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How Much Do Health Literacy and Patient Activation Contribute to Older Adults' Ability to Manage Their Health?

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The AARP Public Policy Institute, formed in 1985, is part of the Policy and Strategy Group at AARP. One of the missions of the Institute is to foster research and analysis on public policy issues of importance to mid-life and older Americans. This publication represents part of that effort.

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Foreword

During the past several years, the Medicare program has published information designed to help people on Medicare make well-informed decisions about their health care and coverage options. Two widely used sources of Medicare information—the Medicare website (www.medicare.gov) and the *Medicare Handbook*—use graphic, narrative, and tabular formats to present information to consumers. The information compares the clinical effectiveness and customer service of Medicare Advantage plans and the costs and benefits of Medicare health plans and also describes covered services. In addition, patients with chronic conditions who partner with their clinicians and engage in self-management of their conditions tend to experience better outcomes. Understanding the importance of their Medicare choices and actively participating in one's care require an individual to have good literacy and health literacy skills.

Because the Medicare population is diverse and the range of health literacy skills and patient activation (i.e., having the knowledge and skill to self-manage) is wide, targeted interventions might help people on Medicare make better use of their health care services. The purpose of this research is to understand the relationship of health literacy and patient activation to Medicare decision making and beneficiaries' adherence to healthy behaviors, such as pursuing regular exercise and a healthy diet, being aware of one's cholesterol and blood pressure levels, and actively participating in physician visits.

AARP engaged the authors to determine the relationships among certain variables so that Medicare counselors, information intermediaries, clinicians, and others can improve their education strategies by providing appropriate, skill-related interventions to Medicare patients on the basis of their health literacy and level of patient activation. We believe this is the first study to assess these relationships.

The study finds that health literacy and patient activation are both important and, in general, influence different outcomes. The Medicare program itself and organizations such as AARP design and develop information to help Medicare beneficiaries make informed choices about how to use their benefits. Organizations must strive to offer materials that teach people on Medicare how to become active participants in their health care. In addition, because it is not realistic to expect that improvement in health literacy can be achieved in the short term, for those with inadequate or marginal skills, the challenge is to design formats that take their needs into account. The findings from this study are timely, as the Medicare Prescription Drug, Modernization, and Improvement Act will require a massive educational effort to help orient people on Medicare to the program's new features, including the prescription drug benefit and the private health plan models that will soon be available.

As Medicare beneficiaries are asked to take more responsibility for the choices they make, it is essential that they have valid, reliable, and easy to understand information to help them do so.

Joyce Dubow Associate Director AARP Public Policy Institute June 2005

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Executive Summary

Background

Health care policy increasingly relies on informed and engaged consumers to control health care costs and improve quality. The core initiatives of the landmark Medicare Prescription Drug, Improvement and Modernization Act of 2003 (MMA) are emblematic of this approach. Notably, the law's prescription drug benefit will require beneficiaries to decide among private prescription drug plans that vary in terms of comprehensiveness, cost, and formularies. Beneficiaries will also have to weigh the costs and benefits of enrolling in the program during the initial start-up period or facing financial penalties if they enroll later. In addition, the MMA includes provisions that will require Medicare beneficiaries to be well-informed about their coverage and treatment options.

Older persons are increasingly expected to make complex health care decisions and take more responsibility for their health care, but it is questionable whether all are capable of the tasks associated with this greater responsibility. National studies have found that older adults have lower literacy and patient activation levels than younger adults. (The term "health literacy" includes skills that encompass the ability to process and understand basic information needed to make appropriate health decisions. The term "patient activation" refers to having the knowledge, skills, beliefs, and confidence to manage one's health.) There is increasing evidence that literacy—in particular, health literacy—and patient activation are related to how well patients understand and manage their health and health care.

Purpose

This study examines the independent influence of health literacy and patient activation in areas in which older adults must have skill or knowledge to manage their health and health care. These areas include Medicare decision making, health-care-related behaviors, healthy behaviors, and chronic disease self-management behaviors. The examination of health literacy and patient activation and their relative contribution to health-related behaviors and health care choices will inform the types of strategies that are likely to be most effective in supporting consumer engagement.

Methodology

The data for this study were collected in spring 2004 from a convenience sample of 293 Medicare beneficiaries age 65 years or older in Eugene/Springfield, Oregon. Subjects first completed the short form of the Test of Functional Health Literacy in Adults (S-TOFHLA) to assess their health literacy. A trained interviewer then administered a questionnaire that included the new Patient Activation Measure (PAM) and questions related to Medicare decision making, health-care-related behaviors, healthy behaviors, and chronic illness self-management. The relationships between the independent variables (health literacy and patient activation) and the dependent measures were examined in bivariate and multivariate models.

Principal Findings

Compared with a national sample of non-institutionalized Medicare beneficiaries age 65 years and older, study participants are older, although they are in better health and have more education. Their health literacy and patient activation levels indicate a relatively high-functioning population.

The analysis indicates that both health literacy and patient activation are significantly and positively related to Medicare decision making and engagement in health-care-related behaviors, healthy behaviors, and chronic disease self-management behaviors. Health literacy, however, appears to have a stronger relationship to Medicare decision making than does patient activation. On the other hand, patient activation has slightly stronger relationships to health-care-related behaviors, healthy behaviors, and self-management behaviors.

In analyses controlling for the influence of age, education, and patient activation, health literacy retains its relationship with some, but not all, outcomes. The relationships between health literacy and the two Medicare decision making outcomes (i.e., confidence in decision making and the ability to use comparative information to make decisions) remain strong. Those with "barely adequate" health literacy have significantly lower levels of decision-making confidence and ability to use comparative information to make health plan choices than those with "adequate" health literacy. Those with "marginal/inadequate" health literacy have even lower levels ability. Health literacy predicts health-care-related behaviors; however, it is associated with only two of the nine healthy and self-management behaviors in multivariate models. (See Table 1.)

Controlling for health literacy, age, and education does not substantively affect the pattern of association between patient activation and the dependent variables. Patient activation is most strongly and positively associated with health-care-related behaviors, taking chronic illness medications as recommended, and knowing what blood pressure level the doctor recommends. Patient activation also predicts all the other healthy and self-management behaviors.

Conclusion

This study is the first, to our knowledge, to examine the relative contributions of health literacy and patient activation on the skills and behaviors that older adults need to effectively manage their health. We find that both patient activation and health literacy are important for older adults; however, the two factors affect different health-related outcomes. Health literacy positively influences Medicare decision making, both one's confidence to make decisions and one's ability to use comparative information to effectively do so. Patient activation, on the other hand, has a greater influence on one's engagement in health-care-related, healthy, and chronic illness self-management behaviors. Interventions that focus on improving patient activation will encourage better health-care-related, healthy, and self-management behaviors; those aimed at addressing literacy or the readability of materials will help older adults make sound Medicare decisions. Much work remains to be done to develop and test effective interventions for improving health literacy and patient activation. This study underscores the importance of such future efforts.

How Much Do Health Literacy and Patient Activation Contribute to Older Adults' Ability to Manage Their Health?

Background

To control health care costs and improve quality, health care policy increasingly relies on consumers to be informed and engaged. The core initiatives of the landmark Medicare Prescription Drug, Improvement and Modernization Act of 2003 (MMA) are emblematic of this approach. Under the MMA's temporary discount drug card program, Medicare beneficiaries must compare card fees, drug costs, and pharmacies to determine whether they want to participate in the program and, if so, which card to select. The MMA prescription drug benefit, which begins in January 2006, will require beneficiaries to decide among private prescription drug plans that vary in terms of comprehensiveness, cost, and formularies, and to weigh the costs and benefits of enrolling in the program during the start-up period or paying financial penalties for enrolling later.

High-quality care for chronic illness relies on informed, activated consumers. The importance of patients' role in self-managing chronic illness—including making daily decisions about medication, exercise, and diet—is increasingly becoming recognized.^{1, 2} The MMA includes provisions to improve chronic illness care through the use of disease management programs.³ These programs, run by health plans and disease management organizations, are specifically intended to educate beneficiaries with severe chronic conditions on how to self-manage their conditions.

While older persons are increasingly expected to make complex health care decisions and play a larger role in directing their own health care, it is questionable whether all are capable of the tasks associated with this greater responsibility. A national survey in 1992 found that low literacy is widespread in the United States, particularly among older respondents.⁴ Over half of respondents age 65 years and older were unable to correctly locate an intersection on a street map or enter personal information on an application. Health literacy skills, which encompass the ability to process and understand basic information needed to make appropriate health decisions,⁵ are strongly associated with health-related outcomes. Those with poor health literacy skills are less knowledgeable about health,^{6–8} receive less preventive care,⁹ have worse chronic illness control,¹⁰ and have higher emergency department and hospital utilization.^{11, 12}

Another factor that may hinder consumers' ability to take more responsibility for health care is their level of activation, which means the knowledge, skills, beliefs, and confidence to manage one's health.¹³ Patient activation levels, which predict health outcomes such as preventive behaviors, are lower among older adults. The related concept of self-efficacy (which refers to having the confidence to undertake a specific health-related task) is positively correlated with effective disease self-management and negatively related to hospital utilization rates.^{2, 14}

To date, research on the health-related effects of patient activation and health literacy have been conducted separately, although it has been suggested that a connection exists.¹⁵ It is possible that health literacy levels influence health outcomes indirectly, through patient activation, in which

case policies aimed at improving literacy would also boost patient activation. However, another possibility is that health literacy and patient activation separately influence health outcomes; in this case, interventions to raise both activation and literacy levels would be required to influence health outcomes.

Purpose

This study examines the relationship between health literacy and patient activation and investigates the influence of each on the various areas in which older adults must have skill or knowledge to manage their health or health care. These areas include Medicare decision making, health-care-related behaviors, healthy behaviors, and chronic disease self-management behaviors; they are described more fully in the next section. The examination of health literacy and patient activation and their effect on health care choices and health and health-care-related behaviors will inform the types of strategies that are likely to be most effective in supporting consumer engagement.

Methodology

The data for this study were collected from a convenience sample of 293 Medicare beneficiaries age 65 years or older in Eugene/Springfield, Oregon. Recruitment and data collection took place during the spring of 2004 at community senior centers; thus, homebound and institutionalized beneficiaries were excluded from the sample. Participation required reading, so it is likely that those with the lowest literacy skills may have chosen not to participate in the study. Participation took approximately 45 minutes. Subjects first completed a health literacy assessment and then a questionnaire that included sociodemographic measures and other measures described below. (The questionnaire was orally administered by trained research staff.) Research subjects were paid for their participation.

Measures

The primary independent variables in this study are health literacy and patient activation. We assessed health literacy using the 14-point font version of the short form of the Test of Functional Health Literacy in Adults (S-TOFHLA), which has been described in detail elsewhere.¹⁶ In brief, the S-TOFHLA tests reading comprehension using health-related passages and the ability to follow instructions on prescription bottles and appointment slips. It is highly correlated with other reading tests, such as the Rapid Estimate of Adult Literacy in Medicine.¹⁶

Respondents' activation levels were assessed using the Patient Activation Measure (PAM) (Appendix A).¹³ This new 22-item patient-reported measure is a unidimensional, probabilistic Guttman-like scale that reflects a developmental model of activation across four stages: (1) believing the patient role is important; (2) having the necessary confidence and knowledge to take action; (2) taking action to maintain and improve one's health; and (4) staying the course even under stress. A slightly different version of the PAM was administered to respondents who reported having a chronic condition.

The study examines the impact of health literacy and activation on the following self-reported sets of dependent variables: (1) Medicare decision making; (2) health-care-related behaviors; (3) healthy behaviors; and (4) chronic illness self-management. We used two measures of Medicare decision making. The first is a five-item index that assesses respondents' level of confidence in making Medicare-related decisions; the index has strong reliability (Chronbach's alpha = 0.82). The items, which use a four-point Likert-type response scale, are detailed in table 1. The second measure tests respondents' ability to use comparative information to make Medicare decisions. Respondents are asked to compare five health plans on the basis of information about two quality attributes (how well doctors communicate and overall member satisfaction with the plan) and three cost attributes (monthly premiums and prescription and office visit co-pays) (see Appendix B).¹⁷ This task is similar to the type of comparisons Medicare recipients make in deciding among managed care plans and the comparisons they will make in the future among prescription drug plans. The plans in this assessment have a clear rank order, with the top plan having the highest scores on both measures and the lowest costs, so no trade-offs are required. Thus, the assessment task is easier than the comparisons most beneficiaries will have to perform in real life.

| | Mean (n=293) | SD |
|--|-----------------|------|
| Confidence in Medicare Decision-Making Index Items (Chronbach's $alpha=0.82$) (Range = 1-4) | · · · / | |
| I prefer not to have the responsibility for making decisions about my Medicare. | 1.90 | 0.81 |
| When it comes to making decisions about my Medicare, I prefer to have someone knowledgeable decide for me. | 2.32 | 0.86 |
| I have difficulty understanding the information about my Medicare coverage. | 2.30 | 0.74 |
| Whenever I make a choice about my Medicare, I worry it will be the wrong one. | 2.07 | 0.73 |
| I am more likely to make a wrong choice if I have lots of different options to choose from. | 2.28 | 0.72 |
| Using Comparative Information to Make Medicare Decisions (Range = $0-2$) | | |
| Number of questions out of two answered correctly (see Appendix B) | 1.53 | 0.75 |
| Health-Care-Related Behaviors Index (Chronbach's alpha= 0.69)(Range = $1-4$) | | |
| Likelihood of seeking out information to learn about how to cope with health problems.* | 3.48 | 0.60 |
| Likelihood of bringing a list of questions and/or issues you want to cover to your doctor visit.* | 3.47 | 0.69 |
| Likelihood of reading about possible complications when your doctor prescribes a new medication for you.* | 3.48 | 0.75 |
| When I do not understand, I am persistent in asking my doctor to explain something until I understand it. | 3.26 | 0.62 |
| Before I go to a new health care provider, I find out as much as I can about his or her qualifications | 3.01 | 0.74 |
| Healthy Behaviors (Range = $1-4$) | | |
| I exercise on a regular basis. | 3.05 | 0.81 |
| I know what my recommended healthy cholesterol level should be. | 2.94 | 0.73 |
| I usually do not pay much attention to how much fat is in my diet. | 2.06 | 0.86 |
| Over the past 4 weeks, I ate at least 5 servings of fruits or vegetables a day. | 2.84 | 0.84 |
| Chronic Disease Self-Management Behaviors (Range = $1-4$) | | |
| I always take my blood pressure/cholesterol lowering/heart medication as my doctor has recommended. (n=191) | 3.52 | 0.58 |
| I keep a written diary of my blood pressure readings. (n=159) | 2.64 | 0.89 |
| I know what blood pressure my doctor would like to see me have. (n=160) | 3.22 | 0.61 |
| I do regular exercises to help manage my arthritis. (n=147) | 2.88 | 0.78 |
| I have a personal plan that helps me manage my arthritis pain. (n=151) Il items used a four-point Likert-type index. For most items, the index was 1=strong | 2.79 | 0.72 |

Table 1. Description of Outcome Measures

All items used a four-point Likert-type index. For most items, the index was 1=strongly disagree, 2=disagree, 3=agree, 4=strongly agree. For those items with an asterisk (*), the scale was 1=very unlikely, 2=unlikely, 3=likely, 4=very likely.

The index of health-care-related behaviors includes five items related to how proactive patients are about working with the health care system (Chronbach's alpha = 0.69). We used items that assess chronic illness self-management and healthy behaviors separately rather than in two summary indices, because (like other authors¹⁸) we found that these tasks were not highly correlated with one another. We asked all respondents about four healthy behaviors; chronic illness self-management questions were disease-specific—two for arthritis, two for high blood pressure, and one for respondents who actually had high blood pressure, high cholesterol, or heart disease.

Analytic Strategy

The sample was first characterized with respect to demographics, health status, health literacy level, and patient activation. Bivariate associations between the independent variables (health literacy and patient activation) and the dependent measures were examined. Then, holding age and education constant, we conducted multivariate regression models for each dependent variable. The variables were entered in the multivariate models in the following order: age, education, health literacy, and patient activation. The R-square change statistic enabled us to determine how much of the variation in the dependent variables could be attributed specifically to health literacy and patient activation. Subsequent analyses examined interactions between health literacy and patient activation to investigate whether a combination of the two resulted in additional impact on the dependent variables. As no interaction terms were significant, they are not reported here.

Many authors have categorized S-TOFHLA scores into three levels: adequate, marginal, and inadequate health literacy. However, our study population is higher functioning than the general Medicare population, so fewer respondents have inadequate health literacy. Therefore, we opted to combine respondents with marginal and inadequate health literacy into one category. Because the conventional range for adequate health literacy is quite large (67–100) and a substantial percentage of our respondents scored in this range, we divided those with adequate health literacy scores into two categories: above and below 90. We found that this three-category approach—inadequate/marginal (0–66); barely adequate (67–89); adequate (90–100)—increased predictive power over models that used the S-TOFHLA score either as continuous or dichotomous with most dependent variables. For bivariate analysis using patient activation, we categorized the PAM into high (56.8+), medium (52.0–56.8), and low (0–52.0) levels based on terciles derived from a national sample of 508 adults age 65 or older.²⁴ In multivariate analysis, the PAM was used in continuous form.

Principal Findings

The study participants range in age from 65 to 97 years; the average is 76 years. They are overwhelmingly women (69%); most report being in "excellent" or "very good" health (52%); and almost half have household incomes below \$15,000 (table 2). Compared with a national sample of noninstitutionalized Medicare beneficiaries age 65 years and older from the Medicare Current Beneficiary Survey, study participants are older, are in better health, and have more education. Study participants' health literacy and patient activation levels indicate a high-functioning population. Only 14 percent have inadequate or marginal health literacy scores.

While there are no S-TOFHLA rates from national samples, studies of new Medicare managed care enrollees in several cities have found rates of inadequate and marginal literacy ranging from 31 percent to 36 percent.^{9, 11} Only 10 percent of our study population fell into the low patient activation category, compared with a third of older adults nationally.

| Variables | Percentage (n=293) |
|----------------------------------|-----------------------|
| Demographics | (11 2)() |
| Age | |
| 65 to 74 | 38.2 |
| 75 to 84 | 52.9 |
| 85 or more | 8.9 |
| Education | |
| Less than high school | 10.2 |
| High school diploma | 27.6 |
| Some college/vocational school | 34.5 |
| College graduate or more | 27.6 |
| Gender | |
| Female | 68.9 |
| Marital Status | |
| Married | 33.9 |
| Household Income | |
| Less than \$15,000 | 47.5 |
| \$15,000 to \$24,999 | 27.1 |
| \$25,000 to \$34,999 | 11.8 |
| \$35,000 or more | 13.6 |
| Self-Rated Health | |
| Excellent/very good | 52.2 |
| Good | 31.1 |
| Fair/poor | 16.7 |
| Chronic Conditions | |
| 0 | 9.9 |
| 1–2 | 39.2 |
| 3+ | 50.9 |
| Patient Activation Measure (PAM) | |
| Low | 10.2 |
| Medium | 28.7 |
| High | 61.1 |
| Health Literacy (S-TOFHLA) | |
| Inadequate/marginal | 13.3 |
| Barely adequate | 26.6 |
| Adequate | 60.1 |

Table 2. Characteristics of Sample

In bivariate analysis, both health literacy and patient activation exhibit significant positive relationships with almost all the dependent variables (tables 3 and 4). In other words, the higher one's level of health literacy or patient activation, the more likely one is to report confidence in Medicare decision making and engagement in health-care-related behaviors, healthy behaviors, and chronic disease self-management behaviors. Health literacy, however, appears more strongly related to Medicare decision making than patient activation is. Only health literacy is predictive of one's ability to use comparative information to make Medicare decisions, and it appears to have a slightly stronger relationship to confidence in decision making than patient activation does (the difference in mean confidence level in those with high and low health literacy is 0.6 points; the difference for high and low patient activation is 0.4 points).

Patient activation shows a slightly stronger relationship to health-care-related, healthy, and selfmanagement behaviors than does health literacy. The two independent variables are also found to be associated with one another. Those with adequate health literacy levels have PAM scores that average 3.5 points higher than those with barely adequate PAM scores, and 7 points higher than those with inadequate/marginal health literacy levels (table 3).

| Patient Activation and Dependent Variables | Mean of Values by Health Literacy Level | | | |
|--|--|------------------------------|------------------|--|
| | Inadequate / Marginal (n=39) | Barely Adequate (n=78) | Adequate (n=176) | |
| Patient Activation (Range = $0-100$) | 57.3 | 60.8 | 64.2*** | |
| Medicare Decision Making (Range = $1-4$) | | | | |
| Confidence in Medicare decision making | 2.4 | 2.6 | 3.0*** | |
| Using comparative information to make Medicare decisions | 1.1 | 1.3 | 1.7*** | |
| <i>Health-Care-Related Behaviors</i> ($Range = 1-4$) | 3.0 | 3.4 | 3.4*** | |
| Healthy Behaviors (Range = $1-4$) | | | | |
| Exercise regularly | 2.7 | 2.9 | 3.2** | |
| Know recommended cholesterol level | 2.5 | 2.9 | 3.1*** | |
| Usually pay attention to fat in diet | 2.6 | 2.9 | 3.1** | |
| Eat at least 5 servings of fruits or vegetables a day | 2.6 | 2.8 | 2.9 | |
| Chronic Disease Self-Management Behaviors (Range = $1-4$) | | | | |
| Take chronic illness medications as recommended | 3.3 | 3.4 | 3.6* | |
| Keep written diary of blood pressure readings | 2.7 | 2.7 | 2.6 | |
| Know what blood pressure doctor would like me to have | 2.9 | 3.1 | 3.3* | |
| Do regular exercises to help manage my arthritis | 2.4 | 2.7 | 3.1** | |
| Have personal plan that helps me manage my arthritis pain | 2.5 | 2.7 | 2.9* | |

Table 3. Bivariate Relationships Between Health Literacy and Patient Activation and the Dependent Measures

*p<0.05, **p<0.01, ***p<0.001. ANOVA test of differences of means among respondents with inadequate/marginal, barely adequate, and adequate health literacy levels.

^a Sample sizes for chronic disease questions vary from 147 to 191 (see table 1).

| Dependent Variables | Mean of Values by Patient Activation Level | | | | |
|---|---|--------|---------|--|--|
| | Low | Medium | High | | |
| | (n=30) | (n=84) | (n=179) | | |
| | | | | | |
| Medicare Decision Making | | | | | |
| Confidence in Medicare decision making | 2.5 | 2.7 | 2.9*** | | |
| Using comparative information to make Medicare decisions | 1.5 | 1.5 | 1.6 | | |
| Health-Care-Related Behaviors | 2.9 | 3.2 | 3.5*** | | |
| Healthy Behaviors | | | | | |
| Exercise regularly | 2.6 | 2.9 | 3.2*** | | |
| Know recommended cholesterol level | 2.4 | 2.8 | 3.1*** | | |
| Usually pay attention to fat in diet | 2.6 | 2.9 | 3.0* | | |
| Eat at least 5 servings of fruits or vegetables a day | 2.3 | 2.6 | 3.1*** | | |
| Chronic Disease Self-Management Behaviors | | | | | |
| Take chronic illness medications as recommended | 3.1 | 3.3 | 3.7*** | | |
| Keep written diary of blood pressure readings | 2.5 | 2.5 | 2.7 | | |
| Know what blood pressure doctor would like me to have | 2.9 | 3.0 | 3.4*** | | |
| Do regular exercises to help manage my arthritis | 2.6 | 2.7 | 3.1* | | |
| Have personal plan that helps me manage my arthritis pain | 2.4 | 2.7 | 2.9* | | |

Table 4. Bivariate Relationships Between Patient Activation and the Dependent Measures

*p<0.05, ***p<0.001. ANOVA test of differences of means among respondents with low, medium, and high patient activation.

In analyses controlling for the influence of age, education, and patient activation, health literacy retains its relationship with some, but not all, outcomes (tables 5–7). The relationships between health literacy and the two Medicare decision-making outcomes remain strong, with R-square change values of 0.068–0.086. Those with barely adequate health literacy have significantly lower levels of decision-making confidence and ability to use comparative information to make health plan choices than those with adequate health literacy, and those with marginal/inadequate health literacy have even lower levels. Health literacy remains predictive of health-care-related behaviors; however, it is associated with only two of the nine healthy and self-management behaviors in multivariate models. This reduced influence was the result of controlling for differences in age and education rather than from patient activation.

Table 5. Key Coefficients from Linear Regression Models Predicting Medicare Decision Making^a

(n=291)

| | Confidence Decision | in Medicare Making | Using Comparative Information to Make Medicare Decisions | | |
|------------------------------|------------------------|-----------------------|--|-----------------------|--|
| | Coefficient | R ² Change | Coefficient | R ² Change | |
| Patient Activation | 0.01*** | 0.053 | 0.00 | 0.001 | |
| Health Literacy | | 0.086 | | 0.068 | |
| Marginal/inadequate | -0.43*** | | -0.55*** | | |
| Barely adequate | -0.27*** | | -0.37*** | | |
| Adequate (reference group) | | | | | |
| Full Model Adjusted R-square | 0.2 | 242 | 0.104 | | |

***p<.001 ^aAll models adjust for education and age. Dashes indicate not applicable

Table 6. Key Coefficients from Linear Regression Models Predicting Health-Care-Related and Healthy Behaviors^a

| | | | | | Healthy Behaviors | | | | | | |
|--------------------|--------------|----------------|-------------|----------------|-------------------|------------------------------|---------------------|-----------------|-----------------------|----------------|--|
| | | | | | Know | | Usually Pay | | Eat At Least 5 | | |
| | Health-Care- | | | | Recommended | | Attention to Fat in | | Servings of Fruits or | | |
| | Related Be | haviors | Exercise Re | egularly | Cholestero | Cholesterol Level (n=288) | | Diet (n=292) | | s a Day | |
| | (n=29 | 2) | (n=29 | 2) | (n=28 | | | | | 92) | |
| | | \mathbf{R}^2 | | \mathbf{R}^2 | | R^2 | | | | | |
| | Coefficien | Chang | Coefficien | Chang | Coefficien | Chang | Coefficie | \mathbf{R}^2 | Coefficien | \mathbb{R}^2 | |
| | t | e | t | e | t | e | nt | Change | t | Change | |
| Patient Activation | 0.02 *** | 0.174 | 0.02 *** | 0.070 | 0.02** | 0.094 | 0.01** | 0.029 | 0.03 *** | 0.109 | |
| Health Literacy | | 0.080 | | 0.013 | | 0.044 | | 0.010 | | 0.013 | |
| Marginal/ | -0.33 *** | | -0.17 | | -0.41 ** | | -0.20 | | -0.16 | | |
| inadequate | | | | | | | | | | | |
| Barely | 0.00 | | -0.08 | | -0.07 | | -0.07 | | -0.03 | | |
| adequate | | | | | | | | | | | |
| Adequate | | | | | | | | | | | |
| (reference | | | | | | | | | | | |
| group) | | | | | | | | | | | |
| Full Model | 0.289 | | 0.160 | | 0.163 | | 0.088 | | 0.129 | | |
| Adjusted R-square | | | | | | | | | | | |

p<.01, *p<.001 ^a Models all adjust for education and age. --Dashes indicate not applicable.

Table 7. Key Coefficients from Linear Regression Models Predicting Chronic Disease Self-Management Behaviors^a

| | Take Chronic Illness Medications as Recommended ^b (n=190) | | Keep Writte of Blood P Readin (n=15 | ressure ngs | Know Wha Pressure I Would Lik Hav (n=15 | Doctor e Me to e | Do Re Exercises Manag Arthr (n=1 | to Help e My ritis | Have Pe Plan That Me Mana Arthritis (n=15 | t Helps age My s Pain |
|---------------------------------|---|--------------------------|--|--------------------------|---|--------------------------|--|--------------------------|---|-----------------------------|
| | Coefficien t | R ² change | Coefficien t | R ² change | Coefficien t | R ² change | Coefficie nt | R ² change | Coefficie nt | R ² change |
| Patient Activation | 0.02*** | 0.121 | 0.03*** | 0.076 | 0.02*** | 0.122 | 0.02** | 0.048 | 0.02** | 0.074 |
| Health Literacy | | 0.024 | | 0.008 | | 0.048 | | 0.065 | | 0.018 |
| Marginal/inadequ ate | -0.09 | | 0.37 | | -0.27 | | -0.54* | | -0.13 | |
| Barely adequate | -0.14 | | 0.19 | | -0.15 | | -0.21 | | -0.08 | |
| Adequate (reference group) | | | | | | | | | | |
| Full Model Adjusted R-square | 0.160 | | 0.084 | | 0.190 | | 0.141 | | 0.133 | |

p<0.01, *p<0.001
^a All models adjust for education and age.
^b Specifically, heart disease, blood pressure, or cholesterol-lowering medications.

--Dashes indicate not applicable

In contrast, controlling for health literacy, age, and education does not substantively affect the pattern of association between patient activation and the dependent variables. Patient activation is most strongly and positively associated with health-care-related behaviors (R-square change = 0.172) and taking chronic illness medications as recommended (R-square change = 0.120). It also predicts all the other healthy and self-management behaviors. Ironically, although those with high activation levels are more confident about making Medicare decisions, they are no more capable of using comparative data to make informed choices than are those with lower activation levels.

Conclusion

The study shows that patient activation and health literacy positively influence the skills and behaviors older adults need to effectively manage their health. We found that the two factors affect different health-related outcomes. Health literacy positively influences Medicare decision making, both one's confidence to make decisions and one's ability to use comparative information to effectively do so. Patient activation, on the other hand, has a greater influence on one's engagement in health-care-related, healthy, and chronic illness self-management behaviors.

While both decision making and engaging in health-related behaviors require the ability to acquire and process information, health-related behaviors require individuals to go beyond understanding what to do. They must also believe in the impact of their actions and be committed to managing their health. It is logical, therefore, that patient activation, which includes having the knowledge, skills, beliefs, and confidence to manage one's health, would be a strong predictor of these behaviors. Health literacy's minimal influence on these outcomes (which include eating healthfully and taking medications as recommended) may be due to the fact that people can learn about these things from many sources, such as providers, television, and written materials, and these messages may be easier to understand than the typical documents describing Medicare options. Medicare decision making, on the other hand, is highly influenced by health literacy, probably because it requires people to derive and synthesize information from complex documents. According to the National Adult Literacy Survey, compared with other literacy-related skills, older adults have less ability than their younger counterparts to interpret written information that requires these skills.⁴

Understanding the relative contributions of health literacy and patient activation to the behaviors and skills older adults need to manage their health is critical to designing targeted and effective interventions. For example, policymakers will have to address the issue of low health literacy if older adults are to make informed choices about the Medicare prescription drug benefit. Improving health literacy levels among older adults may be difficult, because deficits in health literacy are likely due in part to cognitive decline.¹⁹ A more pragmatic approach is to focus on effective ways to communicate complex health information to those with poor reading skills and health literacy, and provide more intensive assistance to those with the greatest need.

The manner in which information is presented can have a large impact on how useful it is and the quality of the decisions based on it.^{20, 21} For example, the use of visual cues and other methods to summarize and interpret information, to make it more "evaluable," has been shown to help those

with lower skills.²² Use of videotapes and easy-to-read brochures has also been found to improve comprehension for those with poor reading skills.¹⁵ Because those with lower skills are no more likely to seek help for Medicare decision making than those with higher skills,²³ a recently developed simple health literacy screening tool consisting of age, education, and self-reported health may provide an easy and effective way to identify those most in need of assistance.²⁴

To improve health-related behaviors, patient activation rather than health literacy should be targeted. While programs to improve patient activation are in their infancy, there is reason to believe such programs can be effective. For example, layperson-led self-management training programs that build skills, share experiences, and provide support have been found to improve patient self-efficacy and reduce hospital utilization.² There is also emerging evidence that health care providers can play a role in increasing patient confidence in managing their health conditions.²⁵ More research is needed to develop and test interventions aimed at improving patient activation and, thus, health-related behaviors.

Work is also needed to refine methods for measuring health literacy. Most studies have treated health literacy as having an impact at specific threshold levels rather than a linear influence. While this study confirms that health literacy is more predictive when modeled using threshold levels, we found that those at the low end of what has generally been considered adequate health literacy (which we have labeled "barely adequate") have significantly less confidence in decision making and ability to use comparative information for decision making than do those at the higher end. For example, only 51 percent of those with barely adequate health literacy were able to correctly select the top two health plans from comparative data, while 80 percent of those with scores of 90 or above on the S-TOFHLA were able to do so. It may be the difficulty of decision making that separates those at the high and low ends of what has conventionally been considered adequate health literacy. Testing threshold levels should be explored in future studies.

Several limitations to this study should be noted. First, the convenience sample in the study is significantly higher functioning than the general Medicare population. While this raises the question of generalizability of the findings, the study does not focus on absolute levels of any measure, and our findings are similar to those found in studies that have examined the effects of health literacy and patient activation separately. Although the sample is higher skilled than the national population, one-third were unable to choose the two best and cheapest health plans in a basic comparative task. This finding underscores the difficulty older adults have in using comparative data to make decisions. Second, the outcome measures in this study are all based on self-report and, therefore, subject to the usual caveats, including social desirability bias. Finally, the study's cross-sectional design does not allow us to make causal inferences. Studies that follow participants over time should be conducted to test whether the relationships observed in this study are causal.

Despite these limitations, this study is the first, to our knowledge, to examine the relative contributions of two factors important to consumers' ability to effectively manage their health. The study finds that patient activation and health literacy are both important factors for older adults, although they influence different outcomes. Health literacy concerns must be addressed for older adults to make sound Medicare decisions; while interventions that focus on improving patient activation will encourage better health-care-related, healthy, and self-management behaviors. Much work remains to be done to develop and test effective interventions for improving both health literacy and patient activation, and this study underscores the importance of such future efforts.

Appendix A. Patient Activation Measure

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I will read some statements that people sometimes make when they talk about their health. Please tell me how much you agree or disagree with each statement as it applies to you personally. If the statement does not apply to you, just let me know and we will move on to the next one.

Q1. Taking an active role in my own health care is the most important factor in determining my health and ability to function.

- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable
- Q2. I know how to prevent further problems with my health condition.
- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable
- Q3. I know what each of my prescribed medications does.
- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable
- Q4. I understand the nature and causes of my health condition(s).
- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable
- Q5. I am confident that I can follow through on medical treatments I need to do at home
- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable

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Q6. I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition.

- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable

Q7. I am confident that I can follow through on medical recommendations my health care provider makes, such as changing my diet or doing regular exercise.

- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable

Q8. I am able to handle symptoms of my health condition on my own at home.

- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable

Q9. I have made the changes in my lifestyle, like diet and exercise, that are recommended for my health condition.

- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable

Q10. I have been able to maintain the lifestyle changes for my health that I have made.

- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable

Q11. I am confident that I can figure out solutions when new situations or problems arise with my health condition.

- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable

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Q12.Maintaining the lifestyle changes that are recommended for my health condition is too hard to do on a daily basis.

- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable

Q13. I know the lifestyle changes, like diet and exercise, that are recommended for my health condition.

- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable

Q14. I am confident that I can tell my health care provider concerns I have, even when he or she does not ask.

- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable
- Q15. I know about the self-treatments for my health condition.
- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable

Q16. I am able to handle problems of my health condition on my own at home.

- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable
- Q17. I know the different medical treatment options available for my health condition.
- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable

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Q18. I am confident that I can find trustworthy sources of information about my health condition and my health choices.

- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable

Q19. I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself.

- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable

Q20. I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress.

- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable

Q21. I am confident that I can keep my health problems from interfering with the things I want to do.

- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable

Q22. When all is said and done, I am the person who is responsible for managing my health condition.

- 1 Disagree strongly
- 2 Disagree
- 3 Agree
- 4 Agree strongly
- 5 Not applicable

A slightly different version of each item is asked of respondents who do not have any

chronic conditions.

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Appendix B. Using Comparative Information to Make Medicare Decisions

Below is the information about how five plans differ (in terms of member ratings and costs). Use the information in this table to pick the health plans you are most likely to enroll in.

| | <u>Member rat</u> <u>the</u> | ings of hov plan comm | | | _ | member ra | tings of th | ne plan | Premium cost per month | Co-pay per office visit | Co-pay per prescription |
|------|---------------------------------|--------------------------|--------------|--------------------|-------------|------------|--------------|-------------------|---------------------------|----------------------------|-------------------------|
| | 0 Poor | 60 Fair | 70 E Good | 80 10 Excellent | 0 0 Poor | 60 Fair | 70 8 Good | 0 10 Excellent | 0 | | |
| Plan | С | | 75 | | | | 76 | | \$75 | \$8 | \$8 |
| Plan | D | | 74 | | | | 72 | | \$100 | \$10 | \$8 |
| Plan | Е | | | 83 | | | | 85 | \$75 | \$8 | \$8 |
| Plan | F | | 73 | | | | 71 | | \$100 | \$10 | \$10 |
| Plan | G | | | 80 | | | 78 | | \$75 | \$8 | \$8 |

1. Please indicate the health plan you'd be <u>most</u> likely to enroll in below. Put an "X" in the box next to your first choice – the plan you are most likely to pick.

| | | □ Plan C | 🗆 Plan D | 🗖 Plan E | 🗖 Plan F | 🗆 Plan G | | | |
|----|---|----------|----------|----------|----------|----------|--|--|--|
| 2. | 2. Please indicate your <u>second</u> choice. Put an "X" in the box next to your second choice. | | | | | | | | |
| | | □ Plan C | 🗆 Plan D | 🗖 Plan E | 🗆 Plan F | □ Plan G | | | |

References

1. Casalino LP. Disease management and the Organization of Physician Practice. *Journal of the American Medical Association*. 2005;293:485–488.

2. Lorig KR, Ritter P, Stewart AL, et al. Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Medical Care*. 2001;39:1217–1223.

Medicare Prescription Drug, Improvement and Modernization Act of 2003,
 Subtitle C, Section 721(a)(2)(B). 2003; 276.

4. Kirsch I, Jungeblut A, Jenkins L, et al. *Adult Literacy in America*. Washington, DC: U.S. Department of Education, 1993.

5. U.S. Department of Health and Human Services. *Healthy People 2010: Understanding and Improving Health. 2nd ed.* Washington, DC: U.S. Government Printing Office, 2000.

6. Gazmararian JA, Williams MV, Peel J, et al. Health literacy and knowledge of chronic disease. *Patient Education and Counseling*. 2003;51:267–275.

7. Williams MV, Baker DW, Parker RM, et al. Relationship of functional health literacy to patients' knowledge of their chronic disease: a study of patients with hypertension and diabetes. *Archives of Internal Medicine*. 1998;158:166–172.

8. Williams M, Baker D, Honig E, et al. Inadequate literacy is a barrier to asthma knowledge and self-care. *Chest.* 1998;114:1008–1015.

9. Scott TL, Gazmararian JA, Williams MV, et al. Health literacy and preventive health care use among Medicare enrollees in a managed care organization. *Medical Care*. 2002;40:395–404.

10. Schillinger D, Grumbach K, Piette J, et al. Association of health literacy with diabetes outcomes. *Journal of the American Medical Association*. 2002;288:475–482.

11. Baker DW, Gazmararian JA, Williams MV, et al. Health literacy and use of outpatient physician services by Medicare managed care enrollees. *Journal of General Internal Medicine*. 2004;19:215–220.

12. Baker DW, Gazmararian JA, Williams MV, et al. Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *American Journal of Public Health*. 2002;92:1278–1283.

13. Hibbard JH, Stockard J, Mahoney ER, et al. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Services Research*. 2004;39(4) Pt 1:1005–1026.

14. Clark NM and Dodge JA. Exploring self-efficacy as a predictor of disease management. *Health Education and Behavior*. 1999;26:72–89.

15. Berkman ND, DeWalt DA, Pignone MP, et al. *Literacy and Health Outcomes*. Agency for Healthcare Research and Quality, 2004.

16. Baker DW, Williams MV, Parker RM, et al. Development of a brief test to measure functional health literacy. *Patient Education and Counseling*. 1999;38:33–42.

17. Hibbard JH, Slovic P. Using a Screening Tool and Using Narratives to Help Support Medicare Beneficiary Choices. Final Report. Centers for Medicare and Medicaid Services, 2003.

18. Toobert DJ, Hampson SE, Glasgow RE. The summary of diabetes self-care activities measure: results from 7 studies and a revised scale. *Diabetes Care*. 2000;23:943–950.

19. Baker DW, Gazmararian JA, Sudano J, et al. The association between age and health literacy among elderly persons. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*. 2000;55:S368–374.

20. Hibbard JH, Slovic P, Peters E, et al. Strategies for reporting health plan performance information to consumers: evidence from controlled studies. *Health Services Research*. 2002;37:291–313.

21. Hibbard JH, Peters E. Supporting informed consumer health care decisions: data presentation approaches that facilitate the use of information in choice. *Annual Review of Public Health*. 2003;24:413–433.

22. Hibbard J, Peters E, Slovic P, et al. Making health care report cards easier to use. *Joint Commission Journal on Quality Improvement*. 2001; 27:591–604.

23. Hibbard J, Slovic P, Peters E, et al. Is the informed-choice approach appropriate for Medicare beneficiaries? *Health Affairs*. 2001;20:199–203.

24. Hibbard JH, Greene J, Tusler M. Can Medicare beneficiaries who have marginal or inadequate health literacy skills be easily identified? Testing the sensitivity and specificity of a short screening test. [under review]. 2005.

25. Greene J, Yedidia MJ. Provider behaviors contributing to patient self-management of chronic illness. [under review]. 2004.