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Cognition, Health Literacy, and Actual and Perceived Medicare Knowledge Among Inner-City Medicare Beneficiaries

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among Inner-City Medicare Beneficiaries

## **Abstract**

**Background:** Poor Medicare knowledge is associated with worse health outcomes, especially in low-income patients. We examined the association of health literacy and cognition with actual and perceived Medicare knowledge in a sample of inner-city older adults.

**Research Design and Subjects:** Cross-sectional analysis of data on 336 adults ages  $\geq 65$  years with Medicare coverage recruited from senior centers and low-income housing facilities in Manhattan, New York.

**Measures:** Actual Medicare knowledge was determined by a summary score of 9 true/false questions about the Medicare program and perceived Medicare knowledge with a single item. Validated measures were used to assess health literacy and general cognition.

**Results:** Among respondents, 63.1% had high actual Medicare knowledge and 36.0% believed they knew what they needed to know about Medicare. Actual and perceived Medicare knowledge were poorly correlated ( $r=-0.01$ ,  $p>0.05$ ). In multivariable models, low health literacy was significantly associated with actual Medicare knowledge ( $\beta = -8.30$ ,  $SE = 2.71$ ,  $p<0.01$ ) but not perceived Medicare knowledge ( $\beta = 0.37$ ,  $SE = 0.22$ ,  $p=0.09$ ). Individuals with low health literacy were more likely to perceive their Medicare knowledge as adequate when actual Medicare knowledge was low (adjusted odds ratio 3.30, 95% confidence intervals 1.20-9.05,  $p<0.05$ ).

**Conclusions:** Older adults with low health literacy are more likely to have poor understanding of the Medicare program and yet more likely to believe that their understanding of the program is adequate. This combination of factors may place them at increased risk of poor access to information about the Medicare program and diminish their ability to make fully informed choices.

## **Introduction**

Medicare provides health insurance for nearly 50 million Americans, mostly adults ages 65 and over. While the program has afforded millions of Americans access to healthcare services, its evolving benefits and cost structures can be difficult to navigate.<sup>1</sup> For example, deciding between traditional fee-for-service Medicare and managed Medicare requires beneficiaries to consider out-of-pocket costs, available services, and choice of physicians. Many beneficiaries, especially those with low income and education, can find the range of choices confusing,<sup>2</sup> may lack adequate knowledge about managed care,<sup>3</sup> and feel unsure about the coverage and benefits offered by various plans.<sup>4</sup> Lack of knowledge about Medicare, importantly, has been linked to worse health outcomes including delayed care, increased emergency department visits, more frequent use of inappropriate medications, and even higher mortality.<sup>5</sup>

Knowledge of Medicare is partly a reflection of an individual's basic literacy skills, which affect their ability to access and process written information. In the 2003 National Adult Literacy Survey, the majority of individuals over 65 years had either below basic or basic prose literacy, document literacy, and quantitative literacy skills; all of which are needed to evaluate health related information.<sup>6</sup> Studies more specifically focused on health literacy have similarly revealed widespread literacy deficits among older adults.<sup>7,8</sup>

Hibbard and colleagues proposed a conceptual model to link health literacy with comprehension of and quality of health insurance decisions.<sup>9</sup> They proposed, then tested and validated, a pathway in which health literacy directly affects comprehension, and is itself influenced by various exogenous factors like education and health. They also showed that the individual's activation was an independent driver of comprehension. Comprehension, in turn,

was hypothesized, and shown, to influence the quality of choices that people make. We expanded on this conceptual model by positing an influential effect of two additional factors, cognition and knowledge perceptions. Cognition and health literacy are tightly linked<sup>10,11</sup> owing to the fact that literacy, whether basic or health oriented, involves various cognitive abilities like working memory and executive function. Yet, while cognition directly affects health literacy, it may not explain all of health literacy's association with comprehension. For example, an individual with some cognitive deficits but good knowledge of the Medicare program may have relatively preserved long term memory and an ability to recall elements of the program demonstrating their knowledge.

The extent to which individuals believe they understand a complicated insurance program like Medicare is another factor that may complicate efforts to support decision-making for people with limited literacy. In prior work, we observed that misperceptions of illness and treatments are closely related to individual behaviors,<sup>12</sup> and these misperceptions are more likely to be observed in older adults with low health literacy.<sup>13,14</sup> We therefore hypothesized that perceptions of Medicare knowledge would be associated with health literacy, yet may not be concordant with their actual understanding of Medicare. In this study, we sought to test these hypotheses in order to provide information that might improve the approach to informing people about insurance and assisting them with complicated insurance-related decision-making.

## **Methods**

### *Subjects and Setting*

Independently living low-income adults in Manhattan, ages 60 years and older, were recruited from 30 community-based settings. Listings from the New York City Department for

the Aging and a listing of Federal Housing and Urban Development-supported low-income housing facilities were used to identify and select senior centers and low-income housing facilities, respectively. Senior centers were either connected with naturally occurring retirement communities (NORC) or were freestanding. All sites were chosen in zip code areas with median household incomes below \$50,000, and men were oversampled because they are outnumbered by women in these communities.<sup>15</sup> Though recruitment differed site by site according to rules set forth by each site's management, enrollment occurred mostly through site-provided meals and site-sponsored special events. In exchange for participation in a longitudinal study about health, health care use, and health insurance, recruited participants were given \$20 for the baseline interview and \$10 for a follow-up interview scheduled 6-9 months later. Only a single member of any household was interviewed, and trained bilingual on-site interviewers conducted interviews in both English and Spanish.

Out of the 456 subjects in the data set, analysis focused on the subgroup of those with Medicare coverage for whom complete data on health literacy and cognition were available (n=336). The demographics of the 120 subjects excluded were similar to the 336 included in terms of race, sex, age, income, and language. This study was approved by the Mount Sinai School of Medicine Institutional Review Board.

### ***Outcome Variables***

Actual Medicare knowledge was a measure of insurance comprehension using nine true or false questions used in the Medicare Current Beneficiary Survey (MCBS).<sup>16</sup> It was reported two ways: 1) the percent of questions answered correctly, and 2) a binary variable indicating high vs. low Medicare knowledge, where high knowledge was defined as answering six or more

questions correctly. The 9-item scale has a Cronbach's alpha of 0.72-0.78 and has demonstrated external validity.<sup>17</sup>

Perceived Medicare knowledge was measured with a single-item assessment, which asks, "Overall, how easy or difficult do you think the Medicare program is to understand?" The 5-point response options range from very easy to very difficult. Those who indicated that program is very or somewhat easy to understand were scored as having high perceived Medicare knowledge.

### ***Independent Variables***

The primary independent variables of interest were health literacy and cognition. Health literacy was assessed using the Short Test of Functional Health Literacy in Adults (S-TOFHLA).<sup>18</sup> The S-TOFHLA is a timed (7-minute) comprehension test consisting of 2 clinically oriented reading passages with 36 words intermittently missing throughout the 2 passages. For each missing word, the respondent must select among 4 choices to complete the sentence in a grammatically correct fashion. Scores range from 0-36 and are divided into 3 levels of health literacy: low (range 0-16), marginal (range 17-22), and adequate (range 23-36). We dichotomized the results as low (inadequate or marginal) vs. adequate health literacy.

Cognitive functioning was assessed with the Folstein Mini Mental Status Exam (MMSE), a dementia screening tool commonly used in clinical and research settings.<sup>19</sup> The MMSE is a 30-item general assessment of cognition that measures performance on tasks in 8 domains that require various cognitive functions, such as working memory, registration, spatial orientation, and executive function, among others. For some analyses, we used a MMSE score of  $\leq 24$  to indicate abnormal cognition, following population-based norms.<sup>20</sup>



We selected covariates that might confound the associations of Medicare knowledge with the main independent variables based on our conceptual framework and the data available to us for this model. Covariates were grouped into three categories, sociodemographics, insurance coverage, and health status. Sociodemographic variables included age, gender, race, education, household income, and preferred language. Type of insurance coverage was used as a proxy for experience with insurance systems. We hypothesized that experience with health plans and insurance coverage in general, as well as healthcare and healthcare systems, would contribute to individuals' knowledge of the Medicare program. Type of insurance coverage was used as the proxy for this experience and it included employer-sponsored insurance, Medicare Advantage, or traditional fee-for-service Medicare. In the event that a person had employer-sponsored coverage and Medicare, we coded them as having the former. We also included a variable for Medigap supplemental coverage. Health status was measured as the number of chronic illnesses (dichotomized as 0-1 vs. 2 or more), self-reported general health, and hospitalization in the prior 12 months.

### **Statistical Analysis**

We used the chi-square test to compare subject characteristics with low Medicare knowledge (actual and perceived) in univariate analyses. We calculated Pearson correlations for comparisons of continuous measures of health literacy and cognition with actual and perceived knowledge scores. We performed multivariable linear regression analyses by regressing actual or perceived Medicare knowledge on the key independent variables while controlling for the variance explained by the pre-specified list of socioeconomic, insurance, and health status

measures. We modeled the associations of health literacy or cognition with actual or perceived Medicare knowledge separately then included both health literacy and cognition in the model.

We also tested the associations of health literacy and cognition with the accuracy of subjects' perceptions of their Medicare knowledge. Individuals were categorized as being accurate estimators of their Medicare knowledge when their perceived knowledge was high or low and their actual knowledge was high or low, respectively. They were categorized as under-estimators if their perception was low but actual knowledge was high, and over-estimators if their perception was high and actual knowledge was low. These three categories were analyzed in separate logistic regression models that accounted for the previously described sociodemographic, insurance, and health status variables.

Less than 1% of respondents had missing data for most questions. SAS statistical software version 9.3 was used for all analyses (SAS Institute, Inc., Cary, NC).

## **Results**

### *Subject Characteristics*

Data were available for 336 individuals. Of these, 30.4% were  $\geq 80$  years, 35.4% were men, 29.5% were African-American, 32.7% were Hispanic, and 47.4% had some college education. Poor health was common. More than two-thirds (67.6%) had  $\geq 2$  chronic illnesses, 22.6% had been hospitalized in the past 12 months, and 40.8% reported poor to fair general health. There was substantial diversity in terms of insurance coverage: 31.0% had employer-sponsored coverage in addition to Medicare, 41.1% had Medicare fee-for-service, and 28.0% had Medicare Advantage. Only 7.7% had Medigap supplemental insurance. One-quarter of respondents (26.2%) had low health literacy and the same proportion (25.9%) had impaired

cognition. The mean MMSE score was 26.9 (2.7).

Respondents correctly answered 67.0% of the Medicare questions and 63.1% were categorized as having high actual Medicare knowledge. The most commonly correctly answered item (87.2 %) was Medicare coverage of an annual flu shot and the least commonly correctly answered item (44.9%) addressed relative coverage of Medicare services by Medicare private vs. fee-for service options (Table 2). Slightly more than a third of respondents (36.0%) perceived themselves as having a high level of Medicare knowledge.

#### *Associations of Health Literacy and Cognition with Actual and Perceived Medicare Knowledge*

Both health literacy and cognitive function were significantly associated with actual and perceived Medicare knowledge in univariate analyses (health literacy vs. actual knowledge,  $r=0.29$ ,  $p<0.001$ ; health literacy vs. perceived knowledge,  $r=0.12$ ,  $p<0.01$ ; cognition vs. actual knowledge,  $r=0.17$ ,  $p<0.01$ ; cognition vs. perceived knowledge,  $r=0.13$ ,  $p<0.05$ ) (Table 3).

In separate multivariable models, low health literacy retained its statistically significant association with actual Medicare knowledge ( $\beta = -8.30$ , SE 2.71,  $p<0.01$ ), as did impaired cognition ( $\beta = -5.39$ , SE 2.33,  $p<0.05$ ) (Table 4). Low health literacy was significantly associated with actual Medicare knowledge but impaired cognition was not when both variables were included in the same model ( $\beta = -6.94$ , SE 2.90,  $p=0.02$  and  $\beta = -3.29$ , SE 2.48,  $p=0.19$ , respectively). In the multivariable models of perceived Medicare knowledge, neither low health literacy nor impaired cognition were significantly associated with the outcome ( $\beta = 0.37$ , SE = 0.22,  $p=0.09$ , and  $\beta = 0.37$ , SE 0.19,  $p=0.05$ , respectively), nor when the variables were included in the same model (Table 5). Adults ages  $\geq 85$  years were consistently more likely to report high levels of perceived Medicare knowledge than adults ages 65-69 years.

*Associations of Health Literacy and Cognition with Accuracy of Perceived Medicare Knowledge*

Low levels of actual knowledge were observed more commonly among individuals with low health literacy vs. adequate health literacy (45.5% vs. 69.4%,  $p < 0.01$ , respectively) and those with impaired vs. intact cognition (52.9% vs. 66.7%,  $p = 0.02$ , respectively) (Table 6). In contrast, individuals with low health literacy more often perceived their knowledge of Medicare to be high, though the difference did not achieve statistical significance (44.3% vs. 33.1%,  $p = 0.06$ , respectively). A similar pattern was observed for individuals with impaired vs. intact cognition (44.8% vs. 32.9%,  $p = 0.05$ , respectively).

Overall, 58.3% of subjects had accurate perceptions of their Medicare knowledge, while 12.2% were over-estimators and 29.5% were under-estimators of their knowledge. Individuals with low health literacy were more likely to be over-estimators of their Medicare knowledge than were those with adequate health literacy (20.5% vs. 9.3%,  $p < 0.01$ ). Those with impaired cognition were also more likely to overestimate their knowledge but the difference did not achieve statistical significance (17.2% vs. 10.4%,  $p = 0.09$ ) (Table 7). In multivariable models, subjects with low health literacy compared to those with adequate health literacy were more likely to overestimate their Medicare knowledge (OR=3.30, 95% CI 1.20-9.05,  $p < 0.05$ ) and less likely to underestimate their Medicare knowledge (OR=0.44, 95% CI 0.20-0.98,  $p < 0.05$ ). Similar patterns were observed for individuals with impaired cognitive function (overestimate Medicare knowledge, OR 2.33, 95% CI 1.06-5.15,  $p = 0.04$ ; underestimate Medicare knowledge, OR 0.49, 95% CI 0.25-0.97,  $p < 0.05$ ).

## Discussion

Understanding Medicare and its options has real-life implications for decision-making and subsequent access to health care services. In this community-based study of inner city older adults, we found that individuals with low health literacy and impaired cognition were more likely to also have less knowledge of the Medicare program. Additionally, we found that people with low health literacy or impaired cognition were also more likely to believe that they had a good understanding of the program than did those with high levels of literacy and cognition even when their level of actual knowledge was low.

Like the findings presented here, other studies have demonstrated a link between limited health literacy and understanding of insurance<sup>3,4</sup> while others have reported that cognitive ability may explain differences in Medicare knowledge.<sup>21,22</sup>

Our findings expand on the prior research in three ways. First, we evaluated the potential mitigating role of cognition for this association, an important consideration given the known association of limited literacy and diminished cognition.<sup>23</sup> We found that accounting for cognitive performance reduced health literacy's association with Medicare knowledge but did not eliminate it, suggesting that factors comprising health literacy other than the purely cognitive play a role in each individual's understanding of Medicare. Nonetheless, that cognition is associated with Medicare knowledge itself highlights the importance of considering this factor in the design of approaches to informing beneficiaries about their options and guiding them through decision making. Secondly, our findings expand the generalizability of prior work in this field by extending study to a population of racially and ethnically diverse sample of older low-income adults in inner-city settings. In such settings, people may have considerable exposure to information about Medicare provided through senior center and community center events and

social supports. Prior work in this field consisted of individuals from suburban and higher socioeconomic status communities and did not have the same level of racial and ethnic diversity as that present in our study sample.

Third, our work revealed a surprising disconnect between subjects' actual and perceived knowledge of the Medicare program. Particularly noteworthy was the observation that individuals with low health literacy and cognitive impairment were more likely to believe they had good knowledge of the Medicare program when they actually demonstrated poor understanding. This finding raises the possibility that such individuals may not seek support or more information when faced with the need to make decisions about their Medicare options, improve their coverage, or reduce insurance-related costs. Results of other studies support this hypothesis. McWilliams and colleagues reported that Medicare beneficiaries with impaired cognition were less likely to take advantage of the range of benefits offered in the Medicare Advantage plans,<sup>1</sup> a problem that might derive in part from challenges they face to accessing information, such as through the Medicare website.<sup>24</sup> Chan and colleagues reported that cognitively impaired older adults were less likely to acquire supplemental Medicare coverage<sup>25</sup> and Kuye et al found them less likely to access low-income subsidies for Medicare Part D.<sup>26</sup>

Whether these problems arise from limited access to information, misinformation, or poor decision-making is unclear. In any event, they suggest that the approach to informing people about the Medicare program and its options and supporting Medicare decision-making may need improvement. Approaches to informing Medicare beneficiaries about their options currently include telephone hotlines, in-person counselling, and web-based support, and often emphasize communication strategies to enhance understanding among beneficiaries with limited health literacy or cognition.<sup>27</sup> In light of our findings, the Medicare program should also

consider developing new approaches to identifying and engaging individuals who feel secure about their level of knowledge but actually have poor understanding of the program and could therefore benefit from targeted counselling.

## **Limitations**

A number of limitations of this study warrant mention. First, we focused on a population of older adults from low-income neighborhoods in New York City and the findings may not generalize to other populations. They do, however, complement research conducted in other settings that have shown similar associations between health literacy or cognition and Medicare knowledge. Second, we used convenience sampling, which could have introduced bias, although the directionality of such bias is unclear. Third, the only measure of cognitive functioning available for our analyses was the Mini-Mental State Exam, which is a screening tool for general cognitive impairment and is not designed to reliably pinpoint deficits in particular cognitive domains, like short and long term memory, executive functioning, or processing speed. Future studies of insurance knowledge and related decision making would benefit from inclusion of specific measures of these and other cognitive functions. Fourth, our assessments of perceived and actual Medicare knowledge are brief and only touch on a very small aspect of the very complex Medicare program. A more comprehensive set of measures regarding actual and perceived Medicare knowledge might reveal variation in the associations of health literacy and cognition with Medicare knowledge. Finally, we conducted several multivariable regression analyses and it is possible that some statistically significant associations could have arisen by chance. Nonetheless, our findings were fairly consistent across analyses.

## **Conclusions**

Medicare beneficiaries face an increasingly complex program and possibly more difficult insurance choices. Healthcare policymakers, healthcare systems and professionals, and others who have a stake in the quality of coverage decisions made by beneficiaries need to be aware that older adults with impaired cognition and limited literacy may have a poorer understanding of their options and may overestimate the level of their understanding of the program. Greater outreach and support may be needed to ensure that older adults and their caregivers have the clarity of understanding needed to optimize their health insurance coverage. The findings of our study add weight to elements of recent legislation, including the Patient Protection and Affordable Care Act and the Plain Writing Act of 2010,<sup>28</sup> designed to ensure that information provided to patients and insurance beneficiaries is accessible and understandable.



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