used equipment and avoiding shipping and handling fees reduce costs substantially.

When program leaders provide the equipment, the cost varies but is typically less per participant than when the participants purchase their own equipment because weights and mats can be purchased at bulk discounts up to 50%. For example, the equipment cost for 10 participants ranges from \$25 to \$40 per participant (and less if used

equipment can be obtained). The meeting space and other items that a program leader must provide to participants include an adequately sized, well-lit room; a parking area; sturdy chairs; and bathroom facilities.

The StrongWomen Program curriculum: workshop and tool kit

The foundation of the StrongWomen Program is the written manual (the tool kit) and the hands-on training for program leaders (the workshop). Collectively, the workshop and tool kit form the curriculum for the program. Neither is a stand-alone entity; each potential leader must attend the workshop to receive the tool kit and subsequently implement the program.

The StrongWomen Workshop

During the full-day workshop (8 hours, including a working lunch), program leaders participate in a series of seminars and hands-on sessions based on the content of the tool kit. During the hands-on sessions, they learn how to instruct participants on the strength training and flexibility exercises. The tool kit describes and illustrates all exercises, and participants model, review, and practice them several times throughout the workshop.

The workshop also introduces program leaders to the two types of assessment and evaluation tools that can be used to measure participants' progress and satisfaction with the program. One tool is a questionnaire designed to help program leaders receive detailed subjective feedback from participants about a range of topics related to their program. The second is an objective measure of change in physical parameters that relate to program participation, including muscular strength, endurance, agility, flexibility, and balance. This second tool is excerpted with permission from the *Senior Fitness Test* (53); it provides norms for each physical assessment for women aged 60 or older.

Proactively minimizing barriers to participation is a priority for increasing access to the program, and the workshop, therefore, includes a 30-minute brainstorming session to address issues related to fees and costs. We strongly encourage program leaders to assist and facilitate participation by any individual who is interested in joining the class, regardless of income. A few of the strategies discussed during the brainstorming session have included soliciting donations (e.g., equipment, money, space, par-

ticipant incentives such as T-shirts and water bottles) and negotiating discounts from local vendors and organizations. We transcribe notes from the discussion as well as other questions and answers posed during the workshop and distribute them to program leaders at the end of the day. Workshop attendance at Tufts University is \$300 per attendee and includes the StrongWomen Program tool kit as well as breakfast and lunch. Cost of attendance at off-site workshops varies, depending on sponsorship and resources, but it never exceeds the \$300 fee.

The StrongWomen Tool Kit

The StrongWomen Tool Kit (54) is a 200-page binder that includes the information and supporting materials that a program leader needs to implement and maintain the StrongWomen Program. In addition to the main content, the tool kit includes several sets of separately collated handouts that are intended for use with participants, their health care providers, and the news media. These handouts include nutrition fact sheets (to give to participants), a packet of peer-reviewed journal articles outlining the benefits of strength training (to give to health care providers), and a sample press release and program summary sheet (to give to the news media). In addition, we provide a physician consent-to-exercise document; we strongly suggest that leaders collect physician consent forms for all participants, but we do not require that they do so. Table 1 presents the tool kit table of contents (54).

Dissemination

Dissemination began in May 2003 in three parts: recruiting leaders and forming key partnerships, soliciting participant interest and supporting program implementation, and promoting growth and sustainability.

Part 1: Recruiting leaders and forming key partnerships

The first group of program leaders were members of organizations that have since become key partners with the StrongWomen Program: hospitals, nonprofit outpatient wellness centers, and the National Extension Association of Family and Consumer Sciences branch of the Cooperative State Research, Education, and Extension Services (hereafter referred to as the Extension Service), which is under the direction of the U.S. Department of Agriculture. Individuals from these organizations had seen the *Strong*

Women books and were interested in operating programs within their own organizations on the basis of the research and practical applications presented in the books. They contacted Tufts University with their interest, and the StrongWomen Program began shortly thereafter.

Hospitals and nonprofit outpatient wellness centers — in particular, women's wellness centers — are important for the StrongWomen Program because they are often at the core of women's health services within a community. In addition to offering standard medical care, such as family practice, gynecology, and endocrinology, women's wellness centers may offer community programming such as outpatient exercise and nutrition classes. Hospitals are also important for the StrongWomen Program because they provide a large audience of potential program participants and they usually have the space and resources necessary for implementing and maintaining the program. Because the StrongWomen Program is in-house at a hospital or wellness center, physicians perceive the program as a safe and viable option for their patients.

Extension Service educators, who are in every county in every state, offer research-based health information and programs to their communities. Collaboration with the StrongWomen Program helps Extension Service agents to bring knowledge, awareness, education, and research-based programming to community members and to increase the Extension Service's reach in underserved and rural locations (a focus area for the Extension Service).

Since the inception of the StrongWomen Program, collaboration with clinics and the Extension Service has been vital to disseminating the program. Knowledge of the program has spread within the networks of these organizations by internal newsletters, bulletin boards, word-of-mouth, and formal presentations at professional meetings. At the national conference of the Extension Service in October 2004, we trained 150 program leaders at a StrongWomen Program Workshop. (Most workshops have 15–40 attendees.) The broad geographic range represented by program leaders at this workshop expanded the dissemination of the StrongWomen Program and supported grassroots awareness.

Prospective program leaders also learn about the StrongWomen Program through the *Strong Women* book series and its related Web site (www.strongwomen.com) and the StrongWomen Program Web site (go.tufts.edu/strongwomen), which can be accessed directly or linked through www.strongwomen.com (38,39). Through www.strongwomen.com, any individual can sign up to receive the free monthly electronic newsletter, which includes the following: a research update, such as new study findings and take-away messages; upcoming public talks, forums, summits, and events; upcoming StrongWomen Workshops; reader questions and our answers; reader success stories; and a recipe of the month. This newsletter has approximately 26,000 subscribers. The StrongWomen Program Web site contains details about the program, the workshop agenda, and upcoming workshop dates and locations. Individuals can contact the program manager through this Web site to request to be added to an e-mail list for upcoming workshop announcements, which are sent regularly throughout the year.

Some program leaders learn about the program and training through the books, Web sites, or some other way, and, therefore, attend the workshop on their own initiative; many program leaders are sent by their employer or an organization. We now require program leaders to be strength training actively at the time they attend the workshop; until the 2004 telephone survey (detailed later in this article), this requirement was only a strong recommendation. In addition, program leaders must implement the StrongWomen Program only in nonprofit organizations, such as senior centers, hospital outpatient centers, Extension Service locations, assisted living facilities, or faith-based organizations. A simple preregistration worksheet assesses the qualifications for nonprofit status.

The StrongWomen Program highly recommends, but does not require, that program leaders have at least two of the following: an educational background in a field such as health services, nutrition, exercise physiology, physical therapy, or public health; some experience in providing exercise instruction; and certification by a reputable health and fitness organization, such as the National Strength and Conditioning Association, the ACSM, or the American Council on Exercise. As of July 2006, program leaders have ranged in age from 21 to 83 years, with a mean age of 50 years, and have had a diverse range of professional backgrounds (Table 2).

Part 2: Soliciting participant interest and supporting program implementation

To help new program leaders implement the StrongWomen

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Program in their communities, we encourage them to follow several steps: 1) read the entire tool kit within 1 week of the workshop; 2) find an organization to host the program and a space to operate the program (if they do not already have ties to a hosting organization); 3) determine the pricing structure, equipment, and schedule for their StrongWomen Program, working with their hosting organization; 4) plan and publicize an informational meeting about the program using the publicity materials provided in the tool kit or other means; and 5) operate their first StrongWomen Program within 3 to 6 months of attending the workshop. New and experienced program leaders can receive support for implementing the StrongWomen Program by e-mail or telephone from the program manager or by networking with other program leaders, many of whom are listed on the StrongWomen Program Web site.

Virtually anyone can be a participant in the StrongWomen Program. Program leaders recruit participants through placing advertisements in local newspapers, posting fliers throughout the community, or making announcements through available newsletters and bulletins. The research that provides the scientific basis for the program was conducted with women aged 40 to 91 years; we developed the exercise programs with this audience in mind. However, women may begin to lose muscle and bone mass at an earlier age, and we encourage program leaders to allow all women, regardless of age, to join the classes. As of July 2006, the age range of participants was 21 to 94 years with a mean of 63 years. Strength training is important for men as well; although we encourage program leaders to include men who wish to join, preliminary data show that most participants are women.

Part 3: Promoting growth and sustainability

A variety of mechanisms are in place for long-term maintenance of the StrongWomen Program. Two maintenance objectives are to educate current and potential program leaders using the most up-to-date evidence-informed programming possible and to continue to assist them in implementing and sustaining their programs.

The program manager spends approximately 15 to 20 hours per week answering 200 to 300 e-mails and 40 to 60 telephone calls from program leaders. The program manager responds to questions from prospective program leaders who are considering attending a workshop and from current program leaders to support implementa-

tion of existing programs. This support includes assisting with space, equipment, and resource issues; helping with incentive and reward programs for participants; working with volunteer assistants to program leaders on class set-up and other issues; and helping program leaders identify modifications for exercises to improve accessibility for some participants. The program manager also publicizes continuing education events and curriculum updates among program leaders through the e-mail list and the StrongWomen Program Web site.

The StrongWomen Ambassador training program is another component of program growth and sustainability. Seven ambassadors conduct workshops in Alaska, Arkansas, Colorado, Kansas, Oregon, and Pennsylvania. These individuals participate in a more extensive training process than the workshop provides, and they are then qualified to hold workshops within their own states to train new program leaders. Ambassadors are also important for program sustainability by serving as local resources for program leaders. To become an ambassador, a program leader must have been actively operating programs in his or her state for at least 6 months. Then he or she must attend a second program leader workshop, which is identical to the first. At this second workshop, we give the teaching materials to the potential ambassadors and instruct them to observe the *teaching process* instead of the workshop content. After the second workshop, we require prospective ambassadors to plan, execute, and follow up on their own workshop attended by members of the public and their hosting organization. In addition to allowing the candidate to demonstrate a mastery of the entire curriculum, this workshop provides an opportunity for the candidate to demonstrate support from his or her sponsoring organization; both demonstrations are requirements for becoming an ambassador. The program manager determines the guidelines and protocols in collaboration with each potential ambassador and the hosting organization (because logistics may vary site by site) and attends the workshop to oversee its complete execution.

The aims for long-term sustainability of the StrongWomen Program are to focus efforts on creating supplementary curriculum materials, such as additional evidence-informed exercise programs that participants will require as their strength and fitness increase; on facilitating the leadership and training of additional ambassadors, who are critical to maintaining the reach and momentum of the program's growth; and on creating advanced work-

shops and educational opportunities for program leaders that will enable them to broaden the scope and capacity of their leadership as agents of positive change in their communities.

Assessment

Adherence to the curriculum — site visits

The program manager conducted site visits at six active StrongWomen Program classes in Kansas, Oregon, and Massachusetts during the first year of dissemination. The primary component of the site visit was observation. During the observation, the program manager observed one or more complete exercise sessions at each site and graded each of the following on a 5-point scale (1 = unacceptable, 2 = needs improvement, 3 = fair, 4 = good, 5 = excellent):

- Adequate space for participants and equipment (i.e., movement through range of motion)
- Equipment safety (e.g., sturdy chairs, appropriate dumbbells, nothing makeshift)
- Location safety and accessibility (e.g., availability of parking, adequate lighting, dry floors)
- Execution of exercise program (i.e., proper use of equipment, speed, demonstration and feedback on exercise form, rest periods, and verbal prompting and encouragement)

Following the observation, the program manager conducted interviews with participants as a group and with leaders individually. Interviews were related to program logistics (e.g., scheduling, class length), level of participant comfort with their leader, opinions on enjoyment of the program, perceived benefits, and suggestions for changes.

The results revealed adherence to the curriculum in terms of space, equipment, location, and exercise program recommendations outlined in the tool kit. Adherence was determined by an average score of at least 4 in all categories. In Kansas, two classes at one site scored an average of 4.25; in Oregon, three classes at one site scored an average of 4.5; and in Massachusetts, three classes at one site scored an average of 4.25.

Both program leaders and participants were satisfied with the program logistics and outcomes related to participation. The primary requests from program leaders were

related to more guidance on fee structures and scheduling, which is now addressed in greater detail during the workshop. Participant concerns were related to scheduling and the desire for additional nutrition information. Scheduling concerns were subsequently addressed with leaders and expanded upon in the tool kit. Although the tool kit already included a chapter on nutrition, a packet of fact sheets on nutrition (similar in content to the information presented to program leaders in the tool kit) is now available for program leaders to distribute to participants.

Telephone survey

By September 2004, 142 program leaders from 13 states had been trained; 139 were women. Of the 139 women, 31 (22%) were from urban areas, 55 (40%) were from suburban areas, and 53 (38%) were from rural areas. Of 130 program leaders with current contact information, 103 participated in a brief telephone survey (response rate, 79%). Of the 103 respondents, 72 (70%) had implemented at least one StrongWomen Program, with a mean class size of 11. The mean time between attending the workshop and starting the first program was 12 weeks (SD, 13 weeks). On the basis of logistic regression analysis that we performed for a previous study (55), we found that program leaders who had strength trained themselves before attending the workshop were more likely than were program leaders to have implemented the StrongWomen Program. We also found that program leaders sent by their employer or an organization to attend the workshop were more likely to have implemented the program than program leaders who attended the workshop on their own initiative (55). We have conducted additional follow-up surveys with program leaders and participants; findings from these data are forthcoming.

Program leader and participant databases

Although we recommend that program leaders return to their communities to implement the StrongWomen Program within 3 to 6 months of the workshop, only some do. Because the program's mission is to increase access to and participation in strength training programs by middle-aged and older women, we track the number of program leaders, their locations across the country, and the number of StrongWomen Programs they implement. We established two databases for this purpose, one for program leaders and one for participants.

the Tufts University Human Institutional Review Board (approval no. 7049).

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Tables

Table 1. Table of Contents for Tool Kit, StrongWomen Community Strength Training Program, 2006

Caution	A note about implementing community exercise programs
Foreword	The inspiration and motivation to develop the program
Mission and Objectives	The mission statement and objectives for the program
Chapter 1	The benefits of strength training for women — the research behind the program
Chapter 2	Starting a program — leaders, sites, space, equipment, promotion, and scheduling
Chapter 3	Participant screening — contact information, medical history, screening tools, and consent
Chapter 4	StrongWomen Program — two strength training programs, general exercise safety
Chapter 5	Keeping track and participant assessments — contact and attendance sheets, exercise logs, evaluations, and assessment tests
Chapter 6	Leadership — leader styles, skills, professionalism, courtesy and respect, communication, and selecting peer leaders
Chapter 7	General physical activity — different modes, walking programs, community involvement
Chapter 8	Nutrition for optimal health
Chapter 9	Frequently asked questions
Chapter 10	Resources
Acknowledgments	Gratitude for individuals and organizations that supported program development
References	Research citations
Handouts	Research packet, tracking packet, nutrition fact sheets, informational/media packet

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Table 2. Program Leaders (N = 881) by Occupation, StrongWomen Community Strength Training Program, 2006

Occupation	No. (%)
Extension agent	379 (43.0)
Fitness instructor or personal trainer	69 (7.8)
Physician or nurse	36 (4.1)
Physical therapist	16 (1.8)
Nutritionist or dietician	14 (1.6)
Other health care worker	52 (5.9)
Community educator or community organizer	51 (5.8)
Academic educator	18 (2.0)
Student	11 (1.2)
Self-employed	12 (1.4)
Other	96 (10.9)
Data field blank on registration form	127 (14.4)

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ORIGINAL RESEARCH

“It Is Our Exercise Family”: Experiences of Ethnic Older Adults in a Group-Based Exercise Program

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PEER REVIEWED

Abstract

Introduction

EnhanceFitness (EF) (formerly the Lifetime Fitness Program) is an evidence-based community exercise program for older adults. From 1998 to 2005, participation of ethnic older adults increased significantly. However, little research is available about what ethnic older adults want or need to continue participation in exercise programs. The purpose of this study was to examine how physical environment, social environment, and individual biology and behavior influence adherence to exercise for ethnic older adults participating in EF.

Methods

Six focus groups were conducted with 52 older adults participating in EF. Facilitators asked questions about factors that helped participants continue exercising in EF. Interviews were audiotaped and transcribed. Transcripts were systematically reviewed using content analysis.

Results

Focus group participants were Chinese (n = 21, 40%), African American (n = 18, 35%), white (n = 10, 19%), and Japanese (n = 3, 6%). Mean (SD) age was 76 years (7.4).

Participants had, on average, participated in EF for 44 months (SD = 37.8). Results revealed four themes related to adherence. First, environmental factors that promoted adherence were location of the classes, transportation, weather, and the facility. Second, design of the exercise program that encouraged adherence included exercise content and type of delivery. Third, social support factors that encouraged adherence were the socializing and support between class participants and support from family, health care providers, and the class instructors. Finally, individual factors that encouraged adherence were personality traits and feelings, past physical activity experience, health benefits, and mental stimulation.

Conclusion

Findings from this study suggest strategies for developing community-based physical activity programs for older adults from ethnically diverse communities.

Introduction

Regular participation in exercise generates physical and psychological benefits and is an essential component for healthy aging (1-5). A structured group exercise program offers additional psychosocial benefits for older adults (6,7). However, few studies target older adults from different ethnic groups. Research on how to attract ethnically diverse older adults into exercise programs is also lacking (8,9). More research is needed about exercise in older ethnic adults (9) who are also at greater risk of morbidity (10). Studying the types of exercise programs that older adults prefer and how these match personal needs, values, and circumstances will help researchers, health care pro-

professionals, and providers of aging services to design and promote successful programs. In our study, we used an ecologic model to examine the perspectives of ethnic older adults and to explore factors that promote exercise adherence. Participants offered a rich variety of information, outlooks, and outcomes extending beyond the literature.

Ecologic model

Researchers have addressed individual and social factors that influence long-term exercise participation of older adults (6,11,12). However, little research examines the influence of environmental factors such as the physical environment and availability of well-designed exercise programs. The determinants of the health “ecologic model,” as discussed in *Healthy People 2010*, illustrate the individuals’ health transactions with their physical and social environments and can be used to study exercise behavior (13). Satariano and McAuley (14) describe the ecologic model by noting that “health depends on the dynamic interaction of biological, behavioral, social, and environmental factors that interact over the life course of individuals, families, neighborhoods, and communities” (pp. 184-5). A feature of this model is that physical environment, social environment, and individual variables of behavior and biology all influence health in an interactive manner (15). The ecologic model was used as a framework in this study to examine older ethnic adults’ adherence to exercise. Although this model includes six determinants that influence an individual’s health behavior, we discuss three that were integral to our study: 1) physical environment, 2) social environment, and 3) the individual’s biology and behavior.

Physical environment describes the settings in which people live, exercise, and interact. Establishing physical activity programs in senior centers, community centers, churches, and retirement homes was key to increased participation (9,16). Participation in an exercise program depends not only on the facility’s convenience but also on its safety, attractiveness, and cost of participation (9,10). Overall, the association of physical environmental factors with older ethnic adults’ exercise patterns remains a neglected area of study (9). A study involving seven ethnic focus groups identified environmental barriers to exercise, including weather, neighborhood safety, fear of crime, program costs, and inadequate availability and reliability of affordable transportation (17).

Social environment refers to interactions with family,

friends, and others in the community as well as cultural customs. Social support from family, friends, program staff, members of the exercise group, or health care providers increases exercise participation (8). The support of community, family members, and friends is especially important to ethnic older adults (10,17). The social networks within exercise groups enhance individual self-efficacy and adherence to, and persistence in, the exercise program (18). When the participants like their instructors, they are more motivated to come to class (19).

Individual behavior and biology refers to a person’s responses, traits, characteristics, feelings, past experience, and health. Self-efficacy — an individual’s belief in her or his ability to successfully perform a specific behavior (20) — is a well-known trait that determines exercise behavior in different populations (14,18). Individuals with strong self-efficacy are more likely to persist with a behavior. This trait influences exercise behavior by moderating behavioral change such as starting an exercise class, determining whether a particular exercise will be attempted, determining the degree of persistence if the exercise is difficult, and determining the success or failure of completing the class (21). Few studies examine self-efficacy and exercise in ethnic older adults. In a study of African American women with arthritis, self-efficacy was the most consistent factor affecting physical activity behavior (22). Motivation and willpower were identified as very important by three Latino focus groups in starting and adhering to an exercise program (23). Attitudinal and psychological beliefs such as a wish to improve health, fitness, and appearance through exercise are held by older as well as younger women (9). Feeling good and enjoying physical activity contribute to higher self-efficacy in older adults (18). Enjoyment and improvement of mental and physical health were valued by older African American women (24).

The EnhanceFitness (EF) Program

EnhanceFitness (EF) (formerly Lifetime Fitness Program) is an evidence-based community exercise program for older adults (16). The EF program is offered in hourly sessions 3 times per week and includes strength, endurance, balance, and flexibility exercises (25). The program is now offered in 53 locations at senior centers and community centers in Seattle and in King County, Washington, and has 177 sites in 18 states. In recent years EF classes have been established for African American, Hispanic, Hmong, Korean, Filipino, Somali, Vietnamese,

American Indian, and Chinese older adults in Seattle. According to EF program director S. J. Snyder, the percentage of EF participants from ethnic communities increased from 1% in 1998 to 25% in 2005 (personal communication, May 2005). Despite the significant increase in ethnic participation, little is known about the factors that may have drawn ethnic older adults to EF.

To address the literature gap, we examined how physical environment, social environment, and individual biology and behavior influenced adherence to exercise among ethnic older adults participating in EF. Our goal is to use the information to generate effective strategies to promote adherence to exercise programs among ethnic older adults. The information will also be useful for future EF program evaluation and development.

Methods

Design and sampling

Six focus groups were conducted in October and November 2005 in two urban neighborhood senior centers and a Chinese church in Seattle. With the assistance of the EF instructors and program coordinator, participants were recruited from three EF exercise sites that had predominantly ethnic participants. Inclusion criteria were participation in the EF program for at least 1 month, being aged 55 or older, and the ability to read and speak English or Cantonese. The ability to read and speak Cantonese was included because one site was a Chinese church in which half the people spoke Cantonese and the other half spoke English. Approval to conduct the study was obtained from the University of Washington Institutional Review Board. Investigators complied with the approved protocol in all stages of the study.

Data collection

Five focus groups were conducted in English and one in Cantonese. The Chinese investigator in this study led one English focus group and the white investigator led the other four English focus groups. Both investigators were graduate nursing students with training in focus group facilitation who had worked with older adults. A Cantonese-speaking Chinese interpreter skilled in focus group interviews conducted the Cantonese-speaking focus group. An interview questionnaire developed by the inves-

tigators was used to explore the influence of physical environment, social environment, and individual behavior and biology on exercise adherence among older ethnic adults (Table 1). Each focus group had 8 to 10 participants and lasted, on average, 70 minutes. All groups were audiotaped. Participants were offered lunch or a gift certificate for participation. Demographic data were collected using a 7-item demographic questionnaire.

Data analysis

Audiotapes were transcribed into Microsoft Word documents. The audiotape of the Cantonese-speaking focus group was translated into English and transcribed by the interpreter who led the group. Content analysis, a process of organizing and integrating narrative, qualitative information according to emerging themes and concepts (26), was used to develop themes. Guided by the ecologic model (13), the investigators independently read and coded each transcript. Contrasts and similarities of themes within and across groups were examined; a final set of themes were merged and categorized to capture aspects of the ecologic model and those not included in the model. The first and second authors discussed relevance of the themes, quotes, and definitions with the third and fourth authors, who have expertise in qualitative research. Demographic data were described with descriptive statistics.

Results

Sample

Fifty-two adults, mean age 76 years (SD = 7.4, range, 62–96 years), participated in the study. They were Chinese (n = 21, 40%), African American (n = 18, 35%), white (n = 10, 19%), and Japanese (n = 3, 6%). Eighty-five percent were female. All participants lived in an urban environment. They had, on average, participated in EF for 44 months (SD = 37.8, range, 2–96 months) and attended EF classes 2 to 3 times per week. Ninety percent indicated that they were highly confident they would continue to attend this EF program for the next 6 months (Tables 2 and 3).

Themes

The identified themes included physical environment, the design of the EF program, social environment, and individual behavior and biology (Table 4).

Physical Environment

Location. Participants at the two senior centers and the church were satisfied with the neighborhood location of EF classes. Some participants had attended other exercise classes but preferred the neighborhood location closer to their home because they could participate in activities at the church and senior centers other than exercise.

Transportation, weather, and facility. Most participants drove to the exercise classes; some walked, carpooled, or rode the bus. Many commented that bus service was nearby. Weather did not appear to be a drawback, except on the rare occasion when it snowed and the class site closed. Participants were satisfied with the facilities where the classes were held. They appreciated the church location because it is large and has a nice indoor gym.

Design of the EF Program

Exercise content, program delivery (e.g., timing, cost), and physical performance evaluation emerged as themes. The participants enthusiastically supported the variety of exercise and the complete body workout that they were getting in class. The exercise content was perceived as systematic, senior-specific, and easy to follow. One participant described the exercises as “covering all the joints from the upper body to lower body through range of motion, balancing, weight-lifting, and aerobics.” They valued this exercise program because it met their health needs. One participant said, “The weights help us to get the benefit from exercising.” The physical performance evaluations that were conducted every 4 months provided feedback to participants about their progress. The morning timing of classes was preferred, as it provided a reason to get up and out of bed. The low- or no-cost EF classes were appreciated and attracted participants to join.

Social Environment

Socializing and support among exercise class participants. Most of the participants enjoyed socializing, building friendships, and being with peers. For some, it was their main social outlet: “It is a way for me to stay in touch with the world, with my community.” Joining the exercise program was especially important to those who lived alone: “I live alone and as long as I belong to the exercise class, that is something to make me get up and get dressed and get out.” Several participants did activi-

ties such as line dancing, shopping, and eating lunch with friends from class.

Having a network of peers was another reason that participants enjoyed the class. Participants helped each other by sharing rides, phoning each other, and demonstrating caring, and enjoyed sharing common issues with their peers. One participant mentioned, “I get to talk, too. If I have a problem, I discuss it and see what they would do about it.”

The exercise class itself formed a social network that provided participants material, verbal, emotional, and sometimes spiritual support. One participant commented, “It is our exercise family!”

Support and influence from family. Family influence and support was another theme. Participants in all groups talked about support from their children, spouses, and other family members for their participation in EF. For instance, their family kept track of them to see if they attended the exercise class. Some families tried not to make plans on their exercise days; others helped them to find out about this program and encouraged them to join. One participant was happy when his wife joined the EF class after he did. A 96-year-old participant said, “My children, every time I get tired and want to stop and lay off, ‘no you go on.’ They drive me here.”

The desire to stay healthy for their family was a strong motivation. Participants exercised because they did not want to be a burden on their family. Others wanted to stay healthy to help take care of a family member or to see their grandchildren. One Chinese participant said, “On my birthday, my grandson gave me 100 pennies and said I want you to live 100 years. I decided to live longer to see my grandchildren. That is why I have a strong desire. I do that for my family.”

Support from health care providers. Many participants started the exercise program because of their health care providers’ encouragement or referrals. One participant said, “When I retired in 1995, my doctor recommended EF and here I am. I have been here for 10 years.” Participants said that their doctors’ positive feedback and supportive attitude helped them to keep exercising. One participant shared: “My doctor that I see for some years, his opening question usually is, are you still exercising?”

Support and influence from exercise instructors. Participants perceived their instructors as people who are enthusiastic, motivating, and who make exercise fun and like older adults. Participants in every focus group said that their instructors were a major reason they continued to participate in EF. They appreciated their instructors' knowledge and expertise and liked the personal help that the instructors provided: "He goes from person to person to show them, to help them, you know, because so many of us are stiff and we are not doing it quite right." When people were absent from class, instructors phoned to check on them. One participant said: "She motivates us, she makes it fun. I hope she never resigns."

Shared language and religion. The Chinese participants all attended the same church, which was where their EF class was held. Several participants from this class stated that they attended EF because their class was conducted in Cantonese and they could understand the instructor's directions. Some English-speaking Chinese participants commented that they enjoyed being with their Cantonese peers and learning the language. Participants mentioned that they wanted to support their church by attending EF classes there.

Individual Behavior and Biology

Personality traits and characteristics. Participants mentioned several personality traits and characteristics that helped them keep exercising. One participant said, "I am very competitive"; another said, "What I enjoy is the competition with myself. I like the healthy feel of competition." Participants identified perseverance, a positive attitude, commitment, and confidence as traits that kept them coming to class. A male participant, for instance, said that his "sense of humor" got him through class and his life. A female participant explained, "Your self-confidence is reinforced when you come here. The sense of well-being and ability and you can do things. Sometimes I forget I'm 86 years old."

Independence and liking to have structure in daily life were commonly mentioned personality traits. Many participants wished to maintain their independence as they aged, and they regarded the EF classes as a way to do so. An African American participant's comment illustrated this idea well: "You want to be independent and you want to be self-sustaining, so this is a drive and I think it is ultimately what everybody is thinking about, because I want

to be on my own. I want to be independent. You want to take care of yourself as long as you can. That is the whole game."

Liking to have structure in daily life was shared by many participants. "I enjoy the routine of 'must get up, must get out,'" said a participant. Most agreed that the structured format of the class was an incentive to them to get out of their houses and into a situation where they exercised with each other.

Personal feelings. Personal feelings that motivated exercise varied. Boredom with her new retired life was the reason that one female participant joined the exercise class. A guilty conscience kept a few participants coming to class. As one man said, "I feel guilty if I don't come. I have to come up with some good excuses." Pride was another personal feeling mentioned by a participant. She said, "I think it was a matter of pride for me. I want to keep active, I want to keep healthy, and keep in shape. I keep denying, you know, some of the forces of my excess weight, but it still is a matter of pride to at least try and do something."

For many participants, the cheerful group dynamic was a reason to come to the exercise class.

Past physical activity experience. Many participants mentioned other physical activities that they currently did or had done in the past as factors related to their participation in EF. The activities included walking, doing exercises at home, baby-sitting, aerobic dancing class, line dancing, yard work, housework, bicycling, walking dogs, Tai Chi, and acting as a caregiver. Among them, walking was most frequently mentioned.

Health benefits of the exercise. Across all focus groups, common health benefits gained from EF were improvement in diseases (e.g., hypertension, diabetes, dyslipidemia, and arthritis), muscle strength, flexibility, balance, and well-being. Most participants discussed how their health had been improved after participating in the exercise classes. Other benefits were losing weight; not getting sick as often; improving cholesterol, blood pressure, diabetes, and pain; improving endurance; and sleeping better. One participant with arthritis said, "Exercise helps me feel less limited."

Mental stimulation. A theme mentioned by all groups was the cognitive benefits gained from the EF classes:

clear thinking, improved memory, and mental well-being. A Chinese participant said, "I come here for happiness, more interesting when there are so many people, more meaningful." Another offered, "I think [exercise] helps us both physically and mentally and spiritually in every way, because to be able to socialize with people and to communicate and have the laughter helps the body to be better and your mind to be stronger." Another participant noted that the exercise class could help prevent depression: "It's really fun and the people you're with crack you up all the time, so no depression here."

Discussion

This qualitative study of six focus groups was conducted to explore the exercise experience of ethnic older adults in EF, a group-based community exercise program. An ecologic model (13) was used to explore physical environment, social and cultural environment, and individual factors that influenced adherence to exercise. Design of the program is a new factor that emerged from the data. Four main findings resulted from this study, and strategies for promoting exercise adherence among ethnic older adults were generated from the findings. We integrated the factors that participants perceived as beneficial into practical strategies for community leaders or program developers. These strategies were proposed especially for promoting exercise adherence in older adults from ethnically diverse communities and have been provided for EF program evaluation and development (Table 5).

Sharing culture

Participants in the two Chinese focus groups talked about the importance of sharing the Cantonese language and specifically attended this class because it was all Chinese. This finding is similar to that of Belza et al (17), in which ethnic older adults from focus groups recommended culture-specific exercise programs, sharing culture and language, recruiting an instructor who speaks the language of the group, and weaving components of the culture into the program. The church location for the Chinese EF class was not only a positive physical environment factor but also motivated Chinese participants to attend because church was part of their life. This finding is supported by previous studies that churches are good settings to start new exercise programs for members (27-29).

Social support

Participants in all focus groups gained social support from exercising in a class with their peers and for this reason looked forward to continuing. There was a sense of strong group cohesion, "a dynamic process reflected by the tendency of a group to stick together and remain united in the pursuit of its instrumental objective and/or for the satisfaction of member affective needs" (29, p. 230). Participants' commitment to their classes came from enjoyment of the class, the instructor, and each other.

Families were important to exercise adherence. Many adult children reportedly helped the participants get to class and encouraged them to keep going. This finding is consistent with that of Belza et al (17), who showed that family encouragement to be physically active is important.

Physical and mental health outcomes

Positive physical and mental health outcomes gained from the EF classes were powerful motivators to adherence. Participants identified multiple health benefits that they had gained from attending EF, including improvements in strength, balance, endurance, flexibility, and chronic diseases. They also attributed cognitive benefits and mental well-being to participation in EF. Published studies do not indicate the importance of findings such as these to ethnic adult participants.

Personality traits, characteristics, and feelings

Our findings suggest that many personality traits, characteristics, or feelings are important to ethnic older adults' adherence to exercise. Being competitive, liking structure in daily life, wanting to maintain independence, enjoying and seeking happiness, being sociable, and being accountable were identified as helpful to adherence, as was having perseverance, a commitment to exercise, a guilty conscience, a sense of humor, a positive attitude, pride, and confidence. Self-efficacy is one of the most studied personality traits contributing to adherence to exercise (9,14,18).

A major strength of this study was that data were obtained directly from ethnic older adults and that they had an opportunity to describe their experiences in their own words. Notably, however, the participants were self-selected and thus might represent a more highly

motivated group of older adults. Findings from this study therefore have limited application to ethnic older adults who drop out of exercise classes and to those who are less social but still like to exercise. Another limitation was the three different focus group facilitators; data obtained during the focus groups might have varied because of different facilitation styles. Lastly, one to two focus groups for each ethnic group is a small sample; additional focus groups should be conducted using a similar interview guide with older adults from the same ethnic communities.

Future research might address the following questions: What is the relationship of group cohesion to adherence? What is the role of family in maintaining exercise in ethnic older adults? How do personality traits and characteristics, other than self-efficacy, influence adherence? What kind of exercise program design increases adherence? How do health care providers' recommendations or referrals affect the commitment of a patient or client to a fitness program? This study supports the roles of the physical environment, design of the program, social environment, and individual biology and behavior in adherence to an exercise program, and suggests strategies for community-based physical activity programs for older adults from ethnically diverse communities.

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Tables

Table 1. Focus Group Questionnaire, EnhanceFitness Program

Question	Probe
Tell us your name and briefly describe your experience in this program.	Family, friends, spouse, pastor, church, health care provider, benefits of exercise, location, like to exercise, beliefs, spirituality beliefs.
How did you find out about this exercise program?	
Why did you initially attend this program?	
What keeps you coming back to this program?	Physical health (muscle strength, balance), mental health (mood), friends, location, class time, personality, feel good, beliefs, spirituality beliefs.
If you missed any classes, what were the reasons?	Transportation, time conflict, location, not motivated.
What are the benefits to you for participating in this exercise program?	Physical health (muscle strength, balance), mental health (mood), friends.
Have you participated in other types of physical activity? If yes, what were they? What are the differences between exercise in this program and your other experiences (past experiences)?	Transportation, location, class time.
What environmental factors encourage you to attend or not to attend this program?	
How do environmental factors affect your attitude to attend this program?	
What personality characteristics do you have that help you to exercise?	Like to plan ahead, prefer to be spontaneous, confidence (self-efficacy).
What changes to this program would help you to continue to participate in it?	Location of the class, class content.

Table 2. Demographics and Characteristics of Participants a in Study of EF Ethnic Older Adults (N = 52), Seattle, Washington, 2005

Demographic or Characteristic	N (%)
Sex	
Female	44 (85)
Male	8 (15)
Race or ethnicity	
Chinese	21 (40)
African American	18 (35)
White	10 (19)
Japanese	3 (6)
Religion	
Christian	36 (69)
Buddhist	5 (10)
Catholic	4 (8)
Jewish	4 (8)

EF indicates EnhanceFitness Exercise Program.

^a Mean (SD) age = 76.8 years (7.4); range, 62-96 years. Mean (SD) duration of EF participation = 44 months (37.8); range, 2-96 months.

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Table 2. (continued) Demographics and Characteristics of Participants^a in Study of EF Ethnic Older Adults (N = 52), Seattle, Washington, 2005

Demographic or Characteristic	N (%)
Religion (continued)	
Other	2 (4)
Atheist	1 (2)
Frequency of EF participation	
About three times a week	30 (58)
About two times a week	15 (29)
About once a week	5 (10)
Less than once a week	0
Missing data	2 (4)
How confident are you that you will continue to attend this exercise program over the next 6 months?	
Completely	39 (75)
Almost totally	8 (15)
Quite a bit	2 (4)
Moderately	1 (2)
Slightly	0
Not at all (0)	0
Missing	2 (4)

EF indicates EnhanceFitness Exercise Program.

^a Mean (SD) age = 76.8 years (7.4); range, 62-96 years. Mean (SD) duration of EF participation = 44 months (37.8); range, 2-96 months.

Table 3. Demographics and Characteristics of Participants by Focus Group in Study of EF Ethnic Older Adults, Seattle, Washington, 2005

Focus Group (N = 52)						
Demographic or Characteristic						
Setting	Chinese Baptist church	Chinese Baptist church	Senior center with mixed ethnicities			
Number of Participants	8	10	8	8	9	9
Ethnicity						
Chinese	8	10	1		2	
African American			2	8		8
White			3		6	1
Japanese			2		1	

EF indicates EnhanceFitness Exercise Program.

^a 0 = not at all, 5 = completely.

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Table 3. (continued) Demographics and Characteristics of Participants by Focus Group in Study of EF Ethnic Older Adults, Seattle, Washington, 2005

Focus Group (N = 52)						
Demographic or Characteristic						
Setting	Chinese Baptist church	Chinese Baptist church	Senior center with mixed ethnicities			
Sex						
Female	7	8	7	7	6	9
Male	1	2	1	1	3	0
Mean (SD)Duration of EF Participation, in months	7 (1)	7 (2)	62 (19)	65 (27)	53 (46)	79 (26)
Confidence for Participation Over Next 6 Months ^a	4	5	5	5	5	5

EF indicates EnhanceFitness Exercise Program.

^a 0 = not at all, 5 = completely.

Table 4. Categories and Themes That Influence Exercise Adherence in Study of EF Ethnic Older Adults, Seattle, Washington, 2005

Category	Definition	Themes and Subthemes
Physical Environment	Settings in which people live, exercise, and interact	<ul style="list-style-type: none"> • Convenient location: senior centers and churches • Transportation, weather, and facility
Design of the EF Program	Characteristics of EF program such as exercise content and program delivery	<ul style="list-style-type: none"> • Design of the exercise content: variety of exercise, complete body workout • Program delivery: morning classes, free or low cost, using weights, and physical performance evaluation
Social Environment	Interactions with family, friends, health care providers, instructors, and other social networks. Includes cultural customs such as language and religion	<ul style="list-style-type: none"> • Socializing: being with peers, main social outlet, sharing rides and calls • Support and influence from family: rides and encouragement • Health care provider support: encouragement, referrals, or both • Instructor's encouragement, personality, and training • Culture-specific factor: shared language and religion
Individual Biology and Behavior	Each person's traits, characteristics, feelings, past experience, and biology (genetics, physical and mental health)	<ul style="list-style-type: none"> • Personality traits and characteristics: being competitive, perseverance, positive attitude, commitment, sense of humor, independence, confidence, seeking to be happy, liking to have structure in daily life • Personal feelings: boredom, guilty conscience, pride, and wanting to feel happy • Past physical activity experiences • Health benefits: improved chronic diseases (dyslipidemia, diabetes, hypertension, and arthritis), improved flexibility, strength, balance, and well-being • Mental stimulation: clear thinking, improved memory, and mental well-being

EF indicates EnhanceFitness Exercise Program.

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Table 5. Strategies to Promote Exercise Adherence in Older Adults From Ethnically Diverse Communities

Categories	Strategies
Physical Environment	<ul style="list-style-type: none"> • Use existing community settings such as churches and senior centers to offer programs. • Have the class location on the main bus lines.
Design of the EF Program	<ul style="list-style-type: none"> • Design the exercise program content to fit older adults' health needs. • Make the exercise content easy for older adults to follow. • Consider having the classes in the morning. • Use the physical evaluation of progress to show older adults their improvement. Encourage them to set new goals.
Social Environment	<ul style="list-style-type: none"> • Encourage older adults to join a group exercise program for socializing and social support. • Have families frequently check with older adults and encourage them to exercise. • Have health care providers give a list of local exercise resources to their clients. • Ask health care providers to encourage older adults to exercise by emphasizing the health benefits, monitoring progress, and giving feedback on health improvements to patients. • Offer culture-specific classes taught by an instructor who shares the language of the group. • Carefully choose and train instructors according to older adults' needs because they are the main reason that older adults stay in the program.
Individual Biology and Behavior	<ul style="list-style-type: none"> • Encourage older adults to join an exercise program to maintain an independent lifestyle. • Emphasize the benefits of joining an exercise program as having a routine of life. • Ask exercise class to share with other people the health benefits and enjoyment they received. • Encourage older adults to use their unique personality traits to help them to exercise.

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ORIGINAL RESEARCH

Evaluating a Preventive Services Index to Adjust for Healthy Behaviors in Observational Studies of Older Adults

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PEER REVIEWED

Abstract

Introduction

Analysis of outcome measures from nonrandomized, observational studies of people participating or not participating in health programs may be suspect because of selection bias. For example, fitness programs may preferentially enroll people who are already committed to healthy lifestyles, including use of preventive services. Some of our earlier studies have attempted to account for this potential bias by including an ad hoc preventive services index created from the patient's number of earlier clinical preventive services, to adjust for health-seeking behaviors. However, this index has not been validated. We formally evaluated the performance of this preventive services index by comparing it with its component parts and to an alternative index derived from principal component analysis by using the weighted sums of the principal components.

Methods

We used data from a cohort of 38,046 older adults. We used the following variables from the administrative database of a health maintenance organization to create this index: fecal occult blood test, flexible sigmoidoscopy, screening mammogram, prostate cancer screening, influenza vaccination, pneumococcal vaccination, and preventive care office visits.

Results

The preventive services index was positively correlated with each of the following components: colon cancer screening ($r = .752$), screening mammogram ($r = .559$), prostate cancer screening ($r = .592$), influenza vaccination ($r = .844$), pneumococcal vaccination ($r = .487$), and preventive care office visits ($r = .737$). An alternative preventive services index, created by using principal component analysis, had similar performance.

Conclusion

A preventive services index created by using administrative data has good face-validity and construct validity and can be used to partially adjust for selection bias in observational studies of cost and use outcomes.

Introduction

Researchers often use observational study designs to examine the relationship between health care interventions and health care costs. However, one of the challenges of observational studies is that selection bias may influence both the study population and the measured outcomes. For instance, reviewers of the bias in nonrandomized intervention studies found that results of nonrandomized studies sometimes differ from results of randomized studies of the same intervention (1). They concluded that "standard methods of case-mix adjustment do not guarantee removal of bias."

Although selection bias can never be completely eliminated in such analyses, certain steps can be taken to minimize its effects. We recently published several articles (2-5) in which we compared the health care costs of people who did or did not participate in a physical activity benefit

offered to Medicare enrollees. Those analyses, which used a retrospective observational cohort design, controlled for covariates from the administrative data that might have influenced the use and cost outcomes. One covariate was a preventive services index. A preventive services index incorporates measures of the prior use of preventive services to describe a person's tendency to use such services. In this article, a preventive services index attempts to account for the self-selected nature of health-oriented people toward health club enrollment and participation. Specifically, we were concerned that people who take an active role in managing their health may use more preventive medical services and may be more likely to enroll in an exercise program, as other researchers have found (6). Such a tendency, rather than the physical activity program itself, could result in lower costs.

Few studies adjust for a person's "prevention-seeking behavior" in observational studies. Researchers who examined the use of statins in preventive therapy (7) used clinical and laboratory data in their models to account for "healthy user status." The authors of a study of menopausal hormone therapy (8) suggested a "healthy user effect." Other researchers have used the term (9) to describe a confounding bias that may affect observational studies of drugs, diets, screening procedures, and other health-related behaviors. To our knowledge, no researchers have used an adjustment for healthy users, in the form of an index, to account for the propensity of people to engage in preventive behaviors, especially a physical activity benefit.

We designed this study to evaluate the validity of a previously created preventive services index, which we have used to control for selection bias in observational studies. We examined this index, constructed from the sum of clinical services available in an administrative database, and compared it with an alternative index created with a different approach, using principal components analysis. We examined the relationship between the indexes and health behaviors and cost outcomes and make suggestions for using this previously created preventive services index in nonrandomized research studies.

Methods

Study sample

Our study population consisted of members of Group

Health Cooperative of Puget Sound (GHC), a large health maintenance organization in Washington State that enrolls nearly 60,000 Medicare beneficiaries. People were eligible for our study if they were aged 65 or older, lived in the community, and were enrolled in GHC between October 1, 1997, and December 31, 2004. All were eligible to use either a fitness program benefit that consisted of membership at a fitness club (Silver Sneakers) or a specially designed physical activity program (EnhanceFitness). The 2 fitness programs are described in detail elsewhere (3,10). In either case, enrollment is triggered when a person either enters or enrolls in a fitness club or goes to an EnhanceFitness class. We constructed an intervention cohort consisting of all members who signed up for the benefit between January 1, 1998, and December 31, 2003, and who had been continuously enrolled at GHC for at least 1 year before enrolling in either fitness program. The date of first enrollment is called the index date. For each person in the intervention cohort, the control group consisted of 3 GHC members who never enrolled in the program and whom we matched by age and sex to each fitness program participant. Controls were assigned the index date of the participant to whom they were matched.

A total of 40,956 seniors met these qualifications. We later excluded 1,400 seniors who lived outside of the 9-county Puget Sound region and were unlikely to participate in a Puget Sound-based fitness program. Of the remaining 39,556 people, we excluded 1,510 because they lacked cost or use data, for a final sample size of 38,046. Institutional review boards at GHC and the University of Washington approved the study protocol.

Database

GHC administrative data were the source of all use, cost, and patient demographic variables. The database included diagnostic and use information from medical staff, nursing, pharmacy, laboratory, radiology, hospital inpatient, and community health services and a cost for each of those services. It also included a variable "RxRisk," which is a measure of chronic disease burden or comorbidity calculated by GHC for each person on the basis of age, sex, and pharmacy use for the 6 months before the index date (11,12). To control for chronic disease, we also used the presence of a participant on a diabetes or heart registry. Diabetes registry patients had a hospital discharge diagnosis of diabetes, nonfasting plasma glucose level of 200 mg/dL or higher, fasting plasma glucose level of 200

mg/dL or higher, a hemoglobin A1c level of 7.0% or higher, or a prescription for insulin. Heart registry patients had a diagnosis of angina, coronary heart disease, or acute myocardial infarction.

Preventive services variables

We designed the preventive services index to make use of all data in the administrative databases related to use of clinical preventive services. These data were fecal occult blood testing and flexible sigmoidoscopy for colon cancer screening, mammograms for breast cancer detection, blood testing for prostate cancer screening, an influenza or a pneumococcal vaccination, and visits coded specifically as a preventive visit up to 2 years before the index date. Insurance benefits completely covered costs of the preventive services in the index for all patients.

For colon cancer screening, we created a new variable by combining number of fecal occult blood tests or a pneumococcal test series and flexible sigmoidoscopies for up to 2 years before the index date up to a maximum of 2. For influenza vaccination we constructed another variable by identifying receipt of influenza vaccine up to 2 years before the index date, counting only 1 per year up to a maximum of 2. Similarly, for pneumococcal vaccinations, we constructed a variable by identifying vaccination up to 2 years before the index date and counted only 1 per year up to a maximum of 2. Screening for prostate cancer was determined by identifying blood tests for prostate-specific antigen (PSA) for up to 2 years before the index date. We counted PSAs if they were coded as a screening PSA test. Only 1 per year was counted up to a maximum of 2. We assessed screening for breast cancer by counting screening mammograms up to 2 years before the index date up to a maximum of 2. Finally, we assessed annual exams or preventive visits for counseling by counting visits coded as preventive visits for up to 2 years before the index date up to a maximum of 2.

Preventive services index

To estimate each person's "prevention-seeking" behavior and to control for selection bias, we used a preventive services index that we created previously. This index used variables available from the GHC administrative database and was the sum of the number of times a person received colon cancer screening (fecal occult blood test or flexible sigmoidoscopy), a screening mammogram, prostate cancer

screening, an influenza vaccination, and a pneumococcal vaccination during the 2 years before an index date (range, 0 to 8). If the person had none of the 4 services in the past 2 years, then the preventive services index was the number of annual examinations or preventive visits the person had in the past 2 years (maximum of 2). Two years was chosen as a time frame for creating the index because, although some preventive services are recommended every year (for example, receipt of influenza vaccine or annual examination), other services are recommended less often (for example, pneumococcal vaccination or mammogram). In addition, measuring the services during a 2-year period allows the inclusion of health-conscious people who get preventive services more or less on an annual basis.

Alternative preventive services index

To determine whether a different weighting of the preventive variables could be more effective than the ad hoc index in accounting for selection bias, we constructed an alternative preventive services index that used principal components analysis, which yields a composite variable that captures much of the information of the preventive variables. The principal components are weighted sums of the original observed items (13). We decided to use all the preventive variables available to us in the administrative database because we believed that an index based on a group of variables reflect patient health-seeking behavior more accurately than an index based on a single variable. Because screening mammograms are available only for women and screening examinations for prostate cancer are available only for men, we created 4 principal component scores to account for the lack of the same variables being available for both sexes. The first alternative index (labeled "men or women") included 4 variables common to both men and women (influenza vaccination, pneumococcal vaccination, preventive visits, and screening for colon cancer), plus a variable that represented the number of mammograms or screenings for prostate cancer. We created a second index using only the 4 variables common to both men and women, which we labeled "men and women." Finally, we created a "men only" index and a "women only" index, each having the 5 behaviors available to each of these sexes.

Statistical analysis

We used *t* tests and cross-tabulation to examine any differences in the demographic characteristics between men

and women in the sample. We used correlation coefficients to describe the relationship between the demographic and use variables and the indexes. We performed principal components analysis by using the FACTOR command in SPSS v.15.0 for Windows (IBM, Chicago, Illinois). We used pairwise deletion, principal component extraction, correlation method, and no rotation to determine the factor loadings of the components of the alternative preventive services index.

Analytical approach

The first step of our analysis plan was to determine the relationship between the preventive services index used in earlier publications and the various items of this preventive services index. We then created a new alternative index by using principal components analysis that included the same items found in the original preventive services index but had 4 variations based on the sex of the participant. We examined the relationship between these preventive services indexes and baseline demographics, fitness program enrollment, and attendance data. Finally, we compared the relationship between the original preventive services index, the alternative principal components analysis preventive services index, and age group.

Results

The mean age of our sample was 73 years; 62% were women (Table 1). Sixteen percent had at least 1 outpatient visit with an International Classification of Diseases (ICD)-9 code for arthritis in the year before the index date. Nineteen percent were on the heart registry and 15% were on the diabetes registry. Twenty-six percent of the participants were enrolled in the EnhanceFitness health fitness program; 21% were in Silver Sneakers. Use of preventive services in the 2 years before the index date was as follows: 40% had an influenza vaccination, 14% had a pneumonia vaccination, 31% had either returned stool cards or had a flexible sigmoidoscopy, 16% of the men had a PSA test, 68% of the women had a mammogram, and 47% had a preventive office visit. The *t* test comparison for the preventive services index between men and women was $t = 35.1$, $df = 30,913$, $P < .001$. The difference between men and women was mostly due to the difference in the frequencies of PSA tests versus mammograms. The mean preventive services index (range, 0-8) was 1.78 (SD, 1.72). The mean annual total per person health

care costs for the year before baseline was \$5,471 (SD, \$10,752), the per person inpatient cost for participants with any inpatient use was \$11,209 (SD, \$14,541), and the per person annual primary care visit cost was \$720 (SD, \$851). Although the standard deviations for most of these continuous measures were large and could affect the results, the 95% confidence intervals were small. The 95% confidence interval for RxRisk, for example, was 2,629 to 2,673. So although the variance was large, most people had values that fell within a narrow range in these continuous baseline measures.

The correlation coefficients between the 6 variables are included in the preventive services index and RxRisk (Table 2). All correlations were significant ($P < .001$) and in the expected direction, and the preventive services index was most strongly correlated with influenza vaccination ($r = 0.844$), colon cancer screening ($r = 0.752$), and preventive office visits ($r = 0.737$). People with more medications for chronic conditions (higher RxRisk) were less likely to have preventive procedures.

The second index was the first principal component of the preventive variables. The correlations between the items and the principal component (factor loadings) showed that, as expected, all of the individual items were highly correlated with the 4 newly created alternative preventive services indexes (Table 3). The factor loadings were fairly consistent between the 4 methods used to determine the new score. Influenza vaccinations and preventive office visits had the highest factor loadings.

The various indexes were similarly and significantly correlated with other patient characteristics when grouped by sex (Table 4). As expected, RxRisk and health care costs were negatively correlated with the factor scores, whereas enrollment and attendance in either the Silver Sneakers or the EnhanceFitness programs were positively correlated with the factor scores. The original index (based on the sum of the preventive services) compared well with the indexes derived from factor analyses. The alternative "women only" index had slightly higher correlations than the "men only" index in almost all of the cost and enrollment characteristics, except for household income (Table 4). Both the original preventive services index and the newly created principal component analysis scores showed sensitivity to age; the scores decreased with age (Figure).

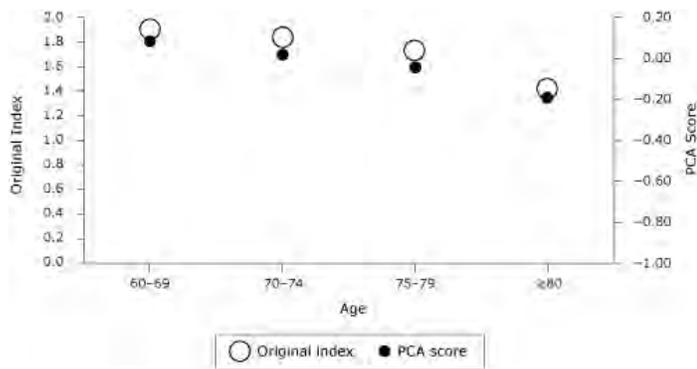


Figure. Original preventive services index and principal component analysis score by age group (N = 38,046). Abbreviations: PCA, principal component analysis; PSA test, prostate-specific antigen. Data are from “PCA: Men or Women” in Table 3, where variables are influenza vaccination, pneumococcal vaccination, colon cancer screening, PSA test, mammogram, and preventive office visit.

Discussion

The purpose of this study was to evaluate the preventive services index and its relationship to patient characteristics and to an alternative index based on principal components analysis. Both indexes were highly correlated with preventive behaviors, in the expected direction. The negative correlation with RxRisk may be attributed to clinical health care providers who have less time to address preventive measures in patients with more chronic illnesses (14,15). These indexes were most highly correlated with enrollment in the Silver Sneakers or the EnhanceFitness programs.

The alternative preventive services indexes, created by using principal components analysis, performed as well or slightly better than the original index based on the sum of 5 preventive services. The correlation coefficients of the principal components analysis for women only (Table 4) were almost always higher than the correlation coefficients for men, suggesting a closer relationship between the use of preventive services and enrollment in a fitness class for older women.

The observation that both the original and alternative preventive indexes decrease with age implies that the oldest adults were less likely to use preventive services. One explanation for this decrease is that as patients reach the end of life, the focus is no longer on preventive care but on pain management, for example. In addition, some preventive services (colon and prostate screening tests) are no

longer recommended for patients beyond a certain age. For example, the PSA test is no longer recommended for men older than 75 years and yet was included in this analysis. This may be one of the limitations of this study.

The original index, a simple arithmetic score, was developed to adjust for possible selection bias reported in studies that found lower subsequent costs for people who took advantage of a physical activity benefit. The cost differential remained significant even after controlling for the preventive services index (B. Williams, unpublished data). In the current analysis, designed to explore the performance of the index, we found that the original index and the variants resulted in similar findings. Because the original preventive services index is easier to calculate than the variants, we recommend its continued use to adjust for this type of selection bias. Thus, this method is generalizable to other research settings in which the sum of clinical services is available from an administrative database.

Strengths and limitations

One of the strengths of this study is that we were able to use the cost and use database of a large managed care organization, which has a total sample of more than 30,000 people. In addition, the preventive services index does not rely on self-report, which can be subject to error.

Our study had some limitations. We did not know the medical history of the participants, including the presence or absence of a previous cancer diagnosis. We summarized the use of screening (as opposed to diagnostic) colon, mammogram, and prostate examination services, which might not be appropriate for a patient with cancer. For example, our summary score may be high for the estimated 4% of the women older than 60 years who may have had a previous diagnosis of breast cancer or for 1% of the men with a possible previous diagnosis of prostate cancer. Similarly, we did not know how many of the women in our sample had had hysterectomies or mastectomies and might not require a screening test for the corresponding cancers. Furthermore, primary care physicians may influence the use of preventive services by suggesting services to their patients. Patients may choose services based on the recommendations of their physician rather than on their own prevention-seeking initiative. On the other hand, these patients are members of GHC, a health maintenance organization, in which preventive services are encouraged by being offered at no additional cost to the patient.

We were also limited by the variables in the GHC database, and we did not have access to data on other preventive health care services such as cholesterol checks or blood pressure screens. The administrative database does not account for reasons a person might choose not to engage in preventive behavior, including transportation problems, mental status, or physical inability. These variables may have contributed additional information to the preventive services index. Also, because our database was restricted to people who were aged 65 years or older, this analysis may not apply to a younger population.

Conclusion

Selection bias is a common problem in nonrandomized, observational studies of health care cost and use. We demonstrated that a preventive services index can be easily created from an administrative database to adjust for selection bias in observational studies. An alternative index derived from principal component analysis could be used, but we recommend using the original index because it is simpler to compute. Overall, the index displayed good properties, suggesting its appropriateness to control for selection bias among people who participate in preventive or disease self-management activities. This method may be generalizable to researchers who have access to medical administrative data and need to adjust for selection bias in observational studies.

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Tables

Table 1. Characteristics of Participants at Baseline, Silver Sneakers and EnhanceFitness Programs^a, 1997-2004 (N = 38,046)

Characteristics	Total Sample		Men (n = 14,443)		Women (n = 23,603)	
Mean age (SD), y	73.2 (6.0)		73.0 (6.0)		73.5 (5.9)	
Age ≥80, %	16.0		16.9		15.5	
Female (%)	62		NA		NA	
Comorbidities						
RxRisk ^b (\$), mean (SD)	2,651 (496 to 4,806)		2,649 (351 to 4,957)		2,652 (590 to 4,714)	
Arthritis, %	16.3		12.9		18.3	
On heart registry, %	19.4		26.2		15.2	
On diabetes registry, %	15.0		18.0		13.2	
Enrolled in health program^b						
Silver Sneakers, %	22.1		24.0		21.0	
EnhanceFitness, %	26.5		26.5		26.4	
Preventive services index and annual cost measures						
Preventive services index,^c mean (SD)	1.78 (1.72)		1.39 (1.67)		2.02 (1.70)	
Annual cost measures						
Total health costs (\$), mean (SD)	5,471 (10,752)		5,961 (11,961)		5,171 (9,928)	
Preventive services	Mean (SD)	%	Mean (SD)	%	Mean (SD)	%
Influenza vaccination	0.67 (0.87)	40.3	0.66 (0.87)	39.5	0.68 (0.88)	40.8
Pneumococcal vaccination	0.14 (0.35)	14.0	0.14 (0.35)	13.7	0.14 (0.35)	14.2
Colon cancer screening	0.38 (0.61)	31.5	0.38 (0.61)	31.4	0.38 (0.60)	31.5
PSA test	0.19 (0.45)	16.5	0.19 (0.45)	16.5	NA	NA
Mammogram	0.79 (0.62)	68.2	NA	NA	0.79 (0.62)	68.2
Preventive office visits	0.56 (0.66)	47.2	0.54 (0.67)	45.5	0.58 (0.66)	48.3

Abbreviations: SD, standard deviation; NA, not applicable; PSA, prostate-specific antigen.

^a RxRisk is a measure of comorbidity and is calculated by Group Health Cooperative for each person based on age, sex, and pharmacy use for the 6 months before the index date.

^b Silver Sneakers and EnhanceFitness are fitness programs. Silver Sneakers is a paid membership at a fitness club; EnhanceFitness is a specially designed physical activity program.

^c Preventive services index is the total number of preventive services that a person used in the 2 years preceding the index date (colon cancer screening [fecal occult blood test or flexible sigmoidoscopy]); screening mammogram; prostate cancer screening; influenza vaccination; or pneumococcal vaccination) (range, 0-8).

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Table 2. Correlation Coefficients Between Original Preventive Services Index and RxRisk, and Preventive Index Variables, Silver Sneakers and EnhanceFitness Programs, 1997-2004 (N = 38,046)^a

No. of Preventive Services in Past 2 Years	Influenza Vaccination	Pneumococcal Vaccination	Colon Cancer Screening	PSA	Mammo-gram	Preventive Office Visit	Preventive Services Index
Pneumococcal vaccination	0.310						
Colon cancer screening	0.549	0.255					
PSA (N = 14,443)	0.337	0.200	0.316				
Mammogram (N = 23,603)	0.237	0.086	0.199				
Preventive office visit	0.688	0.359	0.554	0.518	0.214		
Preventive services index ^b	0.844	0.487	0.752	0.592	0.559	0.737	
RxRisk ^c	-0.047	-0.066	-0.074	-0.090	-0.038	-0.113	-0.083

Abbreviations: PSA, prostate-specific antigen.

^a The Pearson correlation was used to calculate *P* values; *P* was significant at <.001 for all correlations.

^b Preventive services index is the total number of preventive services that a person used in the 2 years before the index date (colon cancer screening [fecal occult blood test or flexible sigmoidoscopy]); screening mammogram; prostate cancer screening; influenza vaccination; or pneumococcal vaccination) (range, 0–8).

^c RxRisk is expressed as predicted 6-month costs and is a measure of comorbidity based on age, sex, and pharmacy use for the 6 months before enrollment in either fitness program.

Table 3. Factor Loadings for the Principal Component Analysis for Components of Preventive Services Index,^a Silver Sneakers and EnhanceFitness Programs, 1997-2004

Preventive Services in Past 2 Years	PCA: Men or Women (N = 38,046)	PCA: Men and Women (N = 38,046)	PCA: Men Only (n = 14,443)	PCA: Women Only (n = 23,603)
Influenza vaccination	0.844	0.855	0.824	0.850
Pneumonia vaccination	0.535	0.554	0.532	0.531
Colon cancer screening	0.767	0.779	0.758	0.768
PSA test (n = 14,443)	0.434	NA	0.630	NA
Mammogram (n = 23,603)		NA	NA	0.393
Preventive office visits	0.866	0.870	0.885	0.859

Abbreviations: PCA, principal component analysis; PSA, prostate-specific antigen test; NA, not applicable.

^a Variables for PCA: men or women – influenza vaccination, pneumococcal vaccination, colon cancer screening, PSA test, mammogram, preventive office visit; for PCA: men and women – influenza vaccination, pneumococcal vaccination, colon cancer screening, preventive office visit; for PCA: men only – influenza vaccination, pneumococcal vaccination, colon cancer screening, PSA test, preventive office visit; for PCA: women only – influenza vaccination, pneumococcal vaccination, colon cancer screening, mammogram, preventive office visit.

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Table 4. Correlation Coefficients of the Original Preventive Services Index or Principal Component Analysis Score, With Other Participant Characteristics, by Sex, Silver Sneakers and EnhanceFitness Programs, 1997-2004

Component	Original Index (n = 38,046)	Original: Men Only (n = 14,443)	Original: Women Only (n = 23,603)	PCA: Men Only (n = 14,443)	PCA: Women Only (n = 23,603)
RxRisk ^a	-0.083	-0.086	-0.084	-0.099	-0.103
ED baseline costs	-0.082	-0.064	-0.093	-0.068	-0.091
Total baseline costs	-0.068	-0.059	-0.066	-0.065	-0.072
Household income ^b	+0.074	+0.081	+0.079	+0.082	+0.075
Enrolled in SS or EF	+0.187	+0.160	+0.209	+0.154	+0.187
SS or EF visits ^c	+0.027	+0.015	+0.064	+0.017	+0.055
SS or EF months	+0.066	+0.066	+0.073	+0.068	+0.071

Abbreviations: PCA, principal component analysis; ED, emergency department; SS, Silver Sneakers; EF, EnhanceFitness program.

^a RxRisk is expressed as predicted 6-month costs and is a measure of comorbidity based on age, sex, and pharmacy use, for the 6 months before enrollment in either fitness program.

^b Census tract median household income.

^c Total number of SS or EF visits attended (or months of follow-up) during the first year after enrollment for seniors who were either SS or EF enrollees (n = 10,090).

ORIGINAL RESEARCH

Health Care Costs and Participation in a Community-Based Health Promotion Program for Older Adults

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PEER REVIEWED

Abstract

Introduction

EnhanceWellness (EW) is a community-based health promotion program that helps prevent disabilities and improves health and functioning in older adults. A previous randomized controlled trial demonstrated a decrease in inpatient use for EW participants but did not evaluate health care costs. We assessed the effect of EW participation on health care costs.

Methods

We performed a retrospective cohort study in King County, Washington. Enrollees in Group Health Cooperative (GHC), a mixed-model health maintenance organization, who were aged 65 years or older and who participated in EW from 1998 through 2005 were matched 1:3 by age and sex to GHC enrollees who did not participate in EW. We matched 218 EW participants by age and sex to 654 nonparticipants. Participants were evaluated for 1 year after the date they began the program. The primary outcome was total health care costs; secondary outcomes were inpatient costs, primary care costs, percentage of hospitalizations, and number of hospital days. We compared

postintervention outcomes between EW participants and nonparticipants by using linear regression. Results were adjusted for prior year costs (or health care use), comorbidity, and preventive health care-seeking behaviors.

Results

Mean age of participants and nonparticipants was 79 years, and 72% of participants and nonparticipants were female. Adjusted total costs in the year following the index date were \$582 lower among EW participants than nonparticipants, but this difference was not significant.

Conclusion

Although EW participation demonstrated health benefits, participation does not appear to result in significant health care cost savings among people receiving health care through a health maintenance organization.

Introduction

Several health promotion and disease prevention programs designed for older adults have been developed and evaluated for their health benefits and resource use (1-5). These programs focus on improving older adults' general health and encouraging self-management of chronic medical conditions. Specific aspects of health improvement, such as improving mental well-being or increasing physical activity, are often the focus of health improvement and are pursued because of a client's interest and motivation. These programs connect clients with information and resources that help them address their personal health concerns, build confidence in health care decision making, and increase physical activity. Such health promotion pro-

grams for older adults improve health outcomes, and they have demonstrated decreased use of health care resources resulting from participation, which results in decreased health care costs (2,3). However, to our knowledge these studies used self-reported data rather than actual health care costs.

EnhanceWellness (EW, formerly known as Health Enhancement Program, or HEP) targets older people at risk for functional decline. Nurses and social workers meet with community-living elders to help increase physical activity, promote social activity, improve mental health, and enhance self-management of chronic conditions to improve health and functioning. In a 1998 randomized controlled trial, EW participants increased their physical activity, decreased their use of psychoactive medications, and decreased their number of hospital days (2). After that study, senior centers in the Seattle, Washington, area began implementing EW, and enrollees of Group Health Cooperative (GHC), a consumer-governed, non-profit health care system that provides both health care and medical coverage, started participating in the program. A follow-up study conducted in 2002 evaluated the program as it operated in the community, outside the controlled setting of a randomized trial (5). This study also demonstrated significant benefits, including a reduction in disability risk factors, improvement in health status, no decrease in functional status, and no increase in self-reported health care use.

EW has been confused with the EnhanceFitness Program (EF) because of their similar names and the fact that both have been studied in a similar older adult population (6,7). However, the programs are distinct: EF is a group exercise program, whereas EW is a comprehensive, participant-centered wellness program that includes a health assessment, a tailored health plan, and motivational support to achieve a self-chosen goal. EW participants, if desired, may include regular physical activity and join EF, a covered benefit for GHC members. Less than 10% of GHC members typically participate in both programs, although not necessarily simultaneously (M. Thompson, oral communication, December 2008).

Although health benefits and a reduction in hospital days have been demonstrated, EW's effect on health care use and costs has not been previously analyzed. The availability of comprehensive cost and use data for GHC members made studying these questions with GHC members

who had participated in EW attractive. We hypothesized that participation in EW would lower overall health care costs, via reductions in costly forms of health care use (especially hospitalizations).

Methods

Study setting

EW is offered at community centers, many of which are senior centers, located in the greater Puget Sound region. Senior Services, a private nonprofit organization with 250 employees established in 1967, operates EW. Nearly all nurses and social workers in EW programs in King County are employed either by Senior Services or by the hosting EW sites. The main sources of funding for Senior Services for EW programs in King County are the Aging and Disability Services of Seattle and King County and the Public Health Department of Seattle and King County. Office space and supplies are often donated by hosting sites. Participants are asked to make a donation at the time of graduation but this amount covers only a small amount of actual EW costs. Senior Services estimated that the cost to administer EW at its King County sites in 2004 was \$400 per participant per year. Although EW has been disseminated beyond King County, Washington, we restricted our study to King County, where GHC is based (8).

GHC is a consumer-governed, mixed-model health maintenance organization (HMO) with more than 500,000 members in the Pacific Northwest; according to our research, approximately 65,000 members are aged 65 years or older, and 27,900 reside in King County. Health outcomes and cost data are available and complete for all GHC members, regardless of whether they receive their care at a GHC-owned health care facility. GHC health care use and cost data have been studied and validated (9), and we used these data to capture our outcomes data. The institutional review boards of the University of Washington and GHC approved the study protocol.

Participants

We chose our sample from GHC members who were aged 65 years or older, resided in King County, and voluntarily participated in EW from March 15, 1998, through April 15, 2005. From this group, we selected par-

ticipants who were continuously enrolled in GHC for at least 1 year before and 1 year after the first day of their EW enrollment. The date of EW enrollment (ie, the first day an EW participant signed a consent form, formally agreeing to participate in the program) was defined as the “index date.” We excluded enrollees who had been in a long-term-care facility during the year before the index date because of the high costs involved that would have skewed the overall results.

Each EW participant was age- and sex-matched to 3 GHC members who had not participated in EW (“non-participants”). Nonparticipants were assigned an index date that corresponded to the index date of the EW participant to whom they were matched, creating comparable pre-index and postindex enrollment periods. Inclusion criteria for nonparticipants were identical to criteria for EW participants. Our analysis included comparisons between 218 EW participants and 654 matched nonparticipants.

Intervention

EW has been described in detail elsewhere (2,3). Briefly, after EW clients complete the program’s health intake questionnaire, which assesses risk factors for functional decline, they meet with a social worker or nurse for approximately 1 hour to discuss personal health concerns, review the findings of the questionnaire, and identify personal health goals. Clients develop strategies for improving health and make “health action plans.” They are encouraged, but not required, to seek out health and community services when needed. These services may include appointments with primary care providers, medical specialists, social services, or mental health services, or participation in an organized exercise program. Clients often need follow-up appointments with the nurse or social worker, either in person or by telephone. The recommended minimum time for program participation was 1 year until November 2003, at which point the recommended minimum time was reduced to 6 months.

Outcome measures

Total health care costs during the year following the index date was the primary outcome measure. Total costs included inpatient, primary care, and nonprimary care outpatient costs. Nonprimary care outpatient costs consisted of outpatient specialty care, outpatient mental

health, emergency department care, outpatient pharmacy, outpatient laboratory, outpatient radiology, long-term care, and drug and alcohol treatment costs. Secondary outcomes were inpatient and primary care costs, percentage of hospitalizations, and number of hospital days. All cost data were captured from the GHC cost accounting system previously described (6,9).

Data analysis

Participation (yes/no) in EW was our main predictor of interest. We included age, sex, prior year health care costs or use (as appropriate), comorbidity, and tendency to use preventive services as covariates in our analyses because these factors typically influence health care use and costs. We assessed comorbidity and chronic disease burden by using the GHC diabetes and heart registries and the Charlson comorbidity index (10). We used the methods of the HMO Research Network, which based its index on the method outlined by Deyo et al (11), with the addition of peripheral vascular disorder procedure codes and outpatient encounters as recommended (10,12,13) to determine our Charlson comorbidity index.

We assessed inclination to use preventive health services by using a preventive services score, which takes into account preventive health services and preventive visits (14,15). This score is the sum of the number of times a study participant received colon cancer screening (fecal occult blood test or flexible sigmoidoscopy), a screening mammogram, prostate cancer screening, an influenza vaccine, or a pneumococcal vaccine during the 2 years immediately preceding the index date (score range, 0-8). If the person had none of the 4 services in the past 2 years, the preventive services score was the number of primary care preventive visits the person had in the past 2 years (maximum, 2).

Median household income and median education were available for analysis at the census block level for more 80% of our participants. These socioeconomic status variables were considered but not included in the final model because their inclusion did not alter our results.

Statistical analysis

The primary analysis focused on differences in health care costs and use between EW participants and matched nonparticipants. We adjusted all costs to 2005 US dollars

by accessing the Medical Care component of the Consumer Price Index for the participant's index year (16). We used 2-tailed *t* tests and χ^2 tests to compare demographic and health-related characteristics and unadjusted health care cost and use measures for participants and their matched comparisons. We used ordinary least squares linear regression to analyze cost differences, adjusting for covariates; this modeling approach yields unbiased estimates of differences in mean costs when the sample size is large (17). Because the distribution of health care costs is often skewed, as many people have no costs and a few have high costs, we repeated our analysis by using log-transformed costs. All analyses were performed using Stata, version 9.0 (StataCorp LP, College Station, Texas).

Results

Most EW participants (88%) spent 6 months or longer in the program; approximately 50% spent 12 or more months, and 20% were in the program for more than 2 years. EW participants were identical to nonparticipants in terms of average age (79 y) and sex (72% female) (Table 1). We noted several significant differences between the groups, including a larger comorbidity burden among EW participants, as measured by a higher Charlson comorbidity index and a larger proportion enrolled in the GHC diabetes and heart disease registries. The preventive services score was significantly higher for EW participants, suggesting a stronger tendency to receive preventive services.

Total costs, inpatient costs, percentage hospitalized, and number of hospital days were not significantly different between participants and nonparticipants, either at baseline or in the year after the index date (Table 2). The only significant difference was in unadjusted primary care costs, which were higher by \$325 in the EW group ($P < .001$) at baseline and \$177 higher in the year after the index date ($P = .04$). After adjusting for age, sex, prior year total costs, preventive services score, Charlson comorbidity index, and presence on the GHC diabetes or heart disease registries, total health care costs in the year after the index date were \$582 lower for EW participants than for nonparticipants, but this difference was not significant. The results were unchanged when we used log-transformed costs. There were no differences in inpatient use or primary care use between the 2 groups at baseline or the year after the index date.

Discussion

We found that, compared with nonparticipants, EW participants had nonsignificantly lower total health care costs and no difference in hospitalizations during the year following EW enrollment. This finding may have resulted from the fact that EW participants in our sample had a significantly larger comorbidity burden than did nonparticipants. Comorbidity is a major driver of hospital costs and total annual costs (18,19). Furthermore, the methods we used to adjust for comorbidity, although widely used, may not have allowed us to fully control for comorbidity differences between study groups (10,11,13)

Many health promotion programs, some designed for the older adult population, have been associated with decreased health risks and decreased health care use (1-3,20-23). Health promotion programs evaluated by Lorig et al and Holland et al most closely resemble the EW program (3,4). These studies evaluated health outcomes and health care use, but neither assessed health care costs. Lorig et al found a significant decrease in hospitalizations and hospital days during their 6-month randomized controlled trial. The average age in this study was 10 years younger than in ours, and the 2 study groups had balanced comorbidities. Conversely, Holland et al did not find a difference in health care use between study groups during their year-long randomized controlled trial of the Health Matters Program in Sacramento, California, a program modeled after EW (4,24). Similar to our analysis, the mean age of participants in Holland's study was 73 years.

There are several differences between our analysis and the original randomized controlled trial that was used to evaluate EW (2). The original trial lasted 12 months, and outcomes were evaluated for the 12 months of program enrollment. After the original trial, EW evolved into a 6-month program, so our analyses included EW participants with varying duration of program participation. For most EW participants, 6 months of EW participation confers favorable effects on disability risk factors (eg, depression, physical inactivity) that are comparable to 12 months of participation (25). However, such reductions in disability risk factors do not appear to translate into lower overall health care costs.

A strength of our analysis was that we reported actual health care costs. To our knowledge, no other analysis of a health-promotion, disability-prevention health resource

has used actual cost data. Health care use is often used as a proxy for costs, or alternatively, costs are estimated from claims data (1,22). Furthermore, our health care use data were derived from automated data sources, which are more accurate in assessing health care use and costs than are self-reported data (26,27).

Our study has several limitations. Our study had an observational design, which can result in residual confounding and selection bias. Residual confounding in relation to the comorbidity differences we observed between study groups is likely, although we attempted to adjust for them. Research published after our study ended demonstrated that total annual costs increase with increasing comorbidity and that 4 conditions — hypertension, depression, use of warfarin, and skin ulcers/cellulitis — should be added to the Charlson comorbidity index to accurately predict total annual costs (19). We used the preventive services score to address selection bias related to the potential tendency of more prevention-oriented people to participate in EW. This score has been used in prior research with GHC members but may not have fully accounted for this form of selection bias (14). We also considered using propensity scores to adjust for selection bias but lacked enough covariates to independently predict program participation.

Another limitation was a lack of detail on health care use. In particular, we could not distinguish increased use that may have been prompted by participation in EW (eg, more visits related to health problems identified by EW). Also, apart from EF, we had no information about exercise and other health promotion programs that EW participants may have pursued as a result of their participation in EW. Finally, our sample size of just over 200 EW participants may have been too small to detect meaningful cost differences given the large variances associated with health care cost and use data.

EW improves the health of older adults at risk for functional decline (28). However, we did not find that overall health care costs were significantly reduced by EW program participation.

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Tables

Table 1. Participant and Nonparticipant Demographic Characteristics, Group Health Cooperative/EnhanceWellness, March 1998-April 2005

Characteristic	Participants (N = 218)	Nonparticipants (N = 654)	P Value
Mean age, y (SD)	78.6 (5.8)	78.6 (5.8)	>.99
% Female	72.5	72.5	>.99
Mean preventive services score (SD) ^a	3.0 (1.2)	2.8 (1.4)	.03
Mean Charlson comorbidity index (SD) ^b	1.0 (1.3)	0.7 (1.2)	<.001
% Listed on GHC diabetes registry	20.6	14.1	.02
% Listed on GHC heart disease registry	43.1	29.2	<.001

^a Derived from the sum of the number of times a subject received colon cancer screening (fecal occult blood test or flexible sigmoidoscopy), a screening mammogram, prostate cancer screening, an influenza vaccine, or a pneumococcal vaccine during the 2 years immediately preceding the index date (score range 0-8; higher scores indicate receipt of more preventive services).

^b See Methods section for a description of this score. The mean Charlson comorbidity index and the percentage of participants listed on the Group Health Cooperative diabetes and heart disease registries were used to measure comorbidity and chronic disease burden.

Table 2. Health Care Costs and Use of Participants and Nonparticipants at Baseline and Year Following Index Date,^a Group Health Cooperative/EnhanceWellness Program, March 1998-April 2005

Variable	Unadjusted Results				Adjusted Results	
	Participants (N = 218)	Nonparticipants (N = 654)	Difference	P Value ^b	Difference	P Value ^b
Cost, \$^c						
Total						
Baseline	7,047	6,207	840	.20	-582	.58
Year 1	8,091	7,977	114	.91		
Inpatient						
Baseline	773	1,116	-343	.29	-804	.22
Year 1	1,334	2,162	-828	.21		

^a The "index date" is date of enrollment (ie, the first day a participant signed a consent form, formally agreeing to participate in the program).

^b P values for unadjusted results derived from t tests; P values for adjusted results derived from linear regression (adjusted for age, sex, prior year costs, preventive services score, Charlson comorbidity index, and presence on the Group Health Cooperative diabetes or heart registries).

^c Results reported in mean 2005 US dollars.

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Table 2. (continued) Health Care Costs and Use of Participants and Nonparticipants at Baseline and Year Following Index Date,^a Group Health Cooperative/EnhanceWellness Program, March 1998-April 2005

Variable	Unadjusted Results				Adjusted Results	
	Participants (N = 218)	Nonparticipants (N = 654)	Difference	P Value ^b	Difference	P Value ^b
Primary care						
Baseline	1,213	888	325	<.001	28	.72
Year 1	1,069	892	177	.04		
Health care use						
No. of hospital days						
Baseline	0.43	0.40	0.03	.78	-0.15	.56
Year 1	0.83	0.89	-0.06	.80		
% Hospitalized						
Baseline	10.6	8.6	2.0	.38	-0.02	.95
Year 1	13.3	13.3	0	>.99		

^a The "index date" is date of enrollment (ie, the first day a participant signed a consent form, formally agreeing to participate in the program).

^b P values for unadjusted results derived from t tests; P values for adjusted results derived from linear regression (adjusted for age, sex, prior year costs, preventive services score, Charlson comorbidity index, and presence on the Group Health Cooperative diabetes or heart registries).

^c Results reported in mean 2005 US dollars.

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ORIGINAL RESEARCH

Implementing and Disseminating an Evidence-Based Program to Prevent Falls in Older Adults, Texas, 2007-2009

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PEER REVIEWED

Abstract

Introduction

Falls are a public health problem for the growing population of older adults. We describe a statewide effort to implement and disseminate A Matter of Balance/Volunteer Lay Leader model, an evidence-based fall-prevention program.

Methods

We analyzed 2 secondary databases: 1) a centralized administrative data set to document implementation processes and structures for delivering the program and 2) a common set of outcome measures for assessing the effect of the program on older Texans. We used multivariate analyses to examine changes on key outcome variables, controlling for major covariates.

Results

From 2007 through 2009, we reached 3,092 older Texas residents. Program capacity was built by certifying 98 master trainers and 402 lay leaders and delivering the program in 227 classes through the Area Agency on Aging network. Immediate outcome results were positive, which

indicates a pathway to promote more successful aging: 1) increases in falls efficacy, 2) improvements in overall physical activity levels, and 3) reductions in interference with everyday normal routines.

Conclusion

Widespread dissemination of a program to prevent falls can promote active aging among people who would otherwise be at risk for a downward cycle of health and functionality. Creating partnerships among different delivery sectors is needed for building community infrastructure to enhance the health of older adults.

Introduction

Falls among seniors are one of the most preventable causes of injuries, disabilities, and loss of independence (1,2). In 2007, there were more than 50,000 falls among Texas residents aged 50 years or older, resulting in more than 12,000 hip fractures and almost \$2 billion in total fall-related hospital charges (3). Modifiable fall risks, falls, the fear of falling, and related negative sequelae may be reduced through educational and behavioral interventions.

A Matter of Balance/Volunteer Lay Leader model (AMOB/VLL) is an evidence-based activity program for community-dwelling older adults; it is intended to reduce fear of falling and increase physical activity levels among seniors. AMOB/VLL can be implemented in 2 versions: a 4-week version with classes that meet twice a week or an 8-week version with weekly classes (4). Early sessions focus on diminishing fears of falling and encouraging



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participants to adopt the mindset that falls are preventable. Later sessions assist participants in changing their environments to reduce fall-related risk factors and teach them exercises to increase strength and balance. Certified master trainers teach lay leaders to deliver the program with fidelity.

Working with the leadership of the Texas Association of Area Agencies on Aging, the Texas Falls Prevention Coalition (www.texasfpc.org/index.php) disseminated AMOB/VLL across partnering Area Agencies on Aging (AAA) service areas. The Texas A&M Health Science Center provided standardized protocols for programs documenting implementation processes (program reach and adoption) and assessing program outcomes.

AMOB/VLL is being distributed nationwide as part of the Administration on Aging Evidence-Based Disease Prevention Grant Program. Our objective was to describe the training and delivery processes through which AMOB/VLL is implemented and disseminated throughout the Texas Association of Area Agencies on Aging. The secondary objective was to examine selected key outcome measures to validate positive findings reported in previous studies.

Methods

We collected administrative- and participant-level data from classes conducted from September 2007 through September 2009. We recruited participants to the program through local AAAs and other partnering community-based organizations. Institutional review board approval was obtained from Texas A&M University. Participation in this study was voluntary, and participants could withdraw from the study at any time.

Measures

The evaluation team created a detailed evaluation manual to standardize implementation processes and obtain common data across all participating sites (www.srph.tamhsc.edu/research/texashealthylifestyles/tfpc/forms.html).

We collected de-identified administrative information to assess the program implementation and dissemination processes (program training capacity, delivery site type,

and geographic spread) from AAA sites. Program coordinators at each participating AAA site kept administrative records that were requested by the evaluation center monthly. This information was checked for completeness and accuracy by the Texas Falls Prevention Coalition coordinator. We obtained information on program capacity, which we defined as the number of master trainers and lay leaders at each participating AAA site. We tracked trainer attrition (the number of active and inactive master trainers and lay leaders) through reports from program coordinators, who kept up-to-date rosters of people available to teach the classes. Consistent with the national implementation of evidence-based programs supported by the Administration on Aging, we used a standardized form to capture the types of delivery organization for each class. We defined program adoption in terms of the number and types of organizations that delivered classes under the auspices of the Texas Falls Prevention Coalition.

Program coordinators who collected administrative data at each participating AAA site coded the class delivery sites as senior centers, residential facilities, community centers, faith-based organizations, health care organizations, workplaces, or others. We used administrative data to illustrate the spread of AAA site participation over time. This information was mapped for each AAA region across the 254 Texas counties. Using participant residential zip codes, we assessed how many participants were served by each AAA site.

We collected baseline assessment data from participants at the beginning of the first class and postintervention data at the end of the last class (session 8). The self-reported assessment questionnaire was 9 pages and consisted of 28 items. Survey instrument items included Likert-type, yes/no, closed-ended, and open-ended questions. The questionnaire took approximately 15 minutes to complete, or longer for respondents who needed assistance.

Participants voluntarily enrolled in Texas Falls Prevention Coalition-sponsored AMOB/VLL classes in 19 AAA participating regions throughout Texas. We included age, sex, race/ethnicity, education level, income, and number of chronic conditions as participant demographic characteristics. We used participant responses — health status indicator variables collected at baseline and post intervention — as outcome variables for this study. The falls efficacy scale ($\alpha = 0.814$, composite score of five 4-point Likert-type scale items, scored 1 for “not sure at all”

and 4 for “absolutely sure”) assessed participants’ perceived ability to prevent falls and injuries from falls (5,6). The health interference scale ($\alpha = 0.924$, composite score of four 5-point Likert-type scale items, scored 1 for “not at all” and 5 for “almost totally”) measured the amount that health interfered with their everyday activities (social activities, hobbies, chores, shopping) (7). Physical activity was assessed by a variant of Behavioral Risk Factor Surveillance System survey items to assess the number of days in the previous week the participant was engaged in moderate-intensity physical activity for at least 30 minutes. We used several related quality-of-life measures to assess the number of days in the previous 30 that health was reported to be “not good,” and the number of days in the previous 30 that the participant was kept from participating in usual activities.

Data analysis

We examined participant data, collected at the beginning and end of the intervention, by using descriptive and multivariate analyses. Not all participants enrolled in the intervention completed instruments at baseline because not all sites collected data for every class they delivered. For participants with available data, we calculated frequencies of demographic characteristics to describe the reach and participant representativeness. We then performed analyses to identify any systematic biases resulting from missing data. The Pearson χ^2 and F tests were used to test for substantial differences in the percentages or means of selected demographic characteristics for participants who completed baseline and postintervention assessments and those with no postintervention assessments.

For multivariate analyses, we used only participant records with complete baseline and postintervention data on all variables. To analyze the AMOB/VLL data for differences from baseline to postintervention, we used a mixed model that accounted for cluster effects with repeated measures. We controlled for age, sex, race/ethnicity, and general health status in each multivariate model. We performed all analyses in SAS version 9.2 (SAS Institute, Inc, Cary, North Carolina).

Results

As of October 1, 2009, a total of 3,092 unique participants were recruited throughout Texas. These participants

averaged 77 years of age (15% were aged ≥ 85); most were women (83%) and were high school graduates (82%). A high proportion of disadvantaged seniors enrolled in the programs (30% were from a racial/ethnic minority group and 40% had incomes $\leq \$15,000/y$). Of the 3,092 participants, 87% had baseline data, 56% had postintervention data, and 51% had both.

Before assessing program effects, we conducted a bivariate analysis to examine the potential existence of significant differences between those participants who had baseline data only versus those with both baseline and postintervention data. A few differences emerged. More participants who had complete data at both time periods, and thus were included in the multivariate analysis, were non-Hispanic white (73% vs 64%), had attended college (58% vs 50%), and reported fewer unhealthy days (4.8 vs 5.9).

The Texas Association of Area Agencies on Aging sponsored 4 centralized master trainings. All participating sites were encouraged to send people in their AAA region to become certified, making them eligible to train lay leaders at their local site. As a large state with a commitment to preventing falls for seniors, Texas now has more trainers than any other state delivering AMOB/VLL. Of the 98 people trained as master trainers, 83 were still actively training. Of the 402 people trained to be lay leaders, 278 were still active. Given these data, the Texas Falls Prevention Coalition leaders recognized lay leader attrition as a problem. Local AAA sites now give more attention to recruitment and retention planning; their goal is to achieve higher retention of volunteer lay leaders and provide support services more efficiently.

As of October 1, 2009, 227 AMOB/VLL classes had been delivered at 146 unique sites. The most frequent implementation sites were senior centers (77 classes) and residential facilities (63 classes). Other sites included faith-based organizations (23 classes), health care organizations (12 classes), and workplaces (7 classes). Programs retained most participants: 76% of class participants completed at least 5 of 8 sessions. The average class size was 15 participants, which was larger than the ideal class size of 8 to 12 participants.

Twenty-six of the 28 AAAs contracted with the Texas Association of Area Agencies on Aging to deliver the AMOB/VLL program, for a potential reach of 236 of 254 Texas counties (Figure). Each participating AAA agreed

to hold a minimum of 6 classes, resulting in approximately 100 participants each. Through this infrastructure, AAAs conducted 227 classes in the 2-year timeframe or an average of nearly 9 classes for the participating AAAs. However, we noted substantial variation in the number of classes delivered; the highest-yield AAA site conducted 31 classes, and 5 sites offered no classes. Although the intent was to expand the program statewide, we found a clustering of programs in more populated areas of the state and limited penetration in the least populated areas.

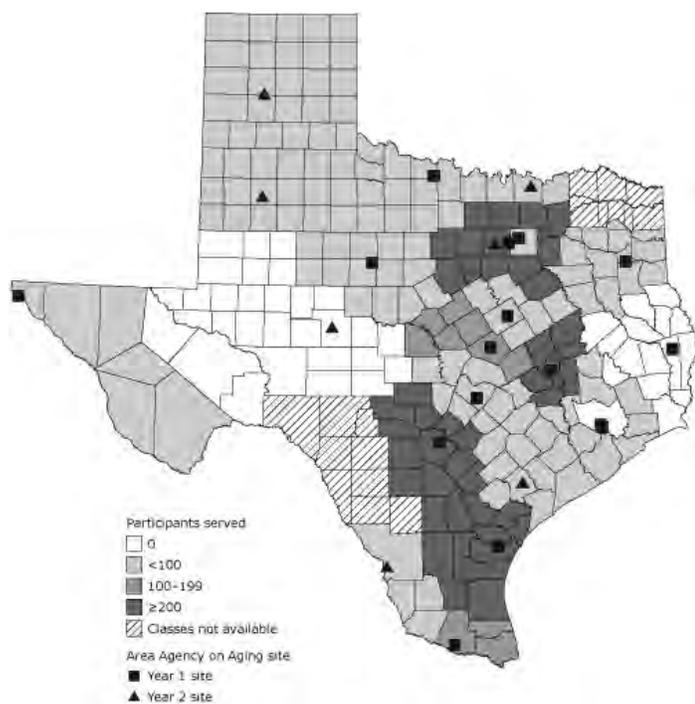


Figure. Geographic reach of A Matter of Balance/Volunteer Lay Leader model in Texas. This map illustrates the sequential uptake of Area Agencies on Aging in the delivery of A Matter of Balance/Volunteer Lay Leader model during the 2 years (2007-2009) of this study. Area Agency on Aging regions are shaded on the basis of the number of participants they served as of October 1, 2009.

Results were uniformly positive for AMOB/VLL participants (Table). Adjusted for key covariates (age, sex, race/ethnicity, self-assessed health), these multivariate analyses show strong effects of the intervention on falls efficacy. Other outcome variables showed more modest effects, including number of days physically active and reductions in health interference. An effect was found for physically unhealthy days but not for mentally unhealthy days.

Discussion

Our findings demonstrate the training and delivery structures necessary for the widespread dissemination of evidence-based programs. Not only do programs need to be *manualized* so others may easily adopt them (8), training capacity must also be adequate to meet the increased delivery demand with fidelity (9). Although state funding provided to Texas Association of Area Agencies on Aging made the infrastructure for disseminating AMOB/VLL statewide possible, programs were not established in all participating counties as anticipated. In the dissemination of any innovation, however, there will be early and late adopters (10). Moreover, geographic spread may not occur evenly in a particular AAA region since the AAAs serve multiple counties in a region, and delivery may be concentrated in a limited service area in a total AAA coverage area.

Additional investigation is needed to more systematically understand why some AAAs were more successful than others in implementing the program. Consistent with prior findings (11), organization size seems to be a factor: AAA sites that had more infrastructure resources could expend extra effort to recruit delivery sites and participants.

Our findings regarding participant outcomes were consistent with those of the original randomized clinical trial (5) and the initial translational research study (6). This research confirms that evidence-based fall-prevention programs are a pathway to healthier aging by modifying risk factors for falls that are associated with a downward cycle of fear and inactivity (2). Of special note, this research examined a broader range of outcomes than employed by the Maine program developers. Our investigation provides an opportunity to advance knowledge about the influence of a low-intensity fall-prevention program on reducing interference in activities of daily life and unhealthy days.

Although the number of participants in this study is larger than that of other examinations of AMOB/VLL (6), there was a substantial decrease from those enrolled to those with complete baseline and postintervention assessments. At the first level (from enrollment to baseline assessment), we believe this decrease reflected the ability of individual delivery sites to collect data instead of indicating any specific systematic bias for an individual participant. However, without data on all participants, we cannot determine whether those who did not become

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part of the database differed. We described the ways that participants with only baseline data differed from those with full data, and as in many intervention studies, more participants with more complete data were non-Hispanic white, healthier, and more educated (12). To help minimize the effects of these differences, these key covariates were used as controls when examining differences between preassessment and postassessment scores. The decrease in participation from baseline to postintervention assessment is typical in community-based studies.

Although we went beyond limited data-collection efforts in other states that implemented AMOB/VLL, we did not include direct association of intervention benefits with fall reduction, objective physical functioning measures, or links to health care use and costs that can make a stronger case for reimbursement (eg, health insurance payer reimbursement by public or private insurance mechanisms). Discussion is taking place at the national level of the need to document programmatic costs and compare these costs with reported outcomes. This is not possible in the current study, where analyses were conducted only at the immediate postintervention period. This study is also subject to a common research limitation — the lack of long-term follow-up data (13). Some sites are collecting 6-month follow-up data that can begin to address the long-term effects of these community programs; however, these data are not currently available. Similarly, data should be collected on factors associated with program maintenance at the organizational level. We note some sites were active in the first year but not the second year. A framework exists for understanding the sustainability of community health promotion programs (11), and future research should focus on understanding the direction of community programming on local, regional, and state levels.

The recent movement toward building healthy communities (14) may guide interventions intended to promote active aging. In this study, the most prevalent delivery sites were those where older adults live (residential facilities such as senior housing, retirement communities, or assisted-living facilities) or those associated with organizations already serving seniors (such as senior centers).

Most local AAAs have reached out to nontraditional aging partners for program delivery (such as parks and recreation departments or general community centers), and these types of partnerships are needed to broadly disseminate the intervention. We recommend that these

types of evidence-based programs be implemented where seniors live, play, or pray, to achieve healthy aging and healthier communities (15). A broader view of falls prevention best practices is needed that will go beyond evidence-based behavioral programming to appreciate the active and supportive roles of surrounding communities.

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Table

Table. Effectiveness of A Matter of Balance/Volunteer Lay Leader Fall-Prevention Program, Texas, 2007-2009

Variable ^a	Baseline	Postintervention	n	t Value	P Value	Cohen d
Falls efficacy scale ^b	12.5	14.1	1,221	19.97	<.001	1.14
No. of days physically active ^c	3.2	3.5	1,233	4.77	<.001	0.27
No. of unhealthy physical days ^c	2.7	2.0	1,267	2.50	.01	0.14
No. of unhealthy mental days ^c	1.6	1.4	1,280	1.16	.25	0.06
No. of days kept from usual activity ^c	1.5	0.9	1,296	3.00	.003	0.17
Health interference scale ^d	8.0	7.5	1,245	4.28	<.001	0.24

^a Covariates were age, sex, race/ethnicity, and general health status. Analyses accounted for cluster effects (by class).

^b Assessed perceived ability to prevent falls and injuries from falls by using the composite score of five 4-point Likert-type scale items, ranging from 5 to 20, scored 1 for "not sure at all" and 4 if "absolutely sure."

^c Assessed for the previous 30 days.

^d Assessed perceived amount that health interfered with everyday activities by using the composite score of four 5-point Likert-type scale items, ranging from 4 to 20, scored 1 for "not at all" and 5 if "almost totally."

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ORIGINAL RESEARCH

Caregivers of Older Adults With Cognitive Impairment

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PEER REVIEWED

Abstract

Introduction

Because of the growing number of caregivers and the awareness of related health and quality-of-life issues, caregiving has emerged as an important public health issue. We examined the characteristics and caregiving experiences of caregivers of people with and without cognitive impairment.

Methods

Participants (n = 668) were adults who responded to the 2005 North Carolina Behavioral Risk Factor Surveillance System. Caregivers were people who provided regular care to a family member or friend aged 60 years or older either with or without cognitive impairment (ie, memory loss, confusion, or Alzheimer's disease).

Results

Demographic characteristics of caregivers of people with cognitive impairment were similar to those of caregivers of people without cognitive impairment. However, compared with caregivers of people without cognitive impairment, caregivers of people with cognitive impairment reported higher levels of disability, were more likely to be paid, and provided care for a longer duration. Care recipients with cognitive impairment were more likely than care recipients

without cognitive impairment to be older, have dementia or confusion, and need assistance with memory and learning.

Conclusion

State-level caregiving surveillance is vital in assessing and responding to the needs of the growing number of caregivers.

Introduction

The expansion of the aging population in the United States is well documented. According to census estimates, 1 in every 5 (20.7%) people in the United States will be aged 65 or older by 2050, compared with 1 in 10 (10.4%) in 2000 (1). Because disability increases with age (2), the number of people who need assistance with activities of daily living (ADL) (eg, bathing) and instrumental activities of daily living (IADL) (eg, meal preparation) will continue to increase as the population ages. Historically, family members and friends have provided most of the assistance needed for the aging population in the United States. Approximately two-thirds of community-dwelling adults who need assistance with ADL rely on family members and friends alone to meet their needs (3).

Informal caregiving is a component of health, social, and aging services infrastructures (4-7). Although no universally accepted definition of informal caregiving exists, it is commonly understood as providing assistance to a family member or friend in a nonprofessional, usually unpaid, role to support the capacity of an individual to remain at home in the community for as long as possible (8). An estimated 16% to 30% of Americans provide informal care (9-11). Furthermore, among caregivers of people aged 60 years or older, between 25% and 29% provide assistance

to someone with cognitive impairment, a memory problem, or a disorder, such as Alzheimer's disease (10,12).

Aspects of cognition, such as memory, thought, and language, influence a person's ability to interact socially and to function independently (13,14). Cognitive impairment can affect a person's memory as well as the ability to perform daily tasks (15). Caregivers of people with cognitive impairment face challenges common to those of other caregivers, but they also encounter issues unique to the characteristics of the recipient's impairment. Studies have shown that providing care for a person with cognitive impairment is more demanding than caring for someone with physical problems alone, as indicated by reports of higher levels of burden, stress, and depression among caregivers of people with cognitive impairment (4,10,16-19).

Studies of caregivers of people with cognitive impairment have shaped our understanding of specific experiences and outcomes related to caregiving. However, such studies typically focus on a specific group of caregivers and care recipients, such as spousal caregivers, primary caregivers, or those seeking care in a clinic (17,18), which do not represent all caregivers in the population. A consistent source of state-level information on caregiving is needed to adequately assess the population and to plan appropriately for programs and services targeting caregivers. Typically, these services are delivered at the state level. Likewise, surveillance systems such as the Behavioral Risk Factor Surveillance System (BRFSS) provide the opportunity to monitor the burden of cognitive impairment, which is critical to understand the effects of these issues on families and communities in the United States (13,20).

Healthy People 2010 recommends the use of population-based data for tracking and measuring health indicators over time (21). One of the systems commonly used to monitor *Healthy People* goals is the BRFSS, an annual, list-assisted, random-digit-dialed telephone survey of the noninstitutionalized adult population of the United States and its territories. The BRFSS has been used to survey Americans on health behaviors and risk factors since 1984. Detailed methods have been described elsewhere (22,23), and information about questions, response characteristics, and methods can be found at www.cdc.gov/brfss.

We examined the characteristics of caregivers of people with and without cognitive impairment and the differences in their caregiving experiences.

Methods

From May through August 2005, an 11-item module of caregiving questions was added to the North Carolina BRFSS (24). These questions were created through collaborative efforts with key national stakeholders as part of a larger pilot study that also involved a follow-back survey of consenting caregivers (24). North Carolina was chosen as the pilot site because the large sample planned for 2005 BRFSS allowed a sufficient number of responses (study plan, $n = 5,000$) within 4 months. This study was approved by the institutional review board of the University of Florida.

Measures

The demographic factors of age, race/ethnicity, sex, education, and income were used to characterize caregivers. Age was reported as a categorical variable (18-34, 35-44, 45-54, 55-64, and ≥ 65 years). Categories for race/ethnicity (non-Hispanic white; non-Hispanic black; other/multi-race, non-Hispanic; and Hispanic), sex, education level (<high school diploma, high school diploma, and >high school diploma), and annual income (<\$25,000; \$25,000-\$34,999; \$35,000-\$49,999; \$50,000-\$74,999; and \geq \$75,000) also were reported.

Health-related quality of life of the caregiver was measured by responses to the following 3 core questions: 1) "Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?"; 2) "Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?"; and 3) "Would you say that in general your health is excellent, very good, good, fair, or poor?" The reliability of these questions is reported elsewhere (25). Social and emotional support was assessed through a single question: "How often do you get the social and emotional support you need?" Life satisfaction was measured by a single question: "In general, how satisfied are you with your life?"

Respondents were characterized as having a disability if they answered yes to either of the 2 following core questions: 1) "Are you limited in any way in any activities because of physical, mental, or emotional problems?" or 2) "Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a spe-

cial bed, or a special telephone?" Objective 6-1 of *Healthy People 2010* suggests that these items be used nationally to assess disability (21).

Respondents were classified as caregivers if they replied yes to the following question: "People may provide regular care or assistance to someone who has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend?" This item was modified from a question asked nationally during the 2000 BRFSS that restricted the definition of caregiver to one who provided care to someone aged 60 or older (9). If respondents provided care for more than 1 person, they were instructed to answer all subsequent questions on the basis of the person for whom they provided the most care. Additionally, caregivers who reported that the care recipient was aged 60 years or older were asked, "Did that person have a problem with memory loss or confusion or a disorder like Alzheimer's disease?" Those who said yes were classified as caregivers of people with cognitive impairment. Because the cognitive impairment question was asked only of caregivers of people aged 60 or older, all analyses were restricted to caregivers of people aged 60 or older.

Caregiving experience

Caregivers were asked a series of questions about their experiences providing care, which included several components: 1) description of the care recipient, 2) type and duration of care provided, and 3) caregiving intensity. Caregivers provided the following information about the person to whom they provided the most care: age (classified as 60-69, 70-79, 80-89, or ≥ 90 years), sex, relationship to caregiver (spouse/partner, other family member, nonfamily member, or paid caregiver), and major health problem (26 diagnoses possible). Unless otherwise noted, caregivers were limited to 1 answer choice per question.

Type of care provided was assessed through a single question: "Given this condition, with which two of the following areas does he/she most need your help?" (response options: learning, remembering, and confusion; seeing or hearing; taking care of oneself, such as eating, dressing, bathing, or toileting; communicating with others; moving around; getting along with people; or feeling anxious or depressed). Duration of care included the questions: "For how long have you provided care for him/her?" and "In an average week, how many hours do you provide care for

him/her because of his/her long-term illness or disability?" Responses to these questions are reported as months of caregiving and average hours of care provided per week.

A variable was created to quantify caregiving intensity. The intensity variable was adapted from a measure of burden in the National Alliance for Caregiving (NAC) and AARP study that measured activities and time spent in caregiving (10) and was constructed as follows: if respondents chose either "taking care of oneself, such as eating, dressing, bathing, or toileting" or "moving around" (items related to ADL) on the type-of-care question, they were assigned 3 points; if caregivers chose both options, they were assigned 4 points. Average hours of care provided per week were divided into 4 categories (0-8, 9-19, 20-39, and ≥ 40). Each category counted as 1 to 4 points, respectively. Points from the 2 questions were added and then categorized into a 5-level caregiver intensity variable, in which higher scores indicated higher levels of intensity. We found a moderately strong correlation between the newly created intensity measure and the 5-level NAC/AARP scale ($r = 0.61$), using data from a subset of respondents ($n = 329$) who participated in a follow-up survey and who answered a full list of questions about ADL and IADL.

Statistical analysis

All analyses were completed by using SPSS version 14.0 with Complex Samples (SPSS Inc, Chicago, Illinois) to account for the sampling design. Because caregiving module data were collected during only a portion of the year (May-August 2005), we adjusted the final weights so that the 4-month period of data collection represented the entire North Carolina population. Statistical analyses using the full 2005 North Carolina BRFSS weights and the reweighting that accounted for the 4-month sample yielded similar results, but we report only the reweighted results. We report means and frequencies as well as 95% confidence intervals. We used independent-sample t tests to compare means and χ^2 tests to compare frequency measures. To test for trends across ordered categorical variables (age, income, education, and intensity), logistic regression models were fit in SPSS wherein the outcome was caregiver status (caring for a person with or without cognitive impairment), and each categorical item was included as the exposure variable, coded in 1-point increments (ie, 1, 2, 3 . . .). The trend test provided a global P value for the trend across ordered levels of a variable rath-

er than individual P values for each level of the variable. This method generalizes the Cochran-Armitage trend test (26) for use with complex survey data (27). Differences were considered significant at $P < .05$.

Results

In total, 5,681 people responded to the caregiver question, of which 895 (15.4% weighted) were caregivers. Of these, 672 reported caring for someone aged 60 or older, and 668 answered the cognitive impairment question; the other 4 respondents were excluded from our analyses because they could not be classified as caregivers of persons with or without cognitive impairment. There were 279 caregivers of people with cognitive impairment (41.5% weighted) and 389 caregivers of people without cognitive impairment (58.5% weighted).

No statistically significant differences were found by age, race/ethnicity, sex, level of education, annual household income, healthy days, self-rated health, social support, or life satisfaction between caregivers of people with and without cognitive impairment (Table 1). A significantly higher proportion of caregivers of people with cognitive impairment had a disability; 24.0% of caregivers of people with cognitive impairment indicated they had a disability compared with 16.1% of caregivers of people without cognitive impairment ($P = .03$). Specifically, 23.4% of caregivers of people with cognitive impairment reported their activities were limited by physical, mental, or emotional problems compared with 15.1% of caregivers of people without cognitive impairment ($P = .02$).

Caregivers of people with cognitive impairment differed significantly from other caregivers in care-recipient attributes and the type of care provided (Table 2). Care recipients with cognitive impairment were significantly older than care recipients without cognitive impairment ($P = .001$), but they were no more likely to be women. Caregivers of people with cognitive impairment were significantly more likely to report being paid than were caregivers of people without cognitive impairment ($P < .001$), although the percentage was low for both groups. Caregivers of people with cognitive impairment were significantly more likely to report that the person they care for had dementia than were caregivers of people without cognitive impairment ($P < .001$), although caregivers of people without cognitive impairment were significantly

more likely to report that the person they care for had cancer ($P = .002$) or heart disease ($P = .03$) than were caregivers of people with cognitive impairment. Caregivers of people with cognitive impairment were significantly more likely to report that the people they care for need help with "learning, remembering, confusion" and significantly less likely to report that the people they care for need help with "moving around" than caregivers of people without cognitive impairment ($P < .001$ for both). Caregivers of people with cognitive impairment provided care for a significantly longer period of time than did caregivers of people without cognitive impairment ($P = .001$). No significant differences were found between the 2 caregiver groups for hours of care provided per week or for caregiving intensity.

Discussion

We found that more than 41% of self-identified caregivers of people aged 60 years or older reported a cognitive impairment in the person for whom they provided care. This percentage is considerably higher than those reported in previous caregiver surveys, such as the NAC/AARP survey that reported a rate of 25% (10). Both the North Carolina BRFSS caregiver module and the NAC/AARP survey were conducted during a 4-month interval; queried respondents using a closed-end question to determine whether the person they cared for had Alzheimer's disease, dementia, or other mental confusion; and relied on the caregiver's assessment rather than a medical diagnosis. However, these surveys varied in terms of respondent eligibility and the age of the care recipient. The 25% prevalence of cognitive impairment (ie, Alzheimer's, dementia, or mental confusion) from the NAC/AARP survey was based on care recipients aged 50 or older; we collected data on care recipients aged 60 years or older. Given that the risk of cognitive impairment and dementia increases with age (14), the prevalence of caregiving for people with such impairments may be higher among older populations of care recipients. The NAC/AARP study included only caregivers who assisted with at least 1 ADL or IADL, yielding a sample of caregivers who potentially provided care to more people who had disabilities than did caregivers in our study. Our study was limited to a single state, whereas the NAC/AARP was a national survey, and the prevalence of cognitive impairment may vary in the United States. For example, the Reasons for Geographic and Racial Differences in Stroke Study showed regional variations in the incidence of stroke and identified a

“stroke belt” located in several states in the southeastern United States (28). Similar regional variation in cognitive impairment may exist.

Caregivers of people with cognitive impairment were more likely than caregivers of people without cognitive impairment to have a disability and to report that their activities were limited by their disability. Furthermore, many of the caregivers themselves reported having a disability, even while caring for a person who required assistance with learning, memory, and confusion. Data from one study showed that 36% of caregivers who were aged 65 years or older were considered to be vulnerable, with their health status ranging from fair to poor, and had a serious health condition (29).

In our study, caregivers of people with cognitive impairment reported lower levels of caregiving intensity than did caregivers in the NAC/AARP study (10). However, the construction of the intensity scales differed because we did not ask caregivers the complete list of ADL and IADL. In our study, 62.0% of caregivers of people with cognitive impairment reported they assisted with at least 1 of the categories of ADL-like activities (self-care or moving around), the same percentage of caregivers of people with Alzheimer’s disease, dementia, or other mental confusion found in the NAC/AARP study (10). Duration of care was not included in the caregiver intensity variable, but long-term caregiving may contribute to caregiver stress or burden, items not measured in our study. In a study of caregivers of people with Alzheimer’s disease, duration of caregiving was not related to caregiver health, when adjusting for behavioral changes in the person receiving care (30). The caregiving intensity measure implies an indirect level of burden or negative impact. A measurement of the positive aspects of caregiving was not captured in our study but may help in future population-based surveillance. One study found that 81% of family caregivers for people with Alzheimer’s disease or some other form of dementia reported gains as well as strains associated with their caregiving experience; the remaining 19% reported only burden (31). Previous studies have found mixed results in mental health outcomes for caregivers of people with dementia compared with other caregivers (4,17,19). The results of our study do not indicate any significant differences in frequent mental distress, social support, or life satisfaction between caregivers of people with and without cognitive impairment, which may mean that all caregivers are at equal risk for

poor mental health outcomes. Future research is needed to investigate the mental health, including stress and depression, of caregivers.

Our study had several limitations. First, cognitive functioning of the care recipient was not formally assessed. Therefore, care recipients classified as being cognitively impaired may not have had clinical symptoms. Second, there was no indication of the care recipient’s severity of cognitive impairment. Previous studies have shown that proxies do not always accurately report disability attributes, such as severity or limitations (32), so proxy assessments of severity of cognitive impairment need validation before inclusion. Third, our data were based on BRFSS respondents in North Carolina, and characteristics of the US population may be different. Future studies should evaluate the possible regional variations in the prevalence of cognitive impairment. Finally, our study included only noninstitutionalized adults (aged ≥ 18 years) who had traditional home telephone landlines. Despite these limitations, the general attributes of the BRFSS, including its population-based sampling technique and the demonstrated reliability and validity of its core measures (33), allowed comparison of informal caregivers of people with and without cognitive impairment in terms of demographic variables and characteristics of care. Future studies should establish the psychometric properties of the caregiver items, including the abbreviated version of the intensity scale.

The number of caregivers in the United States, including the number of caregivers of people with cognitive impairment, is expected to grow (13). If these caregivers are to continue to provide the foundation of care for people who need assistance, their health, both physical and mental, must be assured. Caregivers, particularly caregivers of people with cognitive impairment, dedicate substantial time to providing care, as our results show. Caregivers of people with cognitive impairment may provide care for long periods of time because of the slow progression of many types of dementia (17). Therefore, caregiving is of public health importance, and caregiving surveillance is vital in assessing and responding to the needs of the growing number of caregivers (5). Evaluating trends in cognitive impairment and caregiving over time is also important. Quantifying the number and type of caregivers in a community will improve our understanding of the health and quality-of-life consequences of providing care and will aid in policy making and decision making.

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Tables

Table 1. Characteristics of Caregivers of People With and Without Cognitive Impairment (Weighted), North Carolina Behavioral Risk Factor Surveillance System, 2005^a

Characteristic	Caregivers of People With Cognitive Impairment (n = 279)	Caregivers of People Without Cognitive Impairment (n = 389)	P Value ^b
Age, y			
18-34	19.7 (13.0-28.6)	23.5 (15.4-34.1)	.13 ^c
35-44	16.0 (11.3-22.1)	18.5 (13.9-24.2)	
45-54	27.8 (21.6-34.8)	19.2 (14.8-24.5)	
55-64	20.8 (15.7-27.1)	17.8 (13.6-22.8)	
≥65	15.8 (11.7-21.0)	21.0 (16.5-26.4)	
Race/ethnicity			
Non-Hispanic white	76.7 (70.1-82.2)	74.1 (64.5-81.8)	.63
Non-Hispanic black	15.4 (11.1-21.0)	21.8 (14.3-31.9)	.18
Other/multi-race, non-Hispanic	4.9 (2.5-9.4)	2.4 (1.1-5.2)	.17
Hispanic	3.0 (1.3-6.7)	1.7 (0.6-4.4)	.35
Sex, female	59.9 (51.7-67.6)	60.9 (52.2-68.9)	.89
Education level			
<High school diploma	6.6 (4.1-10.6)	13.9 (7.3-24.8)	.18
High school diploma	29.6 (22.9-37.4)	29.0 (23.0-35.8)	
>High school diploma	63.7 (56.0-70.8)	57.2 (49.0-65.0)	
Annual household income, \$			
<25,000	30.3 (23.6-37.9)	23.3 (17.7-30.1)	.10 ^c
25,000-34,999	14.8 (9.4-22.6)	20.9 (15.3-27.9)	
35,000-49,999	12.7 (8.6-18.4)	20.5 (12.8-31.1)	
50,000-74,999	21.1 (15.3-28.3)	13.6 (9.8-18.6)	
≥75,000	21.0 (15.0-28.6)	21.7 (16.4-28.1)	
Health-related quality of life			
Healthy days in the past 30, mean (95% CI)	24.3 (23.0-25.5)	23.9 (22.4,25.4)	.64 ^d
No. of days physical health not good	2.9 (2.1-3.7)	3.3 (2.4-4.3)	.34 ^d

Abbreviation: CI, confidence interval.

^a Data are reported as % (95% CI), except where indicated. Numbers may not total to 100% because of rounding.

^b Except where indicated, P values are reported for the difference in frequencies between caregivers of people with and without cognitive impairment, as measured by χ^2 test.

^c P value reported for the difference in frequencies between caregivers of people with and without cognitive impairment, as measured by logistic regression to assess trend across ordinal variables.

^d P value reported for the difference in means between caregivers of people with and without cognitive impairment, as measured by t test.

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Table 1. (continued) Characteristics of Caregivers of People With and Without Cognitive Impairment (Weighted), North Carolina Behavioral Risk Factor Surveillance System, 2005^a

Characteristic	Caregivers of People With Cognitive Impairment (n = 279)	Caregivers of People Without Cognitive Impairment (n = 389)	P Value ^b
Health-related quality of life (continued)			
No. of days mental health not good	3.9 (2.7-5.0)	3.7 (2.4-5.0)	.81 ^d
General health rated fair or poor	16.6 (11.9-22.5)	16.2 (12.3-21.2)	.93
Rarely or never receive social or emotional support	8.7 (5.5-13.7)	6.7 (3.9-11.5)	.47
Dissatisfied or very dissatisfied with life	3.7 (2.0-6.8)	2.7 (1.5-5.0)	.49
Disability status			
Have a disability	24.0 (18.6-30.5)	16.1 (12.4-20.8)	.03
Activities limited by physical, mental, or emotional problems	23.4 (18.0-29.9)	15.1 (11.6-19.6)	.02
Use special equipment	7.4 (4.5-12.0)	4.6 (2.7-7.6)	.18

Abbreviation: CI, confidence interval.

^a Data are reported as % (95% CI), except where indicated. Numbers may not total to 100% because of rounding.

^b Except where indicated, P values are reported for the difference in frequencies between caregivers of people with and without cognitive impairment, as measured by χ^2 test.

^c P value reported for the difference in frequencies between caregivers of people with and without cognitive impairment, as measured by logistic regression to assess trend across ordinal variables.

^d P value reported for the difference in means between caregivers of people with and without cognitive impairment, as measured by t test.

Table 2. Characteristics of Caregiving Experience for Caregivers of People With and Without Cognitive Impairment (Weighted), North Carolina Behavioral Risk Factor Surveillance System, 2005^a

Characteristic	Caregivers of People With Cognitive Impairment (n = 279)	Caregivers of People Without Cognitive Impairment (n = 389)	P Value ^b
Age of person receiving care, y			
60-69	10.5 (7.1-15.4)	26.9 (21.3-33.4)	.001 ^c
70-79	33.3 (26.3-41.2)	27.9 (22.0-34.7)	
80-89	46.5 (39.0-54.1)	35.6 (27.9-44.1)	
≥90	9.6 (5.5-16.4)	9.6 (6.2-14.5)	
Sex of person receiving care, female	74.0 (67.5-79.7)	70.5 (63.4-76.4)	.41

Abbreviation: CI, confidence interval.

^a Data are reported as % (95% CI), except as noted. Numbers may not add to 100% because of rounding.

^b Except where indicated, all P values are reported for the difference in frequencies between caregivers of people with and without cognitive impairment, as measured by χ^2 test.

^c P value reported for the difference in frequencies between caregivers of people with and without cognitive impairment, as measured by logistic regression to assess trend across ordinal variables.

^d P value reported for the difference in means between caregivers of people with and without cognitive impairment, as measured by t test.

^e See Methods section for a detailed description of this variable.

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Table 2. (continued) Characteristics of Caregiving Experience for Caregivers of People With and Without Cognitive Impairment (Weighted), North Carolina Behavioral Risk Factor Surveillance System, 2005^a

Characteristic	Caregivers of People With Cognitive Impairment (n = 279)	Caregivers of People Without Cognitive Impairment (n = 389)	P Value ^b
Relationship of caregiver to person receiving care			
Spouse/partner	6.3 (3.9-9.9)	10.0 (7.0-14.0)	.12
Other family member	77.4 (70.9-82.8)	69.2 (60.4-76.8)	.07
Nonfamily member	10.9 (7.5-15.7)	18.9 (11.8-28.8)	.07
Paid caregiver	2.7 (1.1-6.4)	0.1 (0.0-0.7)	<.001
Major health problem of person receiving care			
Cancer	7.1 (4.5-11.3)	15.7 (11.7-20.7)	.002
Dementia	28.9 (22.0-37.0)	0.6 (0.1-3.0)	<.001
Diabetes	5.9 (3.1-10.7)	10.5 (6.2-17.3)	.14
Heart disease	10.5 (7.0-15.6)	17.8 (13.5-23.1)	.03
Stroke	11.2 (7.3-16.8)	11.3 (7.2-17.3)	.97
Areas in which person receiving care needs most help			
Learning, remembering, confusion	37.4 (30.5-44.8)	7.8 (4.2-13.9)	<.001
Seeing or hearing	6.5 (3.9-10.6)	9.4 (6.0-14.5)	.27
Taking care of himself/herself	42.3 (35.1-49.8)	39.2 (31.5-47.6)	.59
Communicating with others	10.3 (6.7-15.6)	7.8 (5.3-11.3)	.32
Moving around	30.5 (23.5-38.6)	51.9 (44.1-59.6)	<.001
Getting along with people	7.1 (4.1-12.1)	4.4 (2.4-7.9)	.24
Feeling anxious or depressed	15.2 (10.8-20.9)	14.9 (11.0-20.0)	.95
Average hours of care per week, mean (95% CI)	20.2 (15.2-25.2)	16.6 (12.8-20.4)	.07 ^d
Length of care in months, mean (95% CI)	45.6 (36.1-55.0)	35.5 (29.6-41.4)	.001 ^d
Caregiving intensity^e			
Level 1	31.6 (24.8-39.2)	21.4 (15.7-28.5)	.25 ^c
Level 2	34.9 (27.1-43.5)	38.0 (29.6-47.2)	
Level 3	14.6 (10.2-20.5)	20.8 (15.3-27.6)	
Level 4	17.0 (12.4-22.9)	17.3 (12.9-22.7)	
Level 5	2.0 (0.7-5.8)	2.5 (1.3-4.9)	

Abbreviation: CI, confidence interval.

^a Data are reported as % (95% CI), except as noted. Numbers may not add to 100% because of rounding.

^b Except where indicated, all P values are reported for the difference in frequencies between caregivers of people with and without cognitive impairment, as measured by χ^2 test.

^c P value reported for the difference in frequencies between caregivers of people with and without cognitive impairment, as measured by logistic regression to assess trend across ordinal variables.

^d P value reported for the difference in means between caregivers of people with and without cognitive impairment, as measured by t test.

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SPECIAL TOPIC

Novel Approach, Using End-of-Life Issues, for Identifying Items for Public Health Surveillance

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PEER REVIEWED

Abstract

Using end-of-life (EOL) issues to provide context, we introduce a novel approach to identify potential items for public health surveillance. Our method involved an environmental scan of existing EOL surveys and included the following steps: 1) consulting experts for advice on critical EOL topics, 2) identifying a broad sample of EOL surveys, and 3) using an abstraction tool to characterize surveys and survey items. We identified 36 EOL surveys; of these, 10 were state-based surveys. Of the 1,495 EOL items (range, 4 to 126 items per survey), 333 items could be classified in 1 of 11 topic areas of interest. Information on the surveys and these 333 items was entered into a database. As a result of this process, we identified topics for which many EOL items already exist and topics for which items should be developed. We describe the value of this approach and potential next steps for our project.

Introduction

Life expectancy in the United States increased by 30 years during the last century (1,2). Most people alive today will die at an older age than in previous years, most likely after a period of chronic illness and physical decline (3,4).

At the same time, studies document serious deficiencies in the care provided to dying people, including undertreatment of pain and communication difficulties between patients, family members, and health care providers regarding end-of-life (EOL) goals (5-7). As a result, EOL issues have gained recognition as a societal (8) and public health (9) concern.

The Institute of Medicine (10) and the National Institutes of Health (11) have emphasized the need for data that can be used to improve the experiences of dying people and their families. In making these recommendations, both organizations focused on data that could be used to improve the experiences of dying people within health care systems. However, they recommended that federal agencies “make incremental changes to [existing] surveys to improve the usefulness of currently collected data in describing aspects of quality of life and quality of care at the end of life” (10). To date, EOL items have not been included in surveillance systems that address issues that affect quality of life. In 2003, 1 of the top 5 recommendations made by stakeholders from diverse fields concerning the role of state health departments in addressing EOL issues was a recommendation to “collect, analyze, and share data about EOL through state surveys, such as the Behavioral Risk Factor Surveillance System” (BRFSS) (12).

Before creating EOL items to address this recommendation, we recognized the need to determine whether items that are appropriate for ongoing public health surveys or surveillance systems already existed and to identify gaps that require the development of new items. To meet these goals, we developed a systematic approach that involved an environmental scan or a search for existing EOL instru-

ments or surveys (hereafter referred to as surveys) and abstracting items within key topic areas.

Methods

As a first step (Figure), we convened a 1-day meeting in February 2006 with 6 people who had expertise in palliative care, EOL survey research, or public health, or some combination of the 3. At the beginning of the meeting, we gave a presentation on public health surveillance methods and how data collected using these methods are used to inform public health activities. Then, we asked the experts to identify and prioritize key EOL topic areas that are appropriate to incorporate into ongoing public health surveys or surveillance systems. The panel members identified 8 critical topics: 1) awareness of EOL options, 2) communications with family members and health care providers about EOL preferences, 3) communications with family members and health care providers about advance directives, 4) general concerns and fears about dying, 5) desires regarding EOL care, 6) location of death of a loved one, 7) unmet needs at the end of the person's life, and 8) pain at the end of the person's life.

Because one of our goals was to identify existing EOL items, we needed to collect and systematically review a broad sample of EOL surveys for items related to these key topic areas. We used an iterative approach for this review to identify surveys that were conducted after 1990. We searched the Internet and published and "gray" literature (articles, technical reports, newsletters, or other documents produced by government agencies, academic institutions, and other groups not indexed or distributed by commercial publishers), and we consulted expert panel members. In addition to providing us with their own surveys, the experts facili-

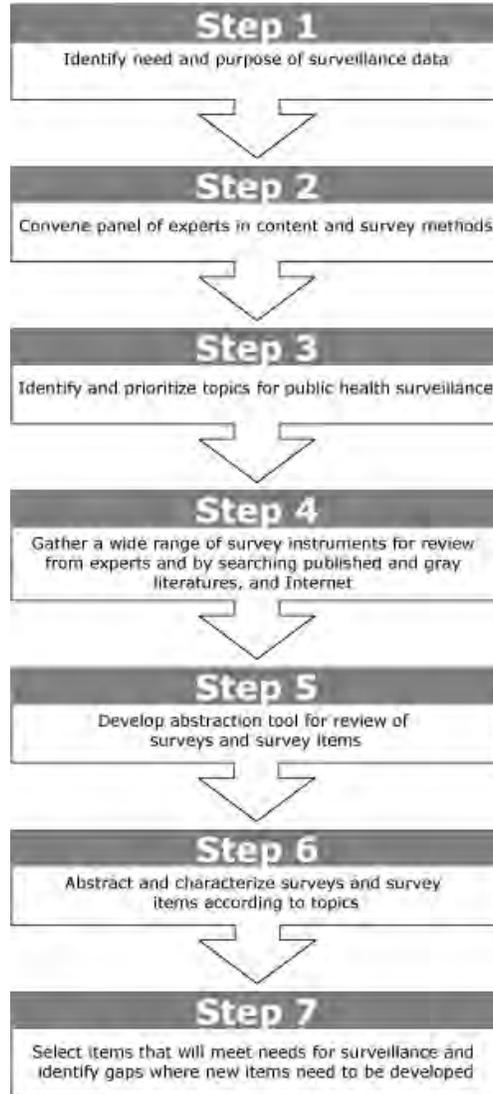


Figure. Step-by-step method for identifying potential survey items for public health surveillance from existing surveys.

tated contacts with other researchers who provided us with additional instruments. Given our interest in identifying items suitable for population-based surveillance, we excluded surveys that focused solely on the processes of care (eg, surveys of health care institutions) or health care professionals or surveys that were not performed in English.

Next, we developed an abstraction tool. Our tool captured information on 2 levels: 1) characteristics of the survey and 2) characteristics of individual items. For each survey, we collected information on the sampling frame (national, state, community, hospital, hospice, or nursing home), type of sample (ie, general public, patient, or family member), and mode of administration (telephone, in-person, written, or multiple modes). Next, we abstracted and classified each survey item according to 1) perspective (retrospective or prospective), 2) response type, and 3) topic. In terms of perspective, we classified items as retrospective if they asked respondents to provide information on the experiences of a family member or significant other who died within a specified time frame (a mortality follow-back approach) (13). We classified items as prospective if they assessed the respondents' personal awareness, attitudes, and behaviors related to EOL issues. We used the following

categories to characterize item response types: Likert-type, multiple-choice, open-ended, ranking, rating, or yes/no response. Our topic categories included the 8 areas identified by the expert panel members and an additional 3 areas (completion of advance directive, concerns about being a burden to others, and health care provider communications with the dying person or family member). All 11 topics are relevant to our efforts to develop and track public health EOL programs.

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As part of the abstraction process, 2 authors classified survey items into 4 overarching categories, which contained the 11 topics. The first category, labeled “knowledge,” consisted of 1 topic, awareness of EOL options. The second category, labeled “attitude,” included 3 topics: concerns about being a burden to others, general concerns and fears about dying, and desires regarding EOL care. The third category, labeled “behavior,” included 3 topics: discussion about EOL preferences, communication about advance directives, and completion of advance directive. The final category, labeled “situation,” included 4 topics: location of death of a loved one, how well this person’s needs were met, whether the person experienced pain at the end of his or her life, and health care provider communications with the dying person or family member. All items were classified into mutually exclusive categories and topics (items were classified into 1 of the 4 overarching categories and 1 of 11 topic areas). In some instances, we found that different surveys included the same item. We abstracted these items only once and recorded the surveys in which they appeared. Any differences between the raters in the classification of surveys or survey items were discussed and resolved before data were entered into the study database.

Results

We identified 36 surveys for our environmental scan (Table 1). Because our search strategy included the published and gray literature, the list of surveys included in our review is available from the authors. Of the surveys, most ($n = 31$, 86%) were performed in the United States; the remaining 5 were conducted in Canada ($n = 4$) or Australia ($n = 1$). In terms of sampling frame, 18 surveys were performed at the national or state level, and the remainder were performed in communities, hospitals, hospices, or nursing homes. Among the national surveys, 3 were public opinion polls, 3 were specific waves of population-based surveys (eg, Longitudinal Survey on Aging, Health and Retirement Study) in which some EOL items were included, and 2 were national mortality follow-back surveys. We found 3 state-added EOL modules for the BRFSS and 7 other surveys that were performed in specific states.

The types of respondents varied considerably. In 20 surveys, the respondents were members of the general public, 11 surveys focused on family members, and 5 surveys were

administered to various patient groups. Various methods were used to administer these surveys: in-person administration was most common ($n = 14$), followed by telephone, written, and telephone and written modes of administration (Table 1).

The 36 surveys contained a total of 1,495 EOL items, covering a wide range of issues (range, 4 to 126 items per survey). Some items were duplicated across surveys. For example, 3 pairs of surveys contained identical items ($n = 55$), and an additional survey included items from 5 other surveys ($n = 30$). Of the 1,410 unique EOL items, 333 could be classified in 1 of the 11 topic areas; the remaining items ($n = 1,077$) did not relate to our topic areas and focused mostly on clinical symptoms experienced by the dying person or specific details about the quality of EOL care received. Overall, we found slightly more retrospective items than prospective items (174 vs 159).

Of the 333 EOL items, 260 were classified in the situation ($n = 136$) or attitude ($n = 124$) categories; fewer items were classified in the knowledge and behavior categories (Table 2). The knowledge and situation categories contained items with only 1 perspective (either retrospective or prospective), whereas the attitude and behavior categories included both retrospective and prospective items. The knowledge items elicited information on respondents’ awareness of various EOL options, such as hospice and palliative care, the Medicare hospice benefit, and advance care planning (data not shown). Of the 124 attitude items, 75 fit within the desires topic and examined different expectations the respondent might have for EOL care (eg, where he or she would like to die, types of care desired, use of life-sustaining treatments).

Nearly all of the items in the behavior category were classified in 2 topic areas: completion of an advance directive ($n = 36$ items) and discussion of EOL preferences and options with others ($n = 17$ items). Few items ($n = 4$) focused on specific communications related to advance directives. Finally, of the 136 items in the situation category, 60 fit in the needs topic area, and the remaining items were evenly distributed between the location of death ($n = 24$ items), pain at the end of the patient’s life ($n = 25$ items), and provider communication ($n = 27$ items) topics. The needs items examined various issues, including the degree to which the dying person’s symptoms were controlled and whether spiritual and psychological support was available to the dying person and family members.

Discussion

Once the public health community recognizes the need for surveillance of a particular health issue, developing suitable items for population-based surveys takes time and resources. We conducted an environmental scan to identify and characterize existing survey items that may be appropriate for surveillance of EOL issues. As a result of this process, we have a thorough understanding of current EOL surveys. In particular, we now know the topic areas for which items already exist and those topics that may require the development of new items. Therefore, our approach identified available items, and in some cases, the dearth of items, and is an efficient method to guide the process of developing surveillance items. For example, we could focus on pilot-testing existing items for their suitability for population-based surveillance and direct our limited resources to developing new items in topic areas that lack tested items.

We were able to locate 36 surveys containing EOL items. Ten of the 36 surveys were conducted in individual states, which indicates interest in this issue at the community level. Conversely, given that most deaths occur in hospitals and other health care settings, we were not surprised to find that most of the items (136 of 333) focused on different situational aspects of EOL care, such as where the respondent's loved one died and whether the dying person experienced pain at the end of his or her life. Similarly, more than half of the attitude-related items focused on the respondents' desires and expectations for EOL care, including their wishes for different aspects of EOL care.

We found few items that addressed respondents' knowledge and understanding of EOL options, such as hospice and palliative care. Furthermore, although we found many items related to the completion of advance directives and discussions about EOL preferences, few items asked whether respondents informed health care providers or family members that they had an advance directive. Studies (14,15) indicate that, even when people complete advance directives, these documents may not come to the attention of their health care providers. Surveillance data could be used to inform public health interventions that encourage communication between health care providers, patients, and family members about advance directives.

Implications for public health practice

Surveillance of EOL issues may pose several challenges, some of which are not unique to this topic. For example, as with other sensitive health issues such as mental health or sexual behaviors, there are taboos associated with discussing EOL issues. Other data indicate that adults are more comfortable talking with their children about safe sex than discussing EOL issues with their parents (16). Recognizing these sensitivities when administering EOL items to respondents is necessary.

Another challenge is that EOL issues are usually considered within the context of the health care system. To a certain extent, this association is understandable, but as our prior work (9,11,17) illustrates, there are many ways for public health to contribute in this area. Because EOL issues are commonly associated with the health care system and are relatively new to the public health community, we have long recognized the importance of educating our public health colleagues about the potential roles that we can play in improving EOL experiences. As we move forward, educating our partners about the public health system and the range of activities that are part of public health practice is critical. For this project, we devoted time during our in-person meeting to educate the expert panel members about public health surveillance, including how data are used to inform public health activities and the costs associated with adding items to current surveillance systems. This approach has also been useful in working with partners to develop surveillance measures for other emerging public health concerns, such as cognitive health.

Finally, the current restrictions on the size of a typical surveillance module are another challenge. Current surveillance systems require that sets of questions focusing on a specific issue contain as few items as possible because of the administrative and implementation costs associated with surveillance procedures and to minimize burden on survey participants. Although we sought advice from experts regarding the critical topics for public health surveillance, these topics are not prioritized. A next step will be to use some type of metric to set priorities among the topics and the items within.

The limited size of a typical surveillance module may influence decisions whether to include retrospective or prospective EOL items. Many EOL surveys that focused on the quality of EOL care involved a retrospective or a

mortality follow-back approach in which respondents are asked to provide information on the experiences of a family member or significant other who died within a specified time frame. We abstracted retrospective items that focused on various situational aspects of EOL care (eg, location of death). If we were to include these items on a surveillance module, another 1 or 2 screening items would be necessary to determine whether the respondent experienced the death of a loved one within a specific time frame and was familiar enough with the circumstances during this period to answer the question. Thus, a retrospective approach would have an impact on the total number of EOL items that could be included in the module as well as the number of respondents who could answer questions.

Conversely, a prospective approach may provide a view of EOL issues that complements previous surveys that have focused on this issue from a health care perspective. The entire sample could respond to prospective items, which may examine the respondents' knowledge, expectations, and behaviors with respect to EOL issues. Such data could help elucidate potential cultural differences regarding EOL planning and discussions and inform programs that target specific groups. Furthermore, periodic collection of population-based data on public attitudes and actions related to advance care planning would be useful in detecting potential changes that may occur when EOL issues are the focus of national attention (eg, 2008 National Health Care Decisions day, Terri Schiavo debate).

Conclusions

We introduce a novel approach for identifying potential items for public health surveillance from the universe of existing questions on EOL issues. Using our environmental scan, we identified 333 items related to critical topics for public health surveillance of EOL issues. Information about the surveys and survey items has been placed in a database that summarizes the findings and provides information to others interested in EOL surveillance. In addition, we identified the gaps for which new items may be developed. We plan to ask state coordinators and policy makers for guidance in developing a smaller set of EOL items for cognitive and pilot testing and determining the need for developing new items. If EOL items are included in population-based surveillance systems, they have the potential to yield information that will provide a broader perspective of EOL issues than has been available to date.

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Tables

Table 1. Characteristics of Surveys^a (N = 36), End-of-Life Survey Scan, 2006

Characteristic	Value
Setting (n)	
National	8
State	10
Community	4
Hospital	9
Hospice	4
Nursing Home	1
Sample (n)	
Public	20
Patient group	5
Family members	11
Mode of administration (n)	
In person	14
Telephone	13
Written	8
Telephone and written	1
Total no. of end-of-life survey items	1495 ^b
Items abstracted (n)	333

Characteristic	Value
Response type (no. of survey items)	
Yes/no	133
Multiple choice	111
Rating	37
Likert scale	42
Open-ended	10
Perspective (no. of items)	
Prospective	159
Retrospective	174
Overarching categories (no. of items)	
Knowledge	16
Attitudes	124
Behavior	57
Situation	136

^a Surveys retrieved through searches of the Internet and published and "gray" (articles, technical reports, newsletters, or other documents produced by governmental agencies, academic institutions, and other groups not indexed or distributed by commercial publishers) literature, as well as from experts. The list of 36 surveys is available on request from the authors.

^b Range was 4 to 126 items per survey.

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Table 2. Distribution of 333 End-of-Life (EOL) Items Within Priority Topics for Public Health Surveillance, End-of-Life Survey Scan, 2006

Overarching Category With Subtopic	Definition of Subtopic	Sample Item	Perspective	No. of Items
Knowledge^a (n = 16)				
Awareness	Knowledge or understanding of EOL options	Do you believe you need more information in order to make the best decisions for your EOL care?	Prospective	16
Attitude^b (n = 124)				
Burden	Concerns about being a burden to others	I am concerned about becoming a burden physically or emotionally on my family because of my illness.	Prospective	11
Concerns and Fears	General concerns and fears about death or dying	I am concerned that my life will be inappropriately prolonged by the use of machines.	Prospective	35
		How much, if at all, does each of these medical matters worry you when you think about your death? The possibility of great physical pain before you die	Retrospective	3
Desires	Expectations about EOL care	How important would each of the following be to you when dealing with your own dying? [Choosing your treatment options]	Prospective	65
		Did [the patient] have specific wishes or plans about the types of medical treatment (he/she) wanted while dying?	Retrospective	10
Behavior^c (n = 57)				
Communications	Communication with health care provider or family members about advance directive	Who, if anyone, have you told that you have signed either or both of these documents?	Prospective	2
		Had you or [the patient] discussed a living will or durable power of attorney for health care with a doctor caring for [the patient]?	Retrospective	2
Completed an advance directive	Completion of advance directives, living will, or durable power of attorney	Can you tell us why you do not have a living will?	Prospective	18
		Do you have written instructions about the type of medical treatment you would want to receive if you were unconscious or somehow unable to communicate?	Retrospective	18
Discuss EOL	Discussion of end-of-life preferences and options with others	Have you ever discussed with your doctor how you would want to be treated if you were dying?	Prospective	12
		Did you or [the patient] and the hospice team make a plan to ensure that any wishes [the patient] had for medical care were followed?	Retrospective	5
Situation^d (n = 136)				
Location	Location of death of loved one	During the last 3 months this person was alive, did he/she receive care through a hospice?	Retrospective	24
Needs	How well was this person's needs met	Were any of the prescribed pain medications that this person was supposed to use difficult to obtain at a local pharmacy?	Retrospective	60

^a Overarching category that involved questions about respondent's understanding.

^b Overarching category that involved questions about respondent's beliefs.

^c Overarching category that involved questions about respondent's actions.

^d Overarching category that involved questions about respondent's perceptions during death of loved one.

(Continued on next page)

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Table 2. (continued) Distribution of 333 End-of-Life (EOL) Items Within Priority Topics for Public Health Surveillance, End-of-Life Survey Scan, 2006

Overarching Category With Subtopic	Definition of Subtopic	Sample Item	Perspective	No. of Items
Situation^d (n = 136) (continued)				
Pain	Experience of pain at the end of patient's life	During [the patient's] last month of life, how much of the time did [the patient] experience pain?	Retrospective	25
Provider	Health care provider communication with dying person or family members	How often were you and [the patient] able to talk to doctors and others who took care of [the patient] when you needed to?	Retrospective	27

^a Overarching category that involved questions about respondent's understanding.

^b Overarching category that involved questions about respondent's beliefs.

^c Overarching category that involved questions about respondent's actions.

^d Overarching category that involved questions about respondent's perceptions during death of loved one.

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