

Satisfaction with quality and access to health care among people with disabling conditions

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Abstract

Objective. To compare satisfaction with health care between persons with and without disabling conditions.

Design. Responses to 1996 Medicare Current Beneficiary Survey.

Setting. Nationally representative of the United States population.

Study participants. Community-dwelling Medicare beneficiaries, older and younger than 65 years ($n = 16\,403$).

Main outcome measure. Adjusted odds of being dissatisfied or very dissatisfied with five general quality measures and five access-to-care measures by five disabling conditions (blind or low vision, deaf or hard of hearing, difficulty walking, difficulty reaching, manual dexterity difficulties). Multivariable logistic regressions on dissatisfaction adjusted for age group, sex, disabling condition, race, ethnicity, urban versus rural residence, education, household income $< \$25\,000$ versus $\geq \$25\,000$, having a usual source of care, proxy respondent, and managed care.

Results. Of an estimated 33.58 million non-institutionalized Medicare beneficiaries, 64.1% (estimated 21.51 million) reported at least one disabling condition. Among younger beneficiaries, 10.4% with any major disability were dissatisfied with their care overall, as were 4.6% without disabilities. Nevertheless, persons with disabilities generally had significantly higher adjusted odds of dissatisfaction. For elderly persons with any major disability, the adjusted odds ratios (95% confidence interval) of dissatisfaction were: 3.2 (2.4–4.3) for overall quality; 3.2 (2.2–4.6) for access to specialists; 4.4 (3.1–6.4) for follow-up; and 4.2 (3.1–5.7) for ease of getting to doctors. Elderly managed care enrollees were less satisfied with access to specialists, but more satisfied with costs.

Conclusion. The quality domains generating the greatest dissatisfaction were anticipated, given the nature of disabling conditions. Improving these areas requires attention inside and outside the health care system. Redesigning practice settings and procedures, and changing payment policies offer the only solutions to some problems.

Keywords: access, blind, deaf, disability, mobility impaired, quality, satisfaction

People who are sick are generally less satisfied with their medical care than those who are well [1]. One explanation is that people with greater needs for services have more interactions with the health care system and therefore more opportunities to be disappointed. Certainly, people with significant health problems are more likely than others to need timely care involving a range of services and to want

information about their conditions, prognoses, and therapeutic options. With more treatment decisions and interventions comes more chance of mishap, involving both technical and interpersonal quality of care.

Here, we look at satisfaction among people with specific functional limitations that present potential challenges for ensuring convenient access, complete communication, and

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comprehensive services: persons who are blind or have low vision, the deaf or hard of hearing, and those with mobility difficulties. People with these conditions are not necessarily 'sick'. Someone who is deaf since early childhood and speaks American sign language (ASL), for example, may be in superb physical health, requiring only routine, preventive care. Nevertheless, since few health care providers speak ASL, organizing effective communication during office visits requires thought and planning.

In addition, the structure of the health care delivery system could affect satisfaction for persons with disabling conditions. Managed care health plans, which limit access to certain providers, could pose logistical barriers to obtaining care, beyond concerns about access to favorite doctors or other caregivers [2]. For instance, since they cannot drive, some blind persons rely on public transportation to move about their communities. If plans do not include providers on convenient bus or subway routes, this could impede the physical ability of some blind persons to reach care.

Regardless of the cause of functional limitations, each carries logistical implications that could affect access to and satisfaction with care. We use a large, federal survey to examine satisfaction with 10 dimensions of care for persons within five categories of potentially disabling conditions. We also consider whether managed care affects satisfaction.

Methods

Database

We examined responses from 16 403 Medicare beneficiaries living in the community interviewed by the 1996 Medicare Current Beneficiary Survey (MCBS). Medicare, the United States federal health insurance program, covers almost all elderly persons (aged ≥ 65 years) and people under the age of 65 years who have met Social Security Administration (SSA) definitions of disability (unable to work for at least 1 year) and have received cash disability insurance payments for 2 years [3]. Today, Medicare covers >5 million younger disabled persons, at annual costs exceeding \$20 billion; enrollment of disabled persons rose 18.6% between 1995 and 1999, compared with a 2.4% increase among elderly people [4]. As described in detail elsewhere [5,6], the MCBS is an ongoing, longitudinal survey of a representative panel of Medicare beneficiaries, with an oversampling of persons under the age of 65 years ($n = 2378$, 14.5%) and ≥ 85 years ($n = 2072$, 12.6%). We eliminated 106 (0.6%) persons receiving Medicare under the special end stage renal disease (ESRD) entitlement, including the only respondents <18 years of age ($n = 2$).

Persons typically remain empaneled in the MCBS for 4 years. Under a rotating panel design, the sample is replenished annually during the September–December round. The MCBS interviews panel members or their proxies in-person three times annually, tracking persons wherever they reside and using two types of survey: (1) a computer-assisted community questionnaire for persons living in the community; and (2) a

facility baseline questionnaire for respondents in long-term care or institutional settings. The facility questionnaire is asked of the institution's administrator or designated staff, not of the Medicare beneficiary, and therefore does not address respondents' perceptions or experiences of care. We use results only from the MCBS community survey, which included questions about demographic characteristics, health status and functioning, satisfaction with care, and usual source of care. We considered both self- and proxy-reported responses. Among persons <65 years, proxies provided 22.4% of responses, while 9.0% of persons ≥ 65 years of age used proxies.

All findings presented here used MCBS sampling weights to produce nationally representative, Medicare population estimates. We used SAS-callable SUDAAN (version 7.5; Research Triangle Institute, Research Triangle Park, NC, USA) for our analyses.

Disability indicators

The MCBS offers several ways to identify persons with potentially disabling conditions. The most obvious is age. At some point, Medicare beneficiaries under the age of 65 years (except those with ESRD) have met the SSA's employment-related definition of disabled [3]. This administrative definition, however, does not necessarily reflect persons' functional capacities over time (e.g. at the time of the 1996 MCBS interview) [7–9]. MCBS interviewers ask whether any of a specified set of conditions (e.g. heart or lung problems, cancer, mental retardation, or psychiatric disorders) originally caused Medicare eligibility [10]. Again, the functional implications of many of these conditions in 1996 are unclear. A number of investigators have relied on perceived health status (excellent, very good, good, fair, poor) and difficulties performing activities of daily living (ADLs) or instrumental ADLs (IADLs) [6,10–12]. These general measures of health and functional problems do not indicate specific sensory or physical limitations that could affect persons' experiences with health care.

Supplemental surveys about health status and functioning are asked annually in the September–December rounds of the MCBS [5]. We used responses to functional status questions to identify five categories of potentially disabling conditions pertaining to vision, hearing, walking, reaching overhead, and grasping and writing (see Appendix). For each category, we created two levels based on respondents' answers about the extent of their difficulties. We assigned people to the most severe level for which they qualified.

The MCBS did not contain indicators of current serious mental illness, and frequencies of markers for debilitating cognitive disorders were very low in the non-institutionalized MCBS panel. Others have used diagnosis codes from provider claims to identify psychiatric conditions in the MCBS sample [13], but this approach is inconsistent with our other disability definitions (which depend on beneficiaries' rather than physicians' reports). Our list of disabling conditions therefore does not include mental illness or cognitive deficits, common causes for SSA disability determinations (and thus eligibility

for Medicare). Among persons under age 65 years in the sample, 733 (30.8%) did not fall into any of our disability categories. Of these people, 54.2% reported that a mental problem (mental retardation, Alzheimer's disease, or mental disorder) originally caused their Medicare eligibility. Among persons aged <65 years in our disability categories, 22.7% reported that a mental problem originally made them eligible for Medicare.

Satisfaction and managed care

The September–December round of the MCBS also includes supplemental surveys on satisfaction with and access to medical care and persons' usual source of care. The questionnaire asks about overall satisfaction and about nine specific areas. Response options are: very satisfied, satisfied, dissatisfied, and very dissatisfied. We grouped dissatisfied and very dissatisfied responses to identify persons unhappy with their care.

In 1996 (round 16), the MCBS added a special supplement of persons enrolled in 'risk' health maintenance organizations (HMOs), 22.9% of our sample, specifically to examine issues relating to managed care. In addition, Medicare administrative records indicate that 22.7% of MCBS respondents had been enrolled in an HMO for at least part of the previous calendar year. These two groups did not overlap precisely (approximately 2.6% of persons had discordant information about HMO participation). We designated persons as having managed care if they were in the HMO supplement or if Medicare administrative records indicated HMO membership during the prior year.

Analyses

We used SUDAAN's direct standardization method to adjust for age, using seven groupings (18–44, 45–64, 65–69, 70–74, 75–79, 80–84, and ≥85 years). When analyses considered persons older and younger than 65 years of age, we used only appropriate age groupings. For each disability category, we produced three multivariable logistic regression models predicting satisfaction with care based on: (1) age group, sex, and presence and extent of the disabling condition; (2) age group, sex, disabling condition, and managed care; and (3) age group, sex, disabling condition, race, ethnicity, residence location (urban versus rural), education, household income (<\$25 000 and ≥\$25 000), having a usual source of care, proxy respondent, and managed care. The third model thus adjusts for a variety of other patient attributes that could affect satisfaction or access to care, to isolate the contribution of disabling condition and managed care. We also ran these models separately for persons under the age of 65 years (i.e. those who qualify for Medicare explicitly because of disability) and those aged ≥65 years. We report adjusted odds ratios (AORs) with 95% confidence intervals (CI).

Results

Of an estimated 33.58 million non-institutionalized Medicare beneficiaries, 64.1% (estimated 21.51 million) reported at

least one of five potentially disabling conditions (Table 1), and 29.5% (estimated 9.89 million) reported more than one. Among people under the age of 65 years (10.9% of non-institutionalized Medicare beneficiaries or 3.67 million), 73.1% (estimated 2.68 million) noted at least one of the five disabling conditions, and 45.4% had more than one.

Demographic characteristics and usual source of care

Among persons aged ≥65 years, those with more severe impairments were older, on average, than those with less severe limitations (Table 2). After adjusting for age, higher percentages of women than men reported all disabling conditions except hearing difficulties. After adjusting for age and sex, higher percentages of black persons than whites reported all disabling conditions except hearing difficulties. Adjusted percentages for Hispanics and persons of other races varied by disabling condition.

At least 90% of persons over the age of 64 years reported having a usual source of care across all disability categories, except the deaf or very hard of hearing (88.8%). Among persons aged <65 years, roughly 85% in four disability categories reported having a usual source of care, as did only 65.4% of blind persons.

Rates of satisfaction with and access to care

Tables 3 and 4 show the percentages, adjusted for age and sex within broad age ranges (<65 and ≥65 years), which reported dissatisfaction with their care for people without a specific disability, with mild or moderate functional difficulties, and with major functional difficulties. Throughout, results for blind people do not consistently follow trends observed for other disabilities. These results should be interpreted cautiously because of the small sample of blind persons ($n = 117$).

People with disabling conditions generally reported significantly higher rates of dissatisfaction, although this varied by dimension of care and by age range. The widest gap in perceptions of care between people with any disability and those without involved availability of specialists for persons under the age of 65 years: almost 13% of those with any disabling condition reported dissatisfaction, compared with 4.5% of those without any difficulties ($P < 0.0001$). This discrepancy was much smaller for older persons, although still highly significant (Table 3). For older persons, the largest discrepancy involved information, with 9.1% of persons with any major difficulty dissatisfied compared with only 3.0% of those without ($P < 0.0001$). Persons with disabling conditions were, overall, also less satisfied with their access to care (Table 4). Costs were particularly problematic. While 17.6% of younger persons without any difficulty reported dissatisfaction with costs, 29.2% of persons with major difficulties were dissatisfied ($P < 0.001$).

In general, persons aged <65 years were less satisfied than those aged ≥65 years, with few exceptions. Even younger persons who did not have any of our five specific disabling

Table 1 Population estimates in millions (population percentages in parentheses)¹ of disabling conditions by age

Disabling condition	All	Age	
		<65 years	≥65 years
All beneficiaries regardless of presence of disabling condition ²	33.58	3.67	29.91
Vision			
Blind	0.21 (0.6)	0.04 (1.2)	0.17 (0.6)
Very low vision	2.88 (8.6)	0.45 (12.3)	2.43 (8.1)
Hearing			
Deaf/very hard of hearing	2.43 (7.2)	0.22 (6.1)	2.20 (7.4)
Hard of hearing	12.41 (37.0)	0.91 (24.9)	11.50 (38.5)
Walking			
Major difficulties	4.97 (14.8)	0.85 (23.0)	4.12 (13.8)
Moderate difficulties	5.17 (15.4)	0.97 (26.5)	4.20 (14.1)
Reaching overhead			
Major difficulties	2.94 (8.8)	0.73 (19.4)	2.24 (7.5)
Moderate difficulties	2.60 (7.8)	0.51 (13.5)	2.10 (7.0)
Grasping and writing			
Major difficulties	2.06 (6.1)	0.45 (12.1)	1.61 (5.4)
Moderate difficulties	2.50 (7.5)	0.54 (14.8)	1.96 (6.6)

Information source: 1996 Medicare Current Beneficiary Survey.

¹Rewighted population estimates for Medicare beneficiaries, excluding those qualifying because of end stage renal disease.

²Of all Medicare beneficiaries, 11.3% were aged <65 years.

conditions had higher rates of dissatisfaction across all dimensions of care than their older counterparts. The discrepancies across age groups appeared greatest for persons reporting being deaf or very hard of hearing. Among the dimensions of care, the numerical discrepancy by age appeared widest for costs: 29.2% of persons aged <65 years with any major difficulty were dissatisfied with costs, compared with 17.8% of older persons with similar difficulties (Table 4).

Adjusted odds ratios of reporting dissatisfaction

The full models, adjusting for all demographic characteristics, having a usual source of care, proxy respondent, and managed care, found that persons with disabling conditions were typically statistically significantly more likely to be dissatisfied with their care, although this varied across the two age groups (Tables 5 and 6). Proxy respondent status was generally insignificant. In the relatively few instances proxy reached significance, *P* values were 0.02–0.05, and findings were inconsistent (sometimes indicating greater, sometimes lesser, satisfaction). Again, results for blind persons rarely reached statistical significance. Odds ratios for older persons were generally higher than for younger persons for each of the five disabling conditions, suggesting that the contribution of specific disability to dissatisfaction was higher among older Medicare beneficiaries.

The aspect of care (Table 5) generating the highest AORs of dissatisfaction varied somewhat across disabilities and age ranges. For younger persons, the AOR for being dissatisfied with availability of specialists was 3.3 (1.8–5.9) for persons

with any major difficulties. Among older persons with any major difficulty, the highest AOR [4.4 (95% CI 3.1–6.4)] involved follow-up care. Among the access dimensions (Table 6), the question about ease of getting to the doctor produced the highest AOR [4.2 (95% CI 3.1–5.7)] of dissatisfaction for older persons with any major difficulty. For younger persons with any major difficulty, the most problematic access issue was availability of medical services, generating an AOR of dissatisfaction of 3.5 (95% CI 2.0–6.0).

We had included race and ethnicity as covariates in our logistic models because of well recognized racial disparities in access to and quality of health care [14,15]. However, both variables rarely reached statistical significance. In persons <65 years of age, when considering any disabling condition, black persons reported greater satisfaction than whites with concern for overall health [AOR for being dissatisfied 0.6 (95% CI 0.4–0.9), *P* = 0.02]. For persons aged ≥65 years, blacks seemed significantly more satisfied than whites with the availability of care [AOR = 0.4 (95% CI 0.2–0.6), *P* = 0.001] and receiving care at the same location [AOR = 0.6 (95% CI 0.3–0.9), *P* = 0.02], and less satisfied with the costs of care [AOR = 1.4 (95% CI 1.1–1.7), *P* = 0.005], while Hispanic persons were less satisfied with ease of getting to the doctor [AOR = 1.9 (95% CI 1.1–3.1), *P* = 0.02].

Managed care

After adjusting for demographic, having any disabling condition, and other characteristics, managed care did not significantly affect satisfaction with most dimensions of care

Table 2 Demographic characteristics by disabling condition

Condition	Mean (SD) age		Demographic characteristic (adjusted percent ¹)					
	<65 years	≥ 65 years	Men	Women	White	Black	Other race	Hispanic
Vision								
Blind	50.7 (9.7)	80.6 (9.3)	0.7	0.8	0.8	0.9	1.4	0.6
Very low vision	51.6 (9.2)	78.3 (8.7)	8.2	10.2	8.8	10.8	8.5	15.2
Hearing								
Deaf/very hard of hearing	49.8 (12.3)	78.3 (9.2)	10.1	6.4	7.8	6.6	10.3	11.4
Hard of hearing								
Walking								
Major difficulties	52.3 (11.3)	75.7 (8.2)	43.9	32.0	38.9	26.9	36.1	27.2
Moderate difficulties	52.0 (10.1)	78.7 (8.0)	12.6	19.0	16.4	20.7	15.2	15.4
Reaching overhead	51.8 (11.6)	76.6 (8.3)	15.8	16.7	15.7	19.2	17.3	20.2
Grasping and writing								
Major difficulties	52.8 (10.5)	77.7 (8.3)	7.3	11.1	9.2	12.0	12.1	12.9
Moderate difficulties	50.5 (11.3)	76.1 (7.7)	7.3	8.7	8.0	9.9	6.3	9.4
Major difficulties	51.2 (11.3)	78.5 (9.7)	6.2	7.3	6.9	7.7	8.4	6.9
Moderate difficulties	51.5 (10.4)	76.9 (8.3)	7.4	8.5	7.9	8.5	10.8	9.4

Information source: 1996 Medicare Current Beneficiary Survey.

¹Reweighted population percentages. Figures by sex, adjusted by age group (18–44, 45–64, 65–69, 70–74, 75–79, 80–84, and ≥ 85 years). Figures by race and ethnicity adjusted by age group and sex.

Table 3 Adjusted percentages¹ of patients dissatisfied with care by disabling condition and age

Disabling condition	Aspect of care and age									
	Overall	Information		Follow-up		Concern		Specialists		
	<65 years	≥65 years	<65 years	≥65 years	<65 years	≥65 years	<65 years	≥65 years	<65 years	≥65 years
Vision										
No or minor difficulty	7.4	3.4	10.9	5.2	6.5	2.8	8.3	4.5	9.2	2.8
Very low vision	13.0 ²	7.3 ³	18.4 ²	9.8 ³	15.1 ²	5.7 ³	13.9	9.2 ³	17.0 ⁴	6.3 ³
Blind	2.4	6.8	2.4	8.0	2.8	2.0	2.4	7.0	0.0 ³	9.1 ⁴
Hearing										
No or minor difficulty	6.7	3.1	10.3	4.8	6.2	2.6	7.4	4.5	7.9	2.6
Hard of hearing	10.8 ²	4.2 ⁴	15.5	6.3 ⁴	9.7	3.4 ²	14.1 ²	5.3 ²	16.5 ⁴	3.4 ²
Deaf/very hard of hearing	13.1 ²	7.1 ³	13.9	10.5 ³	10.6	6.9 ³	9.9	8.3 ⁵	16.6 ²	7.0 ³
Walking										
No or minor difficulty	6.4	3.0	8.9	4.3	6.5	2.3	6.8	4.0	6.8	2.5
Moderate difficulty	7.4	4.9 ³	13.4 ²	8.2 ³	8.4	4.4 ³	11.1 ⁴	6.4 ³	16.6 ³	4.8 ³
Major difficulty	10.8 ⁴	6.6 ³	15.5 ⁵	9.8 ³	6.6	5.6 ³	9.4 ⁴	8.5 ³	11.9 ⁴	5.2 ³
Reaching overhead										
No or minor difficulty	7.4	3.2	10.4	4.9	6.5	2.5	8.4	4.4	8.2	2.7
Moderate difficulty	9.5	6.2 ³	17.3 ²	9.5 ³	9.1	4.9 ⁵	11.8	8.6 ³	12.0	5.5 ⁵
Major difficulty	10.6	7.4 ³	13.2	9.8 ³	9.8	7.2 ³	8.7	8.7 ³	19.4 ⁵	5.1 ³
Grasping and writing										
No or minor difficulty	7.9	3.3	10.8	5.0	6.8	2.8	8.3	4.4	8.7	2.8
Moderate difficulty	7.2	6.8 ³	13.2	9.9 ³	7.7	4.5 ⁴	8.8	8.1 ³	14.8	4.4 ²
Major difficulty	9.8	7.9 ³	16.7	11.1 ³	10.3	7.9 ³	11.6	10.8 ³	15.0 ²	7.1 ³
Any of the above conditions										
No or minor difficulty	4.6	2.4	7.6	3.0	5.9	1.7	5.2	3.3	4.5	1.8
Any moderate difficulty	7.6 ²	3.7 ³	13.4 ²	5.8 ³	7.7	2.9 ³	11.3 ⁴	4.9 ³	12.8 ³	3.2 ⁵
Any major difficulty	10.4 ³	6.3 ³	12.8 ²	9.1 ³	8.0	5.7 ³	8.9 ²	7.9 ³	12.6 ³	5.4 ³

Information source: 1996 Medicare Current Beneficiary Survey.

Overall, 'overall quality of the medical services received in the last year'; Information, 'information given about what was wrong with you'; Follow-up, 'follow-up care received after an initial treatment or operation'; Concern, 'concern of doctors for overall health rather than just for an isolated symptom of disease'; Specialists, 'availability of care by specialists when needs it'.

¹Reweighted population percentages. Figures adjusted by age group and sex.

Statistical significance of differences with people with no or minor difficulties: ² $P=0.05$, ³ $P<0.0001$, ⁴ $P<0.01$, ⁵ $P<0.001$.

Table 4 Adjusted percentages¹ of patients dissatisfied with access by disabling condition and age

Disabling condition	Access to care and age									
	Availability		Ease		Costs		Location		Telephone	
	<65 years	≥65 years	<65 years	≥65 years	<65 years	≥65 years	<65 years	≥65 years	<65 years	≥65 years
Vision										
No or minor difficulty	9.6	4.6	9.3	4.8	22.3	11.1	11.2	4.3	10.8	5.3
Very low vision	20.7 ²	8.8 ³	22.3 ⁴	10.4 ³	41.5 ³	19.3 ³	15.6 ²	7.3 ⁴	17.0 ²	8.6 ³
Blind	23.7	16.1 ²	25.2 ²	19.0 ³	27.0	18.7	4.5	2.5	3.2	5.9
Hearing										
No or minor difficulty	7.6	4.2	8.8	4.6	23.2	11.1	9.2	4.0	10.0	4.8
Hard of hearing	16.7 ⁴	5.7 ²	14.8 ⁵	6.0 ⁵	25.4	11.6	18.3 ³	4.8	14.4 ⁵	6.1 ²
Deaf/very hard of hearing	23.0 ³	7.7 ⁵	21.4 ⁵	9.4 ³	39.0 ⁵	17.3 ³	18.8 ²	8.0 ³	17.2 ²	8.7 ³
Walking										
No or minor difficulty	7.7	4.4	7.6	3.9	19.6	9.9	8.3	3.6	7.5	4.8
Moderate difficulty	12.7 ²	6.1 ²	15.3 ⁴	7.2 ³	31.1 ⁵	13.6 ⁴	18.4 ⁴	6.4 ³	19.9 ³	7.5 ³
Major difficulty	12.9 ⁵	6.9 ⁵	13.5 ⁵	11.2 ³	29.9 ⁴	20.1 ³	12.6 ⁵	8.1 ³	11.4 ⁵	7.8 ⁴
Reaching overhead										
No or minor difficulty	9.6	4.6	9.5	4.6	21.9	10.5	10.6	4.0	9.5	5.0
Moderate difficulty	14.0	6.8 ²	14.7	8.2 ⁴	36.1 ³	17.5 ³	16.7	7.3 ⁴	15.8 ²	10.4 ³
Major difficulty	11.5	7.6 ⁵	14.4	11.8 ³	25.8	21.1 ³	15.6	7.6 ³	14.4 ²	7.0 ²
Grasping and writing										
No or minor difficulty	9.1	4.6	8.5	4.7	22.1	11.0	10.3	4.1	10.7	5.2
Moderate difficulty	14.4	7.4 ⁵	18.0 ⁵	9.1 ³	32.8 ²	16.0 ⁴	17.7	6.5 ⁵	13.6	8.8 ³
Major difficulty	16.7	6.6	18.5 ⁵	12.6 ³	30.8 ²	19.0 ³	13.8	9.4 ³	13.0	9.2 ⁴
Any of the above conditions										
No or minor difficulty	4.3	3.4	5.9	2.5	17.6	8.8	6.7	3.1	5.9	4.4
Any moderate difficulty	12.0 ³	5.1 ²	12.2 ⁵	5.1 ³	25.7 ²	11.1 ⁴	15.8 ⁴	4.3 ³	14.0 ⁴	5.5 ²
Any major difficulty	13.2 ³	7.4 ³	13.5 ³	10.0 ³	29.2 ⁴	17.8 ³	12.5 ⁵	7.8 ³	12.8 ³	7.8 ³

Information source: 1996 Medicare Current Beneficiary Survey.

Availability, 'availability of medical services at night and on weekends'; Ease, 'ease and convenience of getting to a doctor from where person lives'; Costs, 'out-of-pocket costs paid for medical services'; Location, 'getting all medical care needs taken care of at the same location'; Telephone, 'ease of obtaining answers to questions over the telephone about treatment or prescriptions'.

¹Reweighted population percentages. Figures adjusted by age group and sex.

² $P=0.05$, ³ $P<0.0001$, ⁴ $P<0.001$, ⁵ $P<0.01$.

Table 5 Adjusted odds ratios (95% CI)¹ of being dissatisfied with care by disabling condition and age

Disabling condition	Aspect of care and age									
	Overall		Information		Follow-up		Concern		Specialists	
	<65 years	≥65 years	<65 years	≥65 years	<65 years	≥65 years	<65 years	≥65 years	<65 years	≥65 years
Vision										
Very low vision	1.9 ² (1.1–3.2)	2.2 ³ (1.6–2.9)	1.9 ² (1.1–3.1)	2.0 ³ (1.6–2.6)	2.1 ² (1.1–4.0)	2.1 ³ (1.6–2.8)	1.5 (0.8–2.7)	2.3 ³ (1.7–3.0)	2.4 ⁴ (1.4–4.0)	2.5 ³ (1.9–3.2)
Blind	0.5 (0.0–5.0)	1.4 (0.4–4.8)	0.3 (0.0–3.5)	1.8 (0.8–4.2)	0.4 (0.0–3.8)	1.4 (0.4–4.4)	0.3 (0.0–3.9)	1.6 (0.6–4.6)	0.0 ³ (0.0–0.0)	3.7 ⁴ (1.4–9.6)
Hearing										
Hard of hearing	1.6 ² (1.0–2.4)	1.5 ⁵ (1.2–1.9)	1.5 ² (1.0–2.4)	1.3 ² (1.0–1.6)	1.6 (0.9–2.8)	1.4 ² (1.0–1.8)	1.8 ⁴ (1.2–2.7)	1.3 ² (1.0–1.7)	2.0 ⁴ (1.3–3.2)	1.4 ² (1.1–1.9)
Deaf/very hard of hearing	1.9 ² (1.1–3.5)	2.3 ³ (1.6–3.5)	1.6 (0.8–3.3)	2.3 ³ (1.7–3.0)	1.8 (0.9–3.7)	2.6 ³ (1.7–4.1)	1.6 (0.6–3.9)	1.9 ⁵ (1.3–2.7)	1.8 (1.0–3.4)	2.5 ³ (1.6–3.9)
Walking										
Moderate difficulty	1.2 (0.9–1.8)	1.6 ⁵ (1.3–2.2)	1.5 ² (1.1–2.2)	2.0 ³ (1.6–2.5)	1.4 (0.9–2.3)	2.0 ⁵ (1.4–2.8)	1.7 ⁴ (1.2–2.6)	1.8 ³ (1.4–2.3)	2.9 ³ (2.0–4.4)	1.9 ³ (1.4–2.6)
Major difficulty	2.2 ⁴ (1.4–3.6)	2.4 ³ (1.9–3.2)	2.3 ⁵ (1.4–3.8)	2.5 ³ (2.0–3.2)	1.1 (0.6–2.1)	2.7 ³ (2.0–3.6)	2.0 ⁴ (1.3–3.0)	2.4 ³ (1.9–3.1)	1.9 ⁴ (1.2–3.1)	2.0 ³ (1.4–2.8)
Reaching overhead										
Moderate difficulty	1.2 (0.7–2.0)	2.1 ³ (1.5–2.9)	1.9 ² (1.2–3.0)	2.1 ³ (1.6–2.8)	1.4 (0.8–2.5)	2.1 ⁵ (1.4–3.2)	1.5 (0.8–2.6)	2.2 ³ (1.7–3.0)	1.4 (0.8–2.5)	2.1 ³ (1.4–2.9)
Major difficulty	1.2 (0.7–2.0)	2.6 ³ (2.0–3.5)	1.1 (0.7–1.8)	2.2 ³ (1.8–2.8)	1.2 (0.7–2.2)	3.3 ³ (2.3–4.5)	1.0 (0.5–1.7)	2.4 ³ (1.9–3.1)	2.2 ⁵ (1.5–3.3)	2.0 ³ (1.5–2.7)
Grasping and writing										
Moderate difficulty	1.0 (0.6–1.7)	2.1 ³ (1.5–3.1)	1.0 (0.6–1.8)	2.2 ³ (1.7–2.8)	0.9 (0.4–1.9)	1.62 (1.1–2.3)	1.0 (0.6–1.6)	2.0 ³ (1.5–2.7)	1.7 1.0–3.2	1.6 ⁴ (1.1–2.2)
Major difficulty	1.3 (0.8–2.2)	2.7 ³ (1.9–3.9)	1.5 (0.9–2.5)	2.5 ³ (1.8–3.5)	1.7 ² (1.0–2.8)	2.9 ³ (1.8–4.5)	1.6 (0.9–2.8)	2.8 ³ (2.1–3.6)	1.9 ² (1.1–3.1)	2.4 ³ (1.7–3.4)
Any of the above conditions										
Any moderate difficulty	1.8 ⁴ (1.2–2.9)	1.8 ³ (1.4–2.3)	1.8 ² (1.0–3.0)	1.9 ³ (1.5–2.4)	1.4 (0.7–2.9)	2.1 ³ (1.5–3.0)	2.5 ⁴ (1.4–4.5)	1.8 ³ (1.4–2.2)	3.2 ³ (1.8–5.8)	2.0 ⁵ (1.4–2.9)
Any major difficulty	2.6 ³ (1.6–4.2)	3.2 ³ (2.4–4.3)	2.0 ² (1.1–3.6)	3.3 ³ (2.5–4.4)	1.5 (0.7–3.1)	4.4 ³ (3.1–6.4)	2.2 ⁴ (1.2–3.9)	3.1 ³ (2.4–4.1)	3.3 ³ (1.8–5.9)	3.2 ³ (2.2–4.6)

Information source: 1996 Medicare Current Beneficiary Survey.

Overall, ‘overall quality of the medical services received in the last year’; Information, ‘information given about what was wrong with you’; Follow-up, ‘follow-up care received after an initial treatment or operation’; Concern, ‘concern of doctors for overall health rather than just for an isolated symptom of disease’; Specialists, ‘availability of care by specialists when needs it’.

¹Adjusted for age group, sex, disabling condition, race, ethnicity, residence location (urban versus rural), education, household income (<\$25 000 and ≥\$25 000), having a usual source of care, proxy respondent, and managed care.
² $P=0.05$, ³ $P<0.0001$, ⁴ $P<0.01$, ⁵ $P<0.0001$.

Table 6 Adjusted odds ratios (95% CI)¹ of being dissatisfied with access to care by disabling condition and age

Disabling condition	Access to care and age									
	Availability		Ease		Costs		Location		Telephone	
	<65 years	≥65 years	<65 years	≥65 years	<65 years	≥65 years	<65 years	≥65 years	<65 years	≥65 years
Vision										
Very low vision	2.4 ² (1.3-4.3)	2.2 ³ (1.6-3.1)	3.1 ³ (1.8-5.3)	2.2 ³ (1.7-2.9)	2.5 ³ (1.7-3.6)	1.7 ³ (1.5-2.0)	1.8 ⁴ (1.1-2.9)	1.8 ⁵ (1.3-2.6)	1.9 ⁴ (1.1-3.2)	1.9 ³ (1.5-2.5)
Blind	0.5 (0.0-5.6)	4.2 ² (1.5-12.4)	4.4 (1.0-19.3)	3.9 ³ (2.2-7.0)	1.4 (0.5-3.5)	1.4 (0.7-3.0)	0.4 (0.0-3.8)	1.1 (0.2-4.5)	0.3 (0.0-4.2)	1.0 (0.3-3.3)
Hearing										
Hard of hearing	2.4 ⁵ (1.5-3.8)	1.4 ⁴ (1.0-1.9)	1.6 ⁴ (1.1-2.5)	1.3 ² (1.1-1.7)	1.0 (0.7-1.4)	1.1 (1.0-1.3)	2.0 ⁵ (1.4-2.9)	1.2 (1.0-1.5)	1.7 ² (1.1-2.4)	1.3 ⁴ (1.1-1.6)
Deaf/very hard of hearing	3.7 ³ (2.0-6.8)	1.9 ² (1.2-2.8)	2.9 ² (1.4-5.9)	2.0 ³ (1.5-2.8)	2.0 ² (1.2-3.4)	1.6 ⁵ (1.2-2.0)	2.1 ⁴ (1.0-4.3)	2.0 ³ (1.4-2.8)	2.3 ⁴ (1.2-4.4)	1.9 ³ (1.4-2.6)
Walking										
Moderate difficulty	1.8 ⁴ (1.1-3.0)	1.6 ² (1.1-2.2)	2.3 ³ (1.5-3.6)	2.0 ³ (1.5-2.5)	1.6 ² (1.2-2.2)	1.3 ² (1.1-1.6)	2.3 ⁵ (1.5-3.6)	2.0 ³ (1.6-2.6)	2.9 ³ (1.9-4.4)	1.7 ³ (1.3-2.2)
Major difficulty	1.9 ⁴ (1.2-3.2)	1.8 ² (1.2-2.6)	1.9 ⁴ (1.1-3.1)	3.2 ³ (2.5-4.0)	1.9 ⁴ 1.3-2.8)	2.0 ³ (1.7-2.5)	1.9 ² (1.2-2.9)	2.6 ³ (2.0-3.3)	1.9 ⁴ (1.2-3.2)	1.9 ³ (1.4-2.5)
Reaching overhead										
Moderate difficulty	1.3 (0.5-2.3)	1.6 ⁴ (1.1-2.2)	1.5 (0.9-2.6)	1.7 ⁵ (1.3-2.4)	2.0 ³ (1.4-2.7)	1.7 ³ (1.4-2.1)	1.6 (1.0-2.4)	1.9 ³ (1.4-2.7)	1.8 ⁴ (1.0-3.1)	2.3 ³ (1.6-3.1)
Major difficulty	1.2 (0.7-2.0)	1.8 ⁵ (1.2-2.6)	1.4 (0.9-2.1)	2.6 ³ (2.0-3.4)	1.2 (0.8-1.8)	2.1 ³ (1.7-2.6)	1.1 (0.8-1.7)	2.1 ³ (1.6-2.9)	1.8 ⁴ (1.1-2.9)	1.8 ² (1.2-2.5)
Grasping and writing										
Moderate difficulty	1.5 (0.8-2.9)	1.8 ² (1.3-2.6)	2.0 ² (1.2-3.3)	2.0 ³ (1.5-2.7)	1.8 ² (1.2-2.6)	1.4 ² (1.1-1.7)	1.8 ² (1.1-2.7)	1.7 ² (1.2-2.4)	1.3 (0.7-2.3)	1.9 ³ (1.4-2.5)
Major difficulty	1.8 ⁴ (1.0-3.2)	1.5 (0.9-2.4)	2.4 ² (1.4-4.3)	2.8 ³ (2.1-3.8)	1.8 ² (1.2-2.6)	1.8 ³ (1.4-2.3)	1.8 ⁴ (1.0-3.2)	2.7 ³ (1.9-3.7)	1.4 (0.8-2.5)	2.0 ³ (1.4-2.8)
Any of the above conditions										
Any moderate difficulty	3.0 ³ (1.8-4.9)	1.7 ² (1.2-2.4)	2.1 ² (1.2-3.6)	2.0 ³ (1.5-2.7)	1.4 (1.0-2.1)	1.3 ⁵ (1.1-1.6)	2.5 ² (1.4-4.3)	1.7 ³ (1.3-2.2)	2.7 ³ (1.6-4.4)	1.4 ⁴ (1.1-1.8)
Any major difficulty	3.5 ³ (2.0-6.0)	2.6 ³ (1.8-3.9)	2.3 ⁵ (1.4-3.6)	4.2 ³ (3.1-5.7)	2.1 ⁵ (1.4-3.1)	2.1 ³ (1.7-2.5)	2.0 ² (1.2-3.2)	3.4 ³ (2.7-4.3)	2.8 ⁵ (1.6-4.7)	2.2 ³ (1.7-3.0)

Information source: 1996 Medicare Current Beneficiary Survey.

Availability, 'availability of medical services at night and on weekends'; Ease, 'ease and convenience of getting to a doctor from where person lives'; Costs, 'out-of-pocket costs paid for medical services'; Location, 'getting all medical care needs taken care of at the same location'; Telephone, 'ease of obtaining answers to questions over the telephone about treatment or prescriptions'.

¹Adjusted for age group, sex, disabling condition, race, ethnicity, residence location (urban versus rural), education, household income (<\$25,000 and ≥\$25,000), having a usual source of care, proxy respondent, and managed care.

²P<0.01, ³P<0.0001, ⁴P=0.05, ⁵P<0.0001.

Table 7 Adjusted odds ratio (95% CI)¹ of being concerned about quality of care for persons enrolled in HMOs

Quality concern	Age	
	<65 years	≥65 years
Overall	0.9 (0.4–2.0)	1.3 (1.0–1.6) ²
Information	0.6 (0.3–1.3)	1.1 (0.8–1.4)
Follow-up	0.6 (0.3–1.3)	1.3 (1.0–1.8)
Concern	0.8 (0.5–1.6)	1.3 (1.0–1.6) ²
Specialists	0.8 (0.4–1.5)	2.4 (1.8–3.1) ³
Availability	1.6 (0.7–3.3)	1.1 (0.8–1.6)
Ease	1.4 (0.8–2.7)	0.9 (0.8–1.2)
Costs	0.5 (0.3–0.9) ²	0.4 (0.4–0.6) ³
Location	0.5 (0.2–0.9) ²	1.2 (0.9–1.5)
Telephone	1.1 (0.7–1.9)	1.3 (1.0–1.6) ²

Information source: 1996 Medicare Current Beneficiary Survey. Overall, ‘overall quality of the medical services received in the last year’; Information, ‘information given about what was wrong with you’; Follow-up, ‘follow-up care received after an initial treatment or operation’; Concern, ‘concern of doctors for overall health rather than just for an isolated symptom of disease’; Specialists, ‘availability of care by specialists when needs it’; Availability, ‘availability of medical services at night and on weekends’; Ease, ‘ease and convenience of getting to a doctor from where person lives’; Costs, ‘out-of-pocket costs paid for medical services’; Location, ‘getting all medical care needs taken care of at the same location’; Telephone, ‘ease of obtaining answers to questions over the telephone about treatment or prescriptions’.

¹Adjusted by age group, sex, race/ethnicity, urban/rural residence, education, income, proxy respondent, and having any disability. The reference group for the AORs is persons enrolled in fee-for-service Medicare.

Statistical significance of AOR: ² $P \leq 0.05$, ³ $P \leq 0.0001$.

(Table 7). Younger and older Medicare beneficiaries had slightly different views of HMOs, with managed care membership more likely to be associated with dissatisfaction for older persons. In particular, older beneficiaries in HMOs were much less satisfied with access to specialists ($P \leq 0.0001$). HMO members in both age groups, however, were significantly more satisfied with the costs of care.

Discussion

In general, persons with disabilities were satisfied with their care. More than 90% reported overall satisfaction, slightly less than the 98% without disabling conditions. As the extent of disability increased, however, so did the percentage of persons who were dissatisfied, although <10% typically reported problems.

The quality domains generating the greatest dissatisfaction (information about conditions, costs of care, availability and ease of getting to the doctor) seem predictable, given the nature of disabling conditions. Finding ways to improve these areas requires attention both inside and outside the health care system. The only dimension completely controlled by

physicians and other clinicians is providing better information to patients about their medical conditions. This may be more challenging with patients who are blind or deaf ASL users who do not easily read printed English, nevertheless devising strategies to communicate effectively is critically important. Wagner and colleagues examined the research evidence from the United States and Europe about improving health care outcomes, finding that providing information was one of four essential elements when designing systems of care for persons with chronic conditions [16].

Our results also support the other three elements identified by Wagner *et al.*: practice redesign (e.g. appointments, follow-up), patient education, and expert systems (e.g. provider education, consultations) [16]. In particular, improving availability of specialists, planning follow-up care, and enhancing telephone access could significantly ameliorate problems reported by disabled MCBS respondents. Improving the costs of care and ease of reaching doctors’ offices present more intractable difficulties.

The preponderance of problems reported by persons with disabilities reflects the ‘structure’ of the health care delivery system, highlighting the often neglected branch of Donabedian’s structure–process–outcome triad of quality measures [17,18]. Analysts often reduce structure to ‘bricks and mortar’, sometimes including credentialing and provider training. But Donabedian’s original formulation reached more broadly, defining structure as:

‘The relatively stable characteristics of the providers of care, of the tools and resources they have at their disposal, and of the physical and organizational settings in which they work. The concept of structure includes the human, physical, and financial resources that are needed to provide medical care ... [including] the ways that the financing and delivery of health services are organized, both formally and informally.’ [17]

Donabedian’s structural dimension thus encompasses payment policies and mechanisms, such as managed care.

Across our five disability categories, membership in managed care had relatively few associations with dissatisfaction, with several important exceptions. Compared with fee-for-service beneficiaries, managed care enrollees were significantly less satisfied with the availability of specialists and information over the telephone, but much more satisfied with costs of care. Theoretically, managed care, especially HMOs, offers advantages to people with disabilities or chronic illness [19]. Notable programs, such as the Community Medical Alliance in Boston, have successfully used the principles of prepaid care, under a capitated arrangement with Massachusetts Medicaid, to redesign delivery systems for people with severe disabilities [20]. For this program, patients must meet each of three eligibility criteria: permanent triplegia or quadriplegia; need for personal care attendant to maintain independent living; and one of several specified diagnoses (e.g. spinal cord injury, cerebral palsy, end-stage multiple sclerosis, AIDS). Care is provided by clinical teams of physicians and nurse practitioners. During a 32-month period spanning 1992–1994, only 212 persons with severe disabilities were enrolled: the

Community Medical Alliance targets a specific, small population.

Another analysis using the 1996 MCBS found that HMOs were superior to fee-for-service Medicare at providing preventive services [21]. During the 4-year Medical Outcomes Study, the health status of elderly persons and those most physically limited declined more among HMO compared with fee-for-service patients [22]. A 1993 survey of >20 000 active employees of three major corporations found that, compared with 'healthy' respondents, persons with chronic illnesses were significantly less satisfied with their health services, primarily in managed care rather than fee-for-service settings [2]. Ultimately, given our currently fragmented system of care, neither fee-for-service nor managed care may facilitate the desired level of care, especially for people with disabling conditions.

Dissatisfaction with the ease of accessing doctors' offices from where people live also presents a vexing challenge. The indicator of urban versus rural residence in our complete models was statistically insignificant for the ease of access question, as well as other dimensions of care. These results suggest that ease of access is not related primarily to rural residence. Since people with disabling conditions are much less likely to drive than other persons, having reliable public transportation, including systems that accommodate persons with disabilities, is critical. In addition, because people with disabilities are more likely to be poor (incomes <\$25 000), private payment of expensive taxi fares is often impossible. While some Medicaid programs provide taxi vouchers, Medicare does not. A solution to the ease of access problem must go well beyond the purview of the health care system alone.

This study has important limitations relating to its data source. The MCBS provides only self-reports of sensory and physical impairments. While self-reports provide the most authentic information about persons' perceptions of their functioning, the clinical accuracy of these assessments is unknown. Other studies have raised questions about the objectivity of such self-reports [23,24]. Proxies provided over one-fifth of the responses for persons aged <65 years, complicating interpretation of the findings [25–27]. Studies comparing self- with proxy-reports generate varied conclusions, but most suggest that proxies rate physical functional status and emotional and social well-being as more impaired than do patients [26–31]. From our MCBS database, we were unable to capture burden of medical illness. Despite its limitations, the MCBS offers a nationally representative insight into a large segment of the American population.

The good news to arise from our study is that most Medicare beneficiaries with disabling conditions are satisfied with their care. Nevertheless, strategies to mend areas of dissatisfaction will be complicated, requiring changes not only within the health care delivery system but also beyond, throughout local communities. With the aging population and concerns about safe driving among frail elderly persons [32–34], problems getting to doctor's offices from home will probably increase over future decades. Dissatisfaction with costs of care probably reflects inadequate or absent coverage

of prescription drugs or the assistive devices (e.g. eyeglasses, hearing aids, mobility aids) that help people with disabilities perform their daily activities [35,36]. Addressing these problems requires political consensus, which remains elusive. Meanwhile, one area where improvement is certainly possible is provision of complete information and education about self-management to disabled patients. This could help persons with disabilities make informed choices about their health care and about ways they can better enhance their own health [37–39].

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Appendix

Questions and responses from the Medicare Current Beneficiary Survey to define disabling conditions

Disability	Questions and responses from the MCBS
Vision	<p>'Do you wear eyeglasses or contact lenses?' (Yes/No/Blind)</p> <p>'Which statement best describes your vision?' (Wearing glasses/contact lenses)</p> <p>Blind on eyeglasses/contact lens question</p> <p>'A lot of trouble' on vision question</p>
Blind	
Very low vision	
Hearing	<p>'Do you use a hearing aid?' (Yes/No/Deaf)</p> <p>'Which statement best describes your hearing (even with a hearing aid)?'</p> <p>Deaf on hearing aid question, or 'a lot of trouble' on hearing question</p> <p>Uses hearing aid or has 'a little trouble' hearing</p>
Deaf/very hard of hearing	
Hard of hearing	
Walking	<p>'How much difficulty do you have walking a quarter of a mile (two or three blocks)?'</p> <p>'Because of a health or physical problem, do you have any difficulty walking by yourself and without special equipment?'</p> <p>'Unable to walk two to three blocks' or</p> <p>'Doesn't walk' by self without special equipment</p> <p>'A lot of difficulty' walking two to three blocks or 'difficulty' walking by self without equipment</p>
Major difficulties	
Moderate difficulties	
Reaching overhead	<p>'How much difficulty do you have reaching or extending your arms above shoulder level?'</p> <p>Reports being 'unable to do' or having 'a lot' of difficulty reaching</p> <p>Reports 'some' difficulty reaching</p>
Major difficulties	
Moderate difficulties	
Grasping and writing	<p>'How much difficulty do you have either writing or handling and grasping small objects?'</p> <p>Reports being 'unable to do' or having 'a lot' of difficulty with hands</p> <p>Reports 'some' difficulty with hands</p>
Major difficulties	
Moderate difficulties	

Information source: 1996 Medicare Current Beneficiary Survey.