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Unmet need for medical care among Medicare beneficiaries by health insurance literacy and disability

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**Title:**

Unmet need for medical care among Medicare beneficiaries by health insurance literacy and disability

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28 **Abstract (249/250 words)**

29 **Background:** Navigating the US healthcare system requires considerable health insurance  
30 literacy, especially for adults with disabilities. Limited health insurance literacy may lead to  
31 suboptimal treatment, leading to unmet need for medical care.

32 **Objective:** We examined whether unmet need for medical care among Medicare beneficiaries  
33 differs by health insurance literacy and disability status.

34 **Methods:** Using data from the 2010-2019 Medicare Current Beneficiary Survey, we identified  
35 48,989 Medicare beneficiaries, including those in traditional Medicare and Medicare Advantage.  
36 Our outcomes were three measures of unmet need for medical care. Our key independent  
37 variables were health insurance literacy and disability status. For each outcome, we estimated the  
38 adjusted rates of reporting unmet need for medical care by health insurance literacy and  
39 disability while controlling for individual-level characteristics.

40 **Results:** Unmet need for medical care was higher among Medicare beneficiaries with disabilities  
41 across all outcomes, but the highest rates were among those with disabilities and limited health  
42 insurance literacy (27.4% [95% CI: 24.9-29.9] for experiencing delayed care, 17.7% [95% CI:  
43 15.6-19.9] for experiencing trouble in getting needed care, and 20.8% [95% CI: 18.5-23.1] for  
44 not seeing a doctor despite medical need). Notably, there was an increasing trend in experiencing  
45 delayed care and trouble getting needed care among Medicare beneficiaries with disabilities over  
46 time, especially for those with limited health insurance literacy.

47 **Conclusions:** Medicare beneficiaries with disabilities and limited health insurance literacy face  
48 disproportionate unmet need for medical care. Policies are needed to ensure that these  
49 beneficiaries have access to clear and accessible health insurance information.

50 **Keywords:** Medicare; disability; unmet need; health insurance literacy.

51

## 52 INTRODUCTION

53 Adults with disabilities in the United States often experience unmet need for medical care,<sup>1-2</sup>  
54 which can have significant negative consequences on overall health and well-being. This is  
55 especially relevant to Medicare beneficiaries, who tend to have high care needs. Research shows  
56 that a substantial portion of Medicare beneficiaries with disabilities reported unmet need for  
57 medical care, including 23.5% not seeing a doctor despite medical need and 23.8% experiencing  
58 delayed care.<sup>3</sup> This unmet need may be particularly pronounced among vulnerable populations,  
59 such as younger dual-eligible Medicare beneficiaries.<sup>4</sup> Unmet need can arise from a variety of  
60 factors, including financial and non-financial barriers to health care.<sup>5</sup>

61 Navigating the complex US healthcare system requires considerable health insurance  
62 literacy, which is defined as a person's ability to seek, obtain, and understand health insurance  
63 coverage.<sup>6</sup> However, almost one-third of Medicare beneficiaries reported difficulty  
64 understanding the Medicare program.<sup>7</sup> This suggests that limited health insurance literacy may  
65 lead to delayed or suboptimal treatment choices,<sup>8-13</sup> making unmet need for medical care even  
66 more common among those with disabilities. Understanding unmet need for medical care among  
67 those with disabilities is crucial from a policy perspective as it allows us to identify more  
68 targeted interventions and provide insight into effective and actionable policy recommendations.  
69 Despite the potential implications of health insurance literacy for Medicare beneficiaries with  
70 disabilities, there is currently limited evidence.

71 To address the gap in the literature, we examined whether unmet need for medical care  
72 differs among all Medicare beneficiaries, including those in traditional Medicare (TM) and  
73 Medicare Advantage (MA), by health insurance literacy and disability status. We conducted two  
74 main analyses. We first estimated the adjusted rates of reporting unmet need for medical care by

75 health insurance literacy and disability status. Then, we examined trends in unmet need for  
76 medical care by health insurance literacy and disability status.

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**78 METHODS****79 Study design**

80 We employed a cross-sectional study design using data from the 2010-2019 Medicare Current  
81 Beneficiary Survey (MCBS), which is a continuous longitudinal survey of a nationally  
82 representative survey of community-dwelling Medicare beneficiaries. The MCBS provide  
83 information on demographic characteristics, socioeconomic characteristics, health care  
84 utilization, and health status. The survey is conducted in three rounds each year, with each round  
85 consisting of a sample of approximately 12,000 Medicare beneficiaries. In our analysis, we  
86 treated each year's data as an independent annual cross-sectional survey, even though some  
87 beneficiaries were included in the data over multiple years. This indicates that we pooled the data  
88 from all years and conducted a pooled analysis.

89 The MCBS data is released to researchers in two formats: a limited data set with  
90 extensive information and a publicly available data set with limited information. For the years  
91 2010-2016, we used the Limited Data Set File from the MCBS, which collects data through  
92 surveys and claims data. For the years 2017-2019, however, we did not have access to the  
93 Limited Data Set File and thus used the Public Use File, which offers comparatively restricted  
94 information. Despite this difference, we found that the annual sample size was consistent across  
95 years. The 2014 MCBS data were never released and were therefore not included in our analysis.  
96 Our study was approved by the institutional review board of the University of Pennsylvania.

97

**98 Sample**

99 We included all Medicare beneficiaries with 12 months of continuous enrollment in either TM or  
100 MA in a given year, regardless of age. We excluded Medicare beneficiaries who did not have

101 continuous enrollment in Parts A and B benefits, those who died within the year, and those who  
102 switched between MA and TM during the year.

103

104 Measures

105 Our outcomes were three binary measures of unmet need for medical care: experiencing delayed  
106 care, experiencing trouble getting needed care, and not seeing a doctor despite medical need.

107 These variables were derived from the following survey questions: “during the previous year, did  
108 you have any delay in care due to cost?”, “during the previous year, did you have any trouble in  
109 getting health care needs met?”, and “during this year, did you have any health problem or  
110 condition about which you think you should have seen a doctor or other medical person, but did  
111 not?”

112 Our key independent variables were binary measures of health insurance literacy and  
113 disability status. Health insurance literacy was determined based on the following questions:  
114 “overall, how easy or difficult do you think the Medicare program is to understand?” and “how  
115 much do you think you know about the Medicare program?” We categorized the responses into  
116 two levels: easy (very or somewhat easy) vs. difficult (very or somewhat difficult), very much or  
117 much (everything, most of what you need to know, or some of what you need to know) vs. a  
118 little or almost none (a little of what you need to know or almost none of what you need to  
119 know). Those who reported “difficult” or “a little or almost none” were classified as having  
120 limited health insurance literacy. Disability status was assessed using the Current Reason for  
121 Entitlement Code in Medicare. Medicare beneficiaries were asked to indicate whether they were  
122 enrolled in Medicare due to age or disability. To qualify for Medicare benefits due to disability, a  
123 beneficiary must have a disability that is expected to result in death or that has lasted or is

124 expected to last for at least 24 consecutive months. The disability must be so severe that it  
125 prevents the beneficiary from engaging in any substantial gainful activity.

126 To adjust for differences in individual-level characteristics, we included the following  
127 individual-level variables: age, sex, race/ethnicity, education, income, health insurance  
128 (enrollment in TM or MA and Medicare-Medicaid dual eligibility, respectively), marital status,  
129 metropolitan area residence, having a usual source of care, and health status (self-reported  
130 general health status compared with same-age people and overall health status compared with  
131 one year ago, respectively). We selected these variables based on the Andersen behavioral model  
132 of health services utilization, which is a conceptual model that explains the factors that include  
133 individuals' use of health services, including predisposing factors, enabling factors, and need  
134 factors.<sup>14</sup> Specifically, predisposing factors include factors that predict individuals' propensity to  
135 use health services. Enabling factors include factors that hinder or facilitate access to health  
136 services. Need factors include factors that measure evaluated or perceived needs for health care  
137 services. We used this model to guide our empirical model specification.

138

### 139 Statistical analysis

140 We first estimated sample characteristics of Medicare beneficiaries by health insurance literacy  
141 and disability status. To examine the prevalence of unmet need for medical care among Medicare  
142 beneficiaries by health insurance literacy and disability status, we used a linear probability model  
143 while accounting for individual-level characteristics described above, health insurance literacy,  
144 disability status, and their interaction term. Using the marginal effects from the linear probability  
145 models, we estimated the mean adjusted values of the outcomes for each group while holding all  
146 other variables constant except the variable of interest. To assess the robustness of our findings,

147 we conducted the analysis using a logistic regression model. To assess how unmet need for  
148 medical care may change over time, we estimated unadjusted trends in unmet need for medical  
149 care by health insurance literacy and disability status. We combined data for several years (2010-  
150 11, 2012-13, 2015-16, and 2017-19) to produce reliable and stable estimates as low sample sizes  
151 for those with disabilities and limited health insurance literacy can lead to unstable estimates. For  
152 all analyses, we clustered standard errors within individuals as some beneficiaries were included  
153 in the data over the course of multiple years. We also included year-fixed effects. We used  
154 survey weights to generate nationally representative estimates.

155

## 156 **RESULTS**

157 Our final sample included 48,989 Medicare beneficiaries, of whom 27,227 were non-disabled  
158 with health insurance literacy, 15,093 were non-disabled with limited health insurance literacy,  
159 3,900 were disabled with health insurance literacy, and 2,769 were disabled with limited health  
160 insurance literacy (Table 1). Overall, 36.6% of our sample had limited health insurance literacy.  
161 Specifically, 28.7% reported difficulty in understanding the Medicare program and 20.1%  
162 reported limited knowledge about the Medicare program.

163 Our adjusted analysis showed that unmet need for medical care was higher among  
164 Medicare beneficiaries with disabilities than Medicare beneficiaries without disabilities across all  
165 three outcome measures, but the highest rates were among Medicare beneficiaries with  
166 disabilities and limited health insurance literacy (27.4% [95% CI: 24.9-29.9] for experiencing  
167 delayed care, 17.7% [95% CI: 15.6-19.9] for experiencing trouble in getting needed care, and  
168 20.8% [95% CI: 18.5-23.1] for not seeing a doctor despite medical need) (Table 2). In contrast,  
169 unmet need for medical care was the lowest among Medicare beneficiaries without disabilities

170 and with health insurance literacy (3.7% [95% CI: 3.4-4] for experiencing delayed care, 2.2%  
171 [95% CI: 1.9-2.4] for experiencing trouble in getting needed care, and 5.4% [95% CI: 5-5.7] for  
172 not seeing a doctor despite medical need). Notably, Medicare beneficiaries with disabilities and  
173 health insurance literacy were more likely to experience unmet need for medical care than  
174 Medicare beneficiaries without disabilities and with limited health insurance literacy (17.1 [95%  
175 CI: 15.1-19.0] vs. 7.9 [95% CI: 7.4-8.5] for experiencing delayed care, 9.1 [95% CI: 7.6-10.6]  
176 vs. 4.1 [95% CI: 3.8-4.5] for experiencing trouble in getting needed care, and 13.4 [95% CI:  
177 11.6-15.2] vs. 8.5 [95% CI: 8-9.1] for not seeing a doctor despite medical need). Our results  
178 remained similar when we used a logistic regression model (Appendix Table A).

179 Our trend analysis found that unmet need for medical care increased over time among  
180 Medicare beneficiaries with disabilities, but this trend was more pronounced among Medicare  
181 beneficiaries with disabilities and limited health insurance literacy (Figure 1). Specifically, the  
182 proportion of reporting delayed care among Medicare beneficiaries with disabilities and limited  
183 health insurance literacy increased from 21.9% in 2010-2011 to 33.2% in 2017-2019. Also, the  
184 proportion of reporting trouble in getting needed care rose from 16.6% in 2010-2011 to 25.3% in  
185 2017-2019. However, the proportion reporting not seeing a doctor despite medical need  
186 increased only slightly, from 18.0% to 21.8%. Notably, unmet need for medical care remained  
187 unchanged over time among Medicare beneficiaries without disabilities and with health  
188 insurance literacy. Both groups of beneficiaries with disabilities and limited health insurance  
189 literacy and beneficiaries without disabilities and with health insurance literacy experienced an  
190 increasing trend in unmet need, but the magnitude of the change was relatively modest.

191

**192 DISCUSSION**

193 In a nationally representative sample of Medicare beneficiaries, we found that unmet need for  
194 medical care was s higher among those with disabilities, particularly for those with limited health  
195 insurance literacy. Moreover, unmet need for medical care has been increasing over time among  
196 Medicare beneficiaries with disabilities, especially those with limited health insurance literacy.

197 Our finding is consistent with prior research indicating that Medicare beneficiaries with  
198 disabilities have a high need for health care resources, but unmet need for medical care remained  
199 substantial.<sup>3,15</sup> This finding suggests that limited health insurance literacy may be an additional  
200 barrier to accessing health care for people with disabilities. While interview-based research  
201 suggests that access to care has improved among people with disabilities after the  
202 implementation of the Affordable Care Act, a lack of timely and accurate information about  
203 insurance plan coverage remains a significant barrier.<sup>16</sup> Notably, we also found that the gap in  
204 access to care is widening among Medicare beneficiaries with disabilities, especially for those  
205 with limited health insurance literacy. This widening gap may be due to the increasing  
206 complexity of the Medicare program, as governments have adopted several programs and more  
207 options have become available. These findings suggest the need to develop programs that make  
208 health insurance information accessible and understandable, particularly for this population.

209 Other important factors may also contribute to unmet need for medical care, including high out-  
210 of-pocket costs, limits on prescription drug coverage, limited provider networks, and  
211 transportation challenges.<sup>16</sup> However, it is important to note that these factors are not mutually  
212 exclusive, and people with disabilities may face multiple challenges in accessing health care.

213 There are several limitations. First, since we relied on self-reported survey data, our  
214 findings may be subject to reporting bias, including recall bias. Second, we assumed that

215 respondents experienced unmet medical needs at the time of the interview, but the timing of  
216 unmet need may have occurred at another point in the survey year. Third, we treated the non-  
217 elderly disabled population as a homogeneous group, despite the possibility of significant  
218 variations in experiences and needs, particularly between those in institutionalized and  
219 community-based settings. Fourth, the MCBS does not provide a comprehensive measure of  
220 health literacy, such as the 21-item Health Literate Measure. As health literacy is a complex and  
221 multifaceted construct that may not be adequately captured by a few measures, however, this  
222 may limit the generalizability of our findings to populations with other levels of health literacy.  
223 Finally, while we adjusted for individual-level characteristics, there may be unmeasured factors  
224 that influence unmet need for medical care among Medicare beneficiaries with disabilities and  
225 limited health insurance literacy. For example, social support may be one such factor as  
226 individuals with limited social support may be more likely to have unmet needs for medical care.

227

**228 CONCLUSION**

229 Our analysis of a nationally representative sample of Medicare beneficiaries revealed that unmet  
230 need for medical care was higher among those with disabilities than those without disabilities,  
231 but the highest rates of unmet need for medical care were observed among those with disabilities  
232 and limited health insurance literacy. Moreover, we observed an increasing trend in unmet need  
233 for medical care over time, especially for those with disabilities and limited health insurance  
234 literacy. Our findings highlight the need to develop policies to make health insurance  
235 information accessible and understandable, particularly for those with disabilities.

236



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283

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285

286 Figure. Trends in unmet need for medical care among Medicare beneficiaries by health insurance  
287 literacy and disability status.

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Appendix Table. Associations of unmet need for medical care with health insurance literacy and disability status among fee-for-service Medicare beneficiaries.

Variable	Not seeing a doctor despite medical need		Experiencing delayed care		Experiencing trouble getting needed care	
	Coefficient, percentage points	P-value	Coefficient, percentage points	P-value	Coefficient, percentage points	P-value
Age						
<65	Ref		Ref		Ref	
65–75	-7.14	<.001	4.37	0.32	2.68	0.486
>=75	0.70	0.304	4.78	<.001	1.40	<.001
Female	1.47	<.001	1.39	<.001	1.25	<.001
Race/ethnicity						
Non-Hispanic White	Ref		Ref		Ref	
Non-Hispanic Black	0.41	0.569	1.11	0.142	-0.33	0.51
Hispanic	1.30	0.509	2.56	0.037	-0.53	0.455
Others	0.52	0.561	1.35	0.102	1.74	0.01
Education						
Less than high school	Ref		Ref		Ref	
High school or above	-0.21	0.62	-0.42	0.262	1.62	<.001
Income						
Less than \$25000	Ref		Ref		Ref	
More than \$25000	-1.66	0.001	-5.65	<.001	-1.79	<.001
Married	0.25	0.54	0.28	0.45	-0.34	0.216
Residence in metro area	0.12	0.76	-0.36	0.314	-0.03	0.912
Supplemental insurance coverage						
Medicaid	-1.00	0.227	-2.64	0.003	0.11	0.876
Part D	0.11	0.768	0.34	0.325	0.09	0.717
Having a usual source of care	-5.07	<.001	-5.85	<.001	-4.41	0
Poor general health status compared with same-age people	3.25	<.001	-0.16	0.678	-0.03	0.932
Good overall health status compared to one year ago	-7.27	<.001	-6.91	<.001	-6.15	<.001
No health insurance literacy	-2.39	<.001	-4.02	<.001	-1.51	<.001
Disability	18.52	<.001	16.28	<.001	10.74	0.006
Interaction term of no health insurance literacy and disability	-3.68	0.016	-6.91	<.001	-5.90	<.001

Table 1. Sample characteristics of Medicare beneficiaries by health insurance literacy and disability status.

Characteristics	%			
	Non-disabled		Disabled	
	With health insurance literacy (n=27,227)	With limited health insurance literacy (n=15,093)	With health insurance literacy (n=3,900)	With limited health insurance literacy (n=2,769)
Age				
<65	0.1	0.1	88.1	87.5
65–75	43.5	42.6	0.0	0.0
>=75	56.3	57.2	11.8	12.5
Female	55.8	56.6	46.5	46.5
Race/ethnicity				
Non-Hispanic White	81.7	80.0	62.2	68.9
Non-Hispanic Black	8.2	7.6	23.4	15.3
Hispanic	2.5	2.5	1.7	1.9
Others	6.8	8.7	11.7	12.7
Education				
Less than high school	34.2	27.8	14.7	12.7
High school or above	65.8	72.2	85.3	87.3
Income				
Less than \$25000	30.3	37.6	69.9	70.3
More than \$25000	69.7	62.4	30.1	29.7
Married	58.4	56.5	33.3	34.2
Residence in metro area	79.6	76.3	77.7	74.9
Health insurance coverage				
Traditional Medicare	79.6	76.3	77.7	74.9
Medicare Advantage	20.4	23.7	22.3	25.1
Medicare-Medicaid dual eligibility	7.4	9.4	42.2	41.4
Having a usual source of care	95.7	95.0	93.4	89.1
Health status				
Poor general health status compared with same-age people	50.8	56.6	75.7	77.6
Good overall health status compared to one year ago	97.4	96.3	97.2	95.5
Unmet need for medical care				
Experiencing delayed care	3.9	8.2	15.5	25.6
Experiencing trouble getting needed care	2.2	4.1	9.0	17.7
Not seeing a doctor despite medical need	5.2	8.4	14.4	21.6

1 Table 2. Adjusted rates of unmet need for medical care among Medicare beneficiaries by health insurance literacy and disability  
 2 status.

Outcomes	Adjusted rates of reporting unmet need for medical care, % (95% CI) <sup>a</sup>			
	Non-disabled		Disabled	
	With health insurance literacy	With limited health insurance literacy	With health insurance literacy	With limited health insurance literacy
Experiencing delayed care	3.7 (3.4 to 4.0)	7.9 (7.4 to 8.5)	17.1 (15.1 to 19.0)	27.4 (24.9 to 29.9)
Experiencing trouble getting needed care	2.2 (1.9 to 2.4)	4.1 (3.8 to 4.5)	9.1 (7.6 to 10.6)	17.7 (15.6 to 19.9)
Not seeing a doctor despite medical need	5.4 (5.0 to 5.7)	8.5 (8.0 to 9.1)	13.4 (11.6 to 15.2)	20.8 (18.5 to 23.1)

3 <sup>a</sup> We used a linear probability regression model to estimate rates of unmet need for medical care by health insurance literacy and  
 4 disability status, controlling for individual-level characteristics (age, sex, race/ethnicity, education, income, insurance status  
 5 [enrollment in TM or MA and Medicare-Medicaid dual eligibility], marital status, metropolitan area residence, having a usual source  
 6 of care, and health status [self-reported general health status compared with same-age people and overall health status compared with  
 7 one year ago]) and year fixed-effects. We then estimated the adjusted rates of unmet need for medical care using predictive marginal  
 8 effects at representative values obtained from the linear probability regression model.

