
Profile of Medicare Beneficiaries With AIDS: Application of an AIDS Casefinding Algorithm

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This profile of Medicare beneficiaries with acquired immunodeficiency syndrome (AIDS) was developed by applying a casefinding algorithm to virtually all Medicare claims from 1991-93. The algorithm identified more than 37,000 beneficiaries with AIDS, approximately 21,000 of whom were living at the end of 1993. These estimates suggest that as many as 12 percent of people living with AIDS at the end of 1993 were covered by Medicare. Medicare expenditures for these beneficiaries averaged more than \$2,400 per month and totaled more than \$500 million in 1993. These expenditures are likely to rise as more people with AIDS live long enough to qualify for Medicare coverage.

BACKGROUND AND SIGNIFICANCE

Understanding the role Medicare plays in the service system for people with AIDS has become increasingly important. With the advent of new life-prolonging therapies, more people disabled by AIDS will survive long enough to qualify for Medicare. Thus, the number of people with AIDS who are covered by Medicare is likely to rise over time, with a corresponding increase in Medicare expenditures for AIDS.

Little is known about the number or

characteristics of people with AIDS who are covered by Medicare or about the share of AIDS costs borne by the Medicare program. Although several studies have estimated Medicare's share of inpatient hospital costs for treating human immunodeficiency virus (HIV) infection, the only information about the fraction of AIDS care financed by Medicare comes from surveys, such as the AIDS Cost and Services Utilization Survey (ACSUS), which focused on a relatively small (and potentially unrepresentative) sample of AIDS patients (Berk, Maffeo, and Schur, 1993).

This article presents an initial look at the population of people with AIDS who received Medicare-covered care during 1991, 1992, or 1993. The article discusses the AIDS epidemic and Medicare eligibility rules in relation to AIDS, describes the casefinding process and the evidence supporting its potential accuracy, and presents our findings from applying this casefinding process to a 100-percent sample of Medicare beneficiaries from 1991-93. In addition to estimating the number of Medicare beneficiaries with AIDS, we examine cases' eligibility, service use, and expenditure patterns. The results highlight the growing role Medicare is playing in funding AIDS-related care and provide a basis for future AIDS policy.

The AIDS casefinding methodology, which was developed at Mathematica Policy Research, Inc. (Thornton et al., 1997), approximates the 1993 Centers for Disease Control and Prevention (CDC) surveillance case definition for AIDS

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(Centers for Disease Control and Prevention, 1992). The methodology searches the Medicare claims data bases for diagnosis codes that suggest the presence of various elements of the CDC definition, including those for HIV infection and the occurrence of an AIDS-indicator condition. This methodology builds on an earlier approach reported by Keyes, Andrews, and Mason (1991), which was developed by Barbara Turner and extended in her work with the New York State Medicaid staff (Turner, McKee, Fanning, and Markson, 1993a, b).

Overall, we estimate that, at the end of 1993, 12 percent of AIDS cases in the United States were covered by Medicare. Approximately three-fourths of these beneficiaries qualified for Medicare because of a disability; the others were eligible because they were age 65 or older or had end stage renal disease (ESRD). Mortality rates were high among Medicare beneficiaries with AIDS: over 40 percent of the cases we identified between 1991 and 1993 had died by the end of 1993. While living, Medicare beneficiaries with AIDS required substantial levels of medical care; we estimate that Medicare spent more than \$2,400 per enrollment month for these beneficiaries. In contrast, Medicare expenditures for all disabled beneficiaries averaged slightly less than \$4,000 annually. These high expenditures reflect a high level of inpatient care: three-fourths of the beneficiaries with AIDS were admitted as inpatients during the 12 months following their identification by the algorithm.

AIDS Epidemic

The current CDC case definition of AIDS, in place since 1993, classifies persons as having AIDS if they show evidence of HIV infection and either one or more of a group of specified AIDS-defining condi-

tions or a CD4+ T-lymphocyte (CD4 T-cell) count below 200 cells/ μ L (Centers for Disease Control and Prevention, 1992). AIDS-defining conditions include a wide array of disease manifestations resulting from HIV infection; these include the serious opportunistic infection *pneumocystis carinii* pneumonia (PCP) and such cancers as Kaposi's sarcoma. Because AIDS is manifested differently in children under age 13 than in older people, the CDC has specified different groups of AIDS-defining conditions for the two populations.

As of December 1997, 619,690 cases of AIDS had been reported in the United States (Centers for Disease Control and Prevention, 1997b). An even larger number is expected to develop AIDS over the next decade as people infected with HIV progress to AIDS. Estimates of the number who had HIV infection (but not AIDS) in 1992 range from 550,000 to 800,000 (Karon et al., 1996). Statistical models suggest that at least 40,000 Americans are being infected with HIV each year (Centers for Disease Control and Prevention, 1996), and recent data from the 25 States that conduct name-based HIV surveillance suggest that the number of newly diagnosed HIV cases has remained relatively stable since 1994 (Centers for Disease Control and Prevention, 1998). Because the survival time for people with AIDS has increased markedly since the mid-1980s, the number of people living with AIDS at any given time is growing even faster than the number of new AIDS cases diagnosed (Centers for Disease Control and Prevention, 1997a).

CDC data show a steadily increasing life expectancy for people with AIDS: the percentage of adolescents and adults with AIDS who survived at least 2 years after diagnosis rose from 34 percent for those diagnosed in 1988 to 43 percent for those diagnosed in 1991 and 55 percent for those

diagnosed in 1993 (Centers for Disease Control and Prevention, 1991, 1993, and 1995). Median survival time for those diagnosed in 1990 or 1991 was 20.3 months, compared with 11.6 months for those diagnosed in 1984 or 1985 (Jacobson et al., 1993). From 1995 to 1996, for the first time in the epidemic, deaths among persons reported with AIDS decreased (Centers for Disease Control and Prevention, 1997b). New combination anti-retroviral therapies, including protease inhibitors, have dramatically improved not only the survival time for people diagnosed with AIDS but the prospects for AIDS-free survival among those infected with HIV (Palella et al., 1998). However, there is evidence that some people previously treated with antiretroviral therapy can develop multi-drug-resistant strains of HIV (Shafer et al., 1998). Such resistance—along with drug interactions, individual compliance problems, and other issues—means that an estimated 40 to 50 percent of the HIV-infected population will not benefit from available therapies (Hirschel and Francioli, 1998).

Medicare Coverage Rules

In general, people must be age 65 or older, disabled, or suffering from kidney failure to qualify for Medicare. In addition, they typically must have worked and paid into the Social Security system for a substantial period of time. (People over 65 without an adequate work history can buy into the Medicare system.)

A crucial feature of Medicare coverage for people with disabilities—including those disabled by AIDS—is the waiting period before eligibility commences. Disabled people can begin to collect Social Security cash benefits 5 months after the onset of their disability, but must wait an additional 24 months (for a total of 29

months) before they become eligible for Medicare coverage. In contrast, elderly people qualify for Medicare coverage the month they turn 65, and those with ESRD qualify within 3 months of the diagnosis of an irreversible kidney impairment that requires a regular course of dialysis or a kidney transplant to maintain life.

In the early years of the AIDS epidemic, few persons with AIDS survived the 29-month waiting period for Medicare disability coverage, but as management of AIDS-opportunistic infections has improved and drug therapies to slow progress of the disease have become available, life expectancy has increased. Consequently, the number of people with AIDS who survive long enough to obtain Medicare coverage is expected to grow.

METHODS

The AIDS casefinding methodology used in this analysis approximates the 1993 CDC surveillance case definition for AIDS by searching claims data bases for selected diagnosis codes or diagnosis-related group (DRG) codes that suggest the presence of HIV infection and AIDS-indicator conditions (Thornton et al., 1997). For this analysis, we searched for beneficiaries with AIDS by applying the casefinding algorithm to virtually all Medicare claims files from 1991-93.¹

The algorithm searches for two types of evidence of HIV-infection, the first of which is HIV- or AIDS-specific codes. These

¹ We searched five Medicare claims files: (1) Medicare provider analysis and review (MEDPAR) (includes inpatient and nursing facilities), (2) outpatient (includes only outpatient hospital), (3) physician/supplier: Part B, (4) hospice, and (5) home health. We excluded dental claims files, because such claims do not contain diagnoses. In addition, we excluded certain types of claims contained in the five selected files (for example, laboratory, X-ray, and equipment claims), because we believe the diagnostic information in them to be unreliable. For Part B and MEDPAR claims, we searched all diagnosis fields (9 and 10 fields per claim, respectively). For all other claims, we searched the first 10 diagnosis fields, based on an informal analysis which showed that claims rarely included more than 8 diagnoses.

Table 1
AIDS Casefinding Decision Rules for Adolescents and Adults

Requirements for Assignment to Specific Evidence Certainty Levels		Age Groups ¹	
Evidence of AIDS-Indicator Condition(s) ²	Evidence of HIV infection ³	13-60 Years	Over 60 Years
Level 1 One Inpatient or Two Outpatient Claims	One Inpatient or Two Outpatient Claims	x	x
Level 2a One Outpatient Claim	One Inpatient or Two Outpatient Claims	x	x
Level 2b One Inpatient or Two Outpatient Claims	One Outpatient Claim	x	—
Level 3 One Outpatient Claim	One Outpatient Claim	x	—
Level 4 One Inpatient Claim With an AIDS Diagnosis Code ⁴		x	—
Level 5 Two Outpatient Claims With an AIDS Diagnosis Code ⁴		x	—

¹Age is defined as patient age as of the first occurrence of a code for an AIDS-indicator condition or, in the case of people assigned to Level 4 or 5, the first occurrence of an AIDS diagnosis code.

²AIDS-indicator conditions include the opportunistic infections and other diseases determined by the CDC (1992) to be indicative of AIDS among people with HIV infection, as well as conditions highly correlated with low CD4+ T-cell counts.

³Evidence of HIV consists of ICD-9-CM diagnosis codes specific to HIV and/or AIDS (042-044 and 795.8), ICD-9-CM diagnosis codes that denote unspecified disorders involving the immune mechanism (279.1; 279.19; 279.3; 279.4; 279.9), and Medicare DRG codes that indicate HIV infection or AIDS (488-490). However, we excluded from the analysis cases in which (1) the only evidence of HIV infection was one or more of the general immunodeficiency diagnosis codes (codes in the 279 range) and (2) there was evidence of a treatment or condition other than HIV infection that might cause immunodeficiency (for example, collagen diseases or treatment with immunosuppressants following an organ transplant).

⁴AIDS diagnosis codes are the ICD-9-CM codes specific to AIDS (042.x and 043.1) and ICD-9-CM diagnosis codes that denote unspecified disorders involving the immune mechanism (279.1; 279.19; 279.3; 279.4; 279.9).

NOTES: AIDS is acquired immunodeficiency syndrome. HIV is human immunodeficiency virus. CDC is Center for Disease Control and Prevention. ICD-9-CM is *International Classification of Diseases, 9th Revision, Clinical Modification*. DRG is diagnosis-related group.

SOURCE: Thornton et al. (1997).

include *International Classification of Diseases, 9th Revision, Clinical Modification* (ICD-9-CM) diagnosis codes (042 to 044 and 795.8) and Medicare DRG codes (488 to 490) that indicate HIV infection or AIDS.² The second type consists of the ICD-9-CM diagnosis codes that denote unspecified disorders involving the immune system (five codes in the 279 range: 279.1; 279.19; 279.3; 279.4; 279.9), disorders that may, however, be attributable to causes other than AIDS. Before the development of specific codes for HIV infection, the unspecified codes were used to report all disorders of the immune system. To avoid stigma, some patients and physicians still prefer to use the less-specific codes, rather than HIV or AIDS codes.

The algorithm also searches for diagnosis codes associated with the AIDS-defining

conditions specified by the CDC and for diagnosis codes associated with conditions (such as microsporidiosis) that are highly correlated with low CD4+ T-cell counts. (Throughout this article, we refer to both types of conditions as “AIDS-indicator conditions.”) Multiple claims were required to establish the presence of certain conditions, such as recurrent pneumonia or HIV wasting syndrome.³

The algorithm sorted adults and adolescents who met the initial selection criteria into six groups (Table 1). The level of evidence depends on two factors:

Data Comprehensiveness: Whether information is available that indicates (a) HIV infection, and (b) an AIDS-indicator condition.

Data Accuracy: The degree of confidence we placed in the diagnosis coding in the claim. In general, claims filed by inpatient

² After October 1994, the ICD-9-CM system changed so that only one code (042) was used for HIV infection or AIDS (U.S. Department of Health and Human Services, 1994). In addition, the code VO8 was added to indicate asymptomatic HIV infection.

³ The list of AIDS-defining conditions was obtained from the Centers for Disease Control and Prevention (1992). Conditions suggestive of low CD4+T-cell count were determined in conversations with CDC staff. Thornton et al. (1997) provide the specific diagnoses used in the algorithm.

facilities contain more accurate diagnostic information than claims from other providers. Therefore, we required two outpatient claims, dated 30 days apart, whereas we required only one inpatient claim. (The two outpatient claims could be for the same or different conditions.) Also, we considered the specific ICD-9-CM codes for AIDS to be more reliable indicators of HIV infection than of AIDS. Hence, cases with no other evidence of AIDS than these codes were assigned to the lowest evidence levels.

Cases with strong evidence of both an AIDS-indicator condition and HIV infection were assigned to Level 1. Those with strong evidence of an AIDS-indicator condition and weaker evidence of HIV infection (or vice versa) were assigned to Level 2a or 2b. Cases with weaker evidence of both were assigned to Level 3. Those with a diagnosis of AIDS (that is, cases where the claims data contain a specific ICD-9-CM diagnosis of AIDS) but no direct evidence of an AIDS-indicator condition were assigned to Level 4 or 5, depending on the probable accuracy of the AIDS diagnosis.

In classifying cases, the algorithm made two exclusions. First, it excluded people who were more than 60 years old from all evidence levels except 1 and 2a. This exclusion was made because many of the conditions used as indicators of AIDS occur among elderly people in the absence of HIV infection. In order to ensure that our algorithm was specific in identifying AIDS cases, we excluded all seniors who lacked clear evidence of both HIV infection and an AIDS-indicator condition. The second exclusion pertained to those cases in which the only evidence of HIV infection was one or more of the general immunodeficiency diagnosis codes (codes in the 279 range). We excluded from the analysis any of these cases where there was evidence of a treatment or condition other than HIV

infection that might cause immunodeficiency (for example, collagen diseases or treatment with immunosuppressants following an organ transplant).

RESULTS

The casefinding algorithm identified a total of 37,588 AIDS cases among all the Medicare beneficiaries enrolled during the period 1991-93.⁴ Table 2 shows unduplicated counts of people who met the requirements for each evidence level during this 3-year period. (People were assigned to the highest evidence level for which they qualified during the study period.) The distribution of cases among evidence levels is as follows:

- Sixty-five percent of identified cases are in Level 1, the group with strong evidence of both HIV infection and an AIDS-indicator condition (one inpatient or multiple outpatient claims for each).
- Fourteen percent are in Level 2 or 3 and have at least some evidence of both HIV infection and an AIDS-indicator condition.
- Twenty-one percent are in Level 4 or 5, groups identified on the basis of AIDS diagnosis codes alone. Many of those assigned to Levels 4 and 5 had multiple claims suggesting the presence of AIDS, although the claims record contains insufficient information for the higher evidence levels.⁵ (This might occur, for example, when someone has multiple AIDS diagnoses but only a single pneumonia diagnosis, which would be insufficient to establish the AIDS-indicator condition of recurrent pneumonia.)

Table 2 also shows the number of people, by the highest level assigned, thought to

⁴ The total includes Medicare beneficiaries in the 50 States, the District of Columbia, and Puerto Rico.

⁵ Overall, people in Levels 4 and 5 had an average of about 18 claims related to AIDS. Most of these claims contained one of the AIDS diagnosis codes. In all cases, there was insufficient cumulative evidence to identify an AIDS-indicator condition.

Table 2

Algorithm-Identified Medicare AIDS Cases: 1991-93

	1	Evidence Certainty Level ¹					All Levels
		2a	2b	3	4	5	
Total Number of Individuals	24,494	2,821	1,627	626	2,661	5,359	37,588
Percentage of Total Number of Individuals Identified	65.2	7.5	4.3	1.7	7.1	14.3	100
Total Number of Individuals Known to Have Died During Study Period	13,929	788	379	200	910	496	16,702
Percentage of Identified Individuals Known to Have Died During Study Period	56.9	27.9	23.3	31.9	34.2	9.3	44.4
Number of Individuals Not Known to Have Died by the End of Study Period	10,565	2,033	1,248	426	1,751	4,863	20,886

¹ Requirements for assignment to specific evidence certainty levels appear in Table 1.

NOTE: AIDS is acquired immunodeficiency syndrome.

SOURCES: Medicare national claims and enrollment files for 1991-93. AIDS cases were identified using a claims-based casefinding algorithm (Thornton et al., 1997).

be living at the end of the study period. (Because death reporting in the Medicare eligibility files is not complete, the actual number of cases who died during the study period may be higher.) Depending on whether we apply the most restrictive criteria (and include only cases in Level 1) or the least restrictive criteria (and include cases in all levels), our estimates show 10,565 to 20,886 Medicare beneficiaries living with AIDS at the end of 1993, which represent 6 to 12 percent of the approximately 173,000 living AIDS cases in the United States or U.S. territories at the end of 1993 (Centers for Disease Control and Prevention, 1997b).

Demographic Characteristics

Of the 36,891 beneficiaries for whom we have complete records of Medicare-financed utilization and expenditures, 81 percent were male, 61 percent were white, and 68 percent were between the ages of 21 and 45 when identified by the algorithm (Table 3).⁶ The mean age was 43.8 years. The mortality rate was high: 44 percent of the cases were reported to have died by the end of the study period.

Variations Across Evidence Levels

In general, the variations in demographic characteristics across evidence levels suggest that the casefinding criteria for the different evidence levels may have identified different kinds of AIDS cases. More than half (57 percent) of those assigned to Level 1 died before the end of 1993. Mortality rates were lower for the other evidence levels, and considerably lower for some. The vast majority of those in Level 5 (91 percent) were reportedly still living at

the end of the study period. People assigned to this level had multiple outpatient claims with AIDS diagnosis codes. Many also had claims showing some evidence of AIDS-related conditions but not enough to establish an AIDS-indicator condition (as defined by the algorithm). It is reasonable to expect that people in this evidence level would in general be less sick and would therefore have lower mortality rates than those with inpatient claims with AIDS diagnosis codes (Level 4) or those with evidence of both HIV infection and an AIDS-indicator condition (Levels 1, 2, and 3).

Age also varies across evidence levels. Most of this variation can be explained by the fact that people older than 60 at the time of their first relevant claim (the first claim with a diagnosis code suggesting the presence of HIV infection or an AIDS-indicator condition) could be classified only in Levels 1 or 2; hence, the mean age for these levels is higher than average.

Comparison With CDC Data

Not surprisingly, the demographic profile of Medicare beneficiaries with AIDS differs from that of the general AIDS population. Table 4 compares Medicare beneficiaries living with AIDS with all people known to the CDC to be living with AIDS at the end of each of the 3 years under study. In general, cases identified in the Medicare data are older (31 percent were 46 or older at the end of 1993, compared with 17 percent of all AIDS cases alive in 1993) and more likely to be female (23 percent versus 16 percent).⁷

By our estimate, 18 percent of females known to have AIDS (4,725 of 26,700) were covered by Medicare at the end of 1993, compared with 11 percent of males. These

⁶ Our profile excludes the 667 Medicare beneficiaries who were enrolled in managed care at some time during the 3-year study period (1991-93).

⁷ The racial/ethnic breakdowns in the Medicare data are not strictly comparable to those in the CDC data, because persons of Hispanic origin are categorized differently in the two data sets.

Table 3

Demographic Characteristics of Identified Medicare AIDS Cases, by Evidence Level: 1991-93

	Evidence Level					All Levels
	1	2	3	4	5	
Total Individuals	24,015	4,385	613	2,589	5,289	36,891
Vital Status at End of 1993						
Reported Dead	56.8	26.2	32.0	34.1	9.1	44.31
Not Reported Dead	43.2	73.8	68.0	65.9	90.9	55.7
				Percent		
Sex						
Male	81.7	70.7	81.2	84.2	81.4	80.5
Female	18.3	29.3	18.8	15.8	18.6	19.5
Age						
Under 13 Years	(1)	0.1	(1)	(1)	(1)	(1)
13 - 20 Years	0.1	0.6	0.2	0.2	0.3	0.2
21 - 45 Years	65.6	53.7	71.5	81.2	80.1	67.5
46 - 59 Years	12.6	22.8	26.3	17.7	18.6	15.3
60 - 64 Years	2.5	3.3	2.1	0.8	0.9	2.2
65 Years or Over	19.1	19.6	0	0	0	14.8
Mean Age (Years)	45.1	47.4	40.5	38.3	38.3	43.8
Race/Ethnicity						
African American	29.8	27.7	21.7	29.2	23.0	28.4
White	59.9	63.9	66.9	58.6	66.4	61.3
Other/Unknown	10.3	8.4	11.4	12.2	10.5	10.3

¹Less than 0.05 percent.

NOTES: The table includes only persons with complete records of Medicare-financed utilization and expenditures. Excluded from the analysis were 667 persons who were enrolled in managed care plans at some point during the study period. AIDS is acquired immunodeficiency syndrome.

SOURCES: Medicare national claims and enrollment files for 1991-93. AIDS cases were identified using a claims-based casefinding algorithm (Thornton et al., 1997).

Table 4
Living AIDS Cases, by Sex, Age, and Race for Medicare Beneficiaries and All AIDS Cases: 1991-93

Demographic Groups	Cases Alive at End of 1991			Cases Alive at End of 1992			Cases Alive at End of 1993					
	Identified in Medicare Data		Reported to CDC	Identified in Medicare Data		Reported to CDC	Identified in Medicare Data		Reported to CDC			
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent		
Total Individuals ¹	10,262	100	101,000	100	15,598	100	138,600	100	20,537	100	173,100	100
Sex												
Male	7,491	73.0	86,400	87.4	11,706	75.0	116,800	85.9	15,812	77.0	143,500	84.3
Female	2,771	27.0	12,500	12.6	3,892	25.0	19,200	14.1	4,725	23.0	26,700	15.7
Age												
Under 13 Years	5	0	2,048	2.1	10	0.1	2,529	1.9	12	0.1	2,879	1.7
13 - 20 Years	41	0.4	525	0.6	50	0.3	738	0.6	70	0.3	908	0.5
21 - 45 Years	6,077	59.2	80,606	82.1	9,910	61.9	110,137	81.5	14,036	68.3	136,185	80.4
46 - 59 Years	1,696	16.5	12,891	13.1	2,502	16	18,720	13.9	3,244	15.8	25,424	15.0
60 - 64 Years	295	2.9	1,201	1.2	375	2.4	1,681	1.2	426	2.1	2,221	1.3
65 Years or Over	2,148	20.9	873	0.9	2,751	17.6	1,294	1.0	2,749	13.4	1,734	1.0
Mean Age (Years)		46.2		NA		45.0		NA		43.5		NA
Race/Ethnicity²												
African American	3,119	30.4	31,200	31.0	4,579	29.4	45,000	32.9	6,050	29.5	60,400	34.9
White	6,292	61.3	51,900	51.5	9,584	61.4	68,000	49.1	12,519	61.0	80,000	46.2
Other/Unknown	851	8.3	17,700	17.5	1,435	9.1	24,950	18.0	1,968	9.6	32,615	18.9

¹Tabulations for the various breakdowns of total AIDS cases shown in the table were run at different times and do not all sum to the same totals. (The age subgroups sum to 98,144 in 1991, 135,099 in 1992, and 169,351 in 1993.) Medicare cases include only persons with complete records of Medicare financed utilization and expenditures; excluded from the analysis were 667 persons who were enrolled in managed care plans at some point during the study period.

²The racial/ethnic breakdowns in the Medicare data are not strictly comparable to those in the CDC data, since persons of Hispanic origin are categorized differently in the two data sets.

NOTES: AIDS is acquired immunodeficiency syndrome. CDC is Centers for Disease Control and Prevention. NA is not available.

SOURCES: Medicare national claims and enrollment files for 1991-93. AIDS cases were identified using a claims-based casefinding algorithm (Thornton et al., 1997, Centers for Disease Control and Prevention, 1997; and Richard Sellick, unpublished tabulations from CDC data.

Table 5
Number of Identified Medicare AIDS Cases, by Reason for Entitlement: 1991-93

Reason for Entitlement	Number	Percent
Total ¹	36,891	100.00
Aged Without ESRD	5,392	14.6
Aged With ESRD	463	1.3
Disabled Without ESRD	27,280	74.0
Disabled With ESRD	2,066	5.6
ESRD Only	1,688	4.6

¹Total includes two persons for whom eligibility group and enrollment data are missing.

NOTES: The table includes only persons with complete records of Medicare-financed utilization and expenditures. Excluded from the analysis were 667 persons who were enrolled in managed care plans at some point during the study period. AIDS is acquired immunodeficiency syndrome. ESRD is end stage renal disease.

SOURCES: Medicare national claims and enrollment files for 1991-93. AIDS cases were identified using a claims-based casefinding algorithm (Thornton et al., 1997).

disproportionate rates of coverage are consistent with the findings of other studies. For example, Harris and Ball (1994) found that 6.7 percent of hospital discharges for HIV-infected females were covered by Medicare in 1987, compared with 4.4 percent of discharges for HIV-infected males.

Our data also indicate that the percentage of AIDS cases covered by Medicare increases with age. Ten percent of all persons with AIDS age 21 to 45 were covered by Medicare at the end of 1993, compared with 13 percent of those 46 to 59 and 19 percent of those 60 to 64. Our findings regarding persons with AIDS age 65 or older raise several questions. The algorithm identified 2,749 persons with AIDS who were 65 or older at the end of 1993. This total is almost 60 percent greater than the number of elderly AIDS cases known to the CDC at the time (1,734). This discrepancy indicates either that the casefinding algorithm misidentified as AIDS cases persons who do not have AIDS or that there is serious underreporting to the CDC of AIDS cases in this age range.

Eligibility for Medicare

The distribution of eligibility groups among algorithm-identified Medicare beneficiaries with AIDS is generally what we expected. Three-fourths (74 percent) of

the persons with AIDS identified in the Medicare data qualified for coverage on the basis of disability alone (Table 5). Because almost 99 percent of the people diagnosed with AIDS and reported to the CDC by the end of 1993 were under age 65, we expected this to be the major eligibility group. Many of these people probably qualified because of AIDS-related disability, although some may have qualified because of other disabilities, including mental illness.

The algorithm identified a reasonable number of AIDS cases who qualified for Medicare because of ESRD. A total of 4,217 algorithm-identified AIDS cases were diagnosed with ESRD by the end of the study period.⁸ This total represents 12 percent of all the AIDS cases identified in the Medicare data. Persons with ESRD represent just 0.2 percent of the total Medicare population. However, the greater prevalence of ESRD among Medicare beneficiaries with AIDS than among Medicare beneficiaries generally is not surprising, because renal insufficiencies and failure are common among HIV-infected people. In the mid-to-late-1980s, HIV-associated nephropathy was seen in 5 to 10 percent of those with HIV (Staiman, Kwan, and Lowe,

⁸ This number includes 1,688 who qualified on the basis of ESRD, 2,066 who qualified on the basis of disability and ESRD, and 463 who qualified because of age and ESRD. All the children identified as AIDS cases qualified under ESRD provisions.

1996). During the time period covered by our study, AIDS was spreading rapidly among intravenous drug users, the group at the highest risk of developing HIV-associated nephropathy (Schoenfeld, 1990). Typically, HIV-associated nephropathy proceeds to ESRD within 1 year (Staiman, Kwan, and Lowe, 1996). Because people with AIDS who are diagnosed with ESRD can qualify for Medicare coverage within 3 months, we would expect a large proportion of AIDS cases with renal failure to be covered by Medicare. Assuming that estimates of the incidence of HIV-associated nephropathy are correct, more than 8,000 persons living with AIDS at the end of 1993 (5 percent of 173,100) had renal disease and either had or were at risk for ESRD.

Somewhat surprisingly, many of the Medicare beneficiaries identified by the algorithm had been enrolled in Medicare for more than 3 years prior to their identification (Table 6). Although this is plausible for the elderly, some of whom qualified for Medicare before they contracted AIDS, the length of Medicare enrollment for disability and ESRD cases seems too long. Almost one-third (30 percent) of all cases had been covered by Medicare for 3 or more years before classification. Overall, only 18 percent had no prior enrollment (that is, the algorithm classified them as AIDS cases in the first month they were eligible for Medicare), and another 33 percent were classified before they had been enrolled for 1 year.

Among algorithm-identified AIDS cases who qualified as disabled (with or without ESRD), 22 percent were enrolled 3 or more years before they were identified. If these people qualified for Medicare only because of their AIDS diagnosis, the length of their enrollment prior to identification indicates that they had survived at least 5 years with AIDS before the algorithm identified them. In contrast, only 8 percent of all adults liv-

ing with AIDS in June 1993 had survived 5 years or more after their diagnosis (Centers for Disease Control and Prevention, 1993). This longevity suggests either that a number of Medicare beneficiaries with AIDS qualified for Medicare on the basis of a disability that began before the onset of AIDS or that people with AIDS who live long enough to qualify for Medicare on the basis of disability are an unusual subset of the AIDS population.

The enrollment patterns for algorithm-identified ESRD cases seem more problematic. Of 4,217 AIDS cases identified in the Medicare data who were diagnosed with ESRD by the end of the study period, 50 percent had survived 1 or more years—and 29 percent had survived 3 or more years—by the time the algorithm identified them.⁹ Evidence of high mortality rates among HIV-infected persons who develop ESRD (Vapnek and McAninch, 1990) suggests that some ESRD cases the algorithm identified were either misidentified as AIDS cases or had renal failure (and Medicare eligibility) before they contracted AIDS.

Mortality

The mortality rate for the AIDS cases identified was high: 44 percent of the people identified between 1991 and 1993 died before the end of the study period. Annual mortality rates were quite constant. Figure 1 illustrates the flow into and out of the group of living AIDS cases in each year of our study period. In 1991, 13,908 cases were identified by the algorithm. By year's end, 3,646 (26 percent) had died. In 1992, an additional 10,743 cases were identified by the algorithm, bringing the total number of cases covered by Medicare at some

⁹ These figures aggregate the three eligibility groups with ESRD: those with ESRD only, ESRD and disability, and ESRD and age over 64.

Table 6

Frequency Distribution of Years of Enrollment Prior to Identification for Medicare Beneficiaries, by Reason for Entitlement: 1991-93

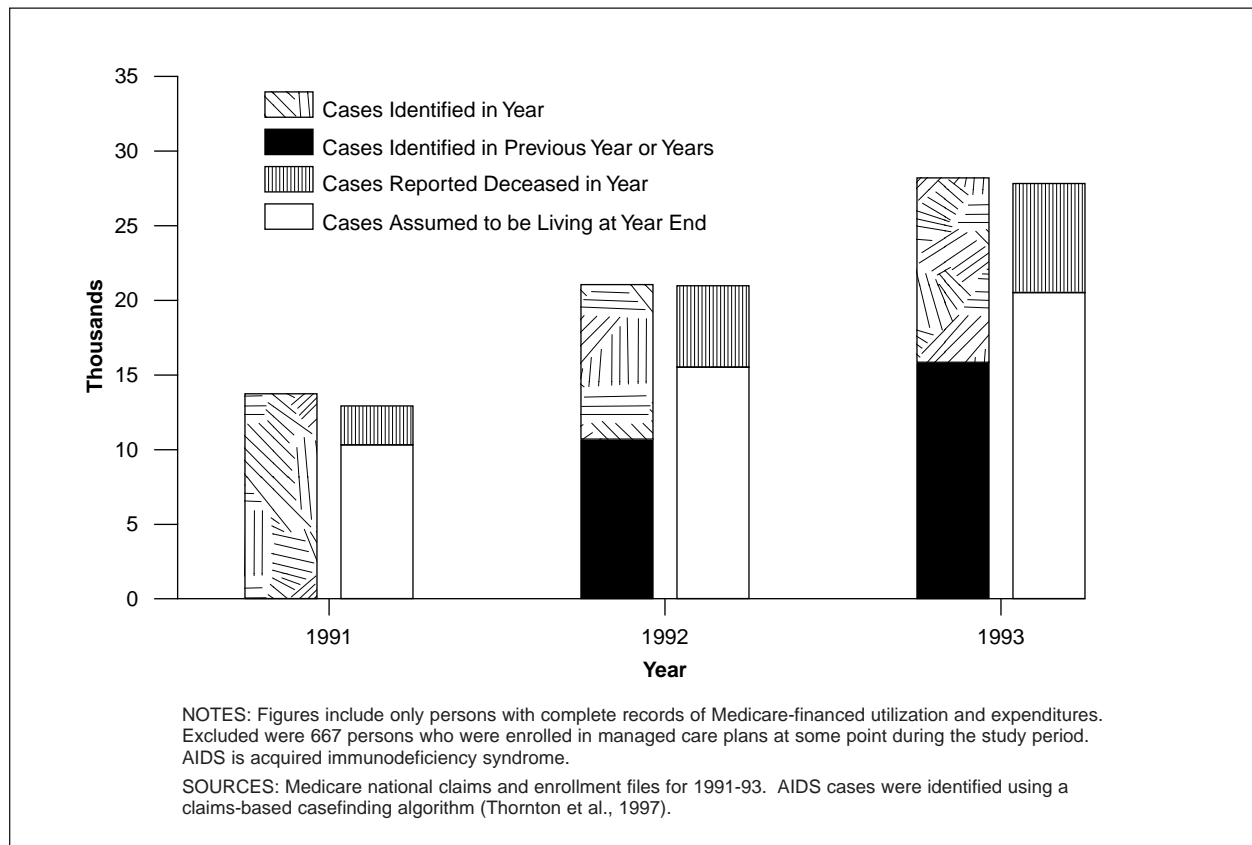
Prior Enrollment	Percent of Identified AIDS Cases, by Reason for Entitlement							Total (N=36,891)
	Aged Without ESRD (N=5,392)	Aged With ESRD (N=463)	Disabled Without ESRD (N=27,280)	Disabled With ESRD (N=2,066)	ESRD Only (N=1,688)			
Total ¹	100.00	100.00	100.00	100.00	100.00	100.00	100.00	100.00
None	2.2	3.9	18.6	28.7	43.0			17.7
Less Than 1 Year	8.5	8.9	39.3	23.9	24.1			32.8
1 Year to Less Than 2 Years	7.8	7.6	13.6	12.8	10.6			12.5
2 Years to Less Than 3 Years	6.6	7.6	7.1	8.6	6.3			7.0
3 or More Years	73.7	71.5	21.5	26.0	15.9			29.8
Unknown	1.3	0.7	0	0	0.1			0.2

¹Total includes two persons for whom reasons for entitlement or length of enrollment are missing.

NOTES: The table includes only persons with complete records of Medicare-financed utilization and expenditures. Excluded from the analysis were 667 persons who were enrolled in managed care plans at some point during the study period. AIDS is acquired immunodeficiency syndrome. ESRD is end stage renal disease.

SOURCES: Medicare national claims and enrollment files for 1991-93. AIDS cases were identified using a claims-based casefinding algorithm (Thornton et al., 1997).

Figure 1
Medicare AIDS Cases Identified and Reported Deceased: 1991-93



point during the year to 21,005. By year's end, 5,407 (26 percent) of these cases had died. In 1993, an additional 12,240 cases were identified, bringing the total number of cases covered by Medicare at some point during the year to 27,838. By year's end, 7,301 (26 percent) had died.

Utilization and Expenditure Patterns for Medicare Beneficiaries with AIDS

People with AIDS use substantial amounts of medical care. For example, Hellinger (1993a, b) estimated that the cost of treating people with AIDS averaged \$2,764 per month (1992 dollars). Similarly, the Community Medical Alliance (CMA), a capitated managed care program for people with AIDS in the Boston area, reports that the average monthly cost of treating

its AIDS patients was \$2,699 at the end of 1993 (Master, 1996).¹⁰ CMA, like Medicare, does not cover pharmaceuticals, so while its cost estimates substantially understate total treatment costs, they do provide a useful benchmark for Medicare planning efforts.

Medicare expenditures for beneficiaries with AIDS are high (Table 7). Our analysis of claims data from 1991 through 1993 finds that Medicare spent over \$1.2 billion on care for the 36,891 beneficiaries for whom we have complete records of care, from the month in which the algorithm identified them to the end of 1993; this corresponds to an average expenditure of \$32,892 per beneficiary. The average

¹⁰ Master (1996) also reports that CMA's costs have risen substantially over time and that, by early 1995, average costs per month exceeded \$4,300. However, newer combination therapies may materially reduce this expenditure level.

Table 7
Medicare Expenditures Per Enrolled Month After Identification

Reason for Entitlement	Total Expenditures Between Identification and End of 1993 (in Millions of Dollars)	Number of Cases	Average Expenditures Between Identification and End of 1993	Mean Number of Enrolled Months	Mean Dollars Per Enrolled Month
Total Identified AIDS Cases ¹	1,213.40	36,891	32,892	13.30	2,482
Aged Without ESRD	159.10	5,392	29,513	15.00	1,963
Aged With ESRD	45.90	463	99,055	24.90	3,972
Disabled Without ESRD	705.30	27,280	25,855	11.80	2,197
Disabled With ESRD	179.40	2,066	86,857	21.20	4,036
ESRD Only	123.50	1,688	78,192	18.10	4,038

¹Total includes two observations for which eligibility group and enrollment data are missing.

NOTES: The table includes only persons with complete records of Medicare-financed utilization and expenditures. Excluded from the analysis were 667 persons who were enrolled in managed care plans at some point during the study period. Figures include the month in which the algorithm identified the AIDS case. AIDS is acquired immunodeficiency syndrome. ESRD is end stage renal disease.

SOURCES: Medicare national claims and enrollment files for 1991-93. AIDS cases were identified using a claims-based casefinding algorithm (Thornton et al., 1997).

length of Medicare enrollment from the time a person was identified as having AIDS to the end of the study period was 13.3 months; thus, during this period, the average cost per enrollment month was \$2,482.

Not surprisingly, care for beneficiaries with AIDS and ESRD was substantially more expensive than for those who had AIDS only. The three eligibility groups with ESRD had average monthly expenditures of approximately \$4,000. In contrast, disabled beneficiaries without ESRD had average monthly expenditures of \$2,197, while aged beneficiaries without ESRD had average monthly expenditures of \$1,963.

To gain a better understanding of the determinants of average expenditure levels, we examined the subsample of 25,826 Medicare beneficiaries with AIDS whom we identified by the end of January 1993 (Table 8). By focusing on this subsample, we can assess mortality, service use, and expenditure patterns over a 12-month period. Among this subsample, 37 percent died within the 12-month period. The average time living (and enrolled) was 9.5 months.

As was the case for the full sample, total Medicare expenditures for this subsample

were substantial. Total Medicare expenditures for the 12 months after identification were more than \$672 million, even though over one-third of the sample did not live the full 12 months. Average costs per month enrolled for the subsample were \$2,734, a figure slightly higher than that observed for the full sample. Two-thirds of these expenditures were for inpatient care. Most of the remaining costs (29 percent) were for outpatient and other acute care. Costs for home health care and institutional long-term care accounted for only a few percentage points of the total.

Our estimates indicate that during this period, Medicare expenditures for a year's worth of care for beneficiaries with AIDS were almost \$26,000 per person (this figure reflects an average duration of enrollment during that year of 9.5 months). These expenditures were substantially higher than those for all disabled Medicare enrollees. Average annual Medicare expenditures per disabled enrollee averaged \$3,994 in 1992; expenditures per disabled enrollee who had covered Medicare expenditures during the year were about 35 percent higher, at \$5,426 per year (Social Security Administration, 1995). The costs for beneficiaries with AIDS were

Table 8

Medicare Expenditures for Identified AIDS Cases During the 12 Months Following Identification

Number of Beneficiaries Observed for 12 Months	25,826
Total Expenditures for the 12 Months	\$672,000,000
Average Months Living During the 12 Months	9.5 months
Expenditures Per Enrollment Month	\$2,734
Percent of Expenditures For:	
Inpatient Care	66.6
Outpatient Care ¹	29.3
Home Health Care	3.0
Institutional Care	1.1

¹Outpatient care includes all care not included elsewhere.

NOTES: The table includes only persons with complete records of Medicare-financed utilization and expenditures. Excluded from the analysis were 667 persons who were enrolled in managed care plans at some point during the study period. AIDS acquired immunodeficiency syndrome.

SOURCES: Medicare national claims and enrollment files for 1991-93. AIDS cases were identified using a claims-based casefinding algorithm (Thornton et al., 1997).

more in line with those for all beneficiaries with ESRD, which averaged \$30,827 during 1992 (Health Care Financing Administration, 1995).

The expenditure levels reflect high use of inpatient care. Medicare beneficiaries with AIDS tended to use a substantial amount of inpatient care during the 12 months after they were identified. Three-fourths had at least one inpatient admission in those 12 months. Those beneficiaries who had an inpatient stay averaged more than 2 stays and over 33 days in an inpatient setting during the 12 months. In comparison, only 20 percent of all non-elderly Medicare disabled beneficiaries had an inpatient stay (Social Security Administration, 1995). There was somewhat less use of home health and nursing home care by beneficiaries with AIDS. Only one-fourth received any home health care, and only 5 percent had a Medicare-covered institutional long-term care stay.

DISCUSSION

Our findings suggest that claims-based casefinding is a feasible method for identifying Medicare beneficiaries with AIDS. Furthermore, our estimate that Medicare covered 12 percent of the people living with AIDS in 1993 raises a number of important policy issues for Medicare.

Accuracy of the Casefinding Algorithm

Overall, the algorithm appears to be quite sensitive and reasonably specific when applied to Medicare data. Evidence of the accuracy of the AIDS casefinding algorithm comes partly from verification studies performed on the earlier algorithms on which ours is based (Keyes, Andrews, and Mason, 1991; Fanning et al., 1994). Those verification studies found that the algorithms were sensitive in detecting known AIDS cases in Medicaid claims data. The specificity of the algorithms, however, was not as good.¹¹ Because Medicare files contain more diagnostic information than the Medicaid files used with the earlier algorithms and because our algorithm included significant refinements, we believe it has even greater accuracy than the earlier algorithms.

Additional evidence of the algorithm's accuracy comes from the consistency between our findings and those based on other data. We estimate that 12 percent of

¹¹ For example, Keyes, Andrews, and Mason (1991) used the Medi-Cal AIDS Special Research File (which the State of California created by matching Medicaid claims files to its AIDS registry) to verify AIDS status of cases selected by their casefinding algorithm. Of 976 AIDS cases verified on the Medi-Cal AIDS Special Research File, Keyes et al. found that 93 percent had been identified by their casefinding algorithm. Of the 1,152 Medicaid recipients that their algorithm identified as being AIDS cases, only 78 percent were known to California's AIDS registry.

AIDS cases were covered by Medicare at the end of 1993, which was up from 10 percent at the end of 1991. Analyses of hospital discharge data from the latter half of the 1980s typically put the proportion of all HIV-related admissions covered by Medicare (a figure that should exceed the fraction of AIDS-related admissions covered by Medicare) at 2 to 6 percent (Andrulis, Weslowski, and Gage, 1989; Green and Arno 1990; and Ball and Turner 1991). It is reasonable to expect our estimates to be higher than those based on data from earlier years, as we expect the proportion of AIDS cases covered by Medicare to have increased over time as new treatments enabled people with AIDS to live longer. Our estimate is consistent with more recent data from the ACSUS, which indicate that, in mid-1992, approximately 12 percent of persons with AIDS (identified through medical records) had Medicare coverage (Fleishman, 1997).¹²

In addition, trends observed in the Medicare data are consistent with known trends in the onset of AIDS and the enrollment of persons with AIDS in the Medicare program. In 1992 and 1993, the number of living AIDS cases identified in the Medicare data rose more quickly than the number of living AIDS cases known to the CDC. We estimate that the number of Medicare beneficiaries with AIDS grew from 15,598 in 1992 to 20,537 in 1993 (32 percent).¹³ This finding is consistent with

evidence indicating that persons with AIDS are living longer (Centers for Disease Control and Prevention, 1997), which should enable more of them to qualify for Medicare coverage. The number of males with AIDS who are covered by Medicare increased at a faster rate (35 percent) than the male AIDS population (23 percent), but the number of females with AIDS who are covered by Medicare increased more slowly (21 percent) than the female AIDS population (39 percent). These numbers are consistent with evidence indicating that the rate of increase in newly diagnosed cases (who would typically be reported to the CDC but not immediately eligible for Medicare) is higher among females than males (Centers for Disease Control and Prevention, 1995).

One surprising finding relates to elderly beneficiaries. The algorithm finds almost 60 percent more people with AIDS over age 65 than are reported by the CDC. The evidence from the Medicare claims files for the greater number is fairly compelling since the algorithm included only those elderly people for whom there was strong evidence of both HIV infection and an AIDS-indicator condition. Furthermore, the algorithm excluded those beneficiaries who had diagnoses for conditions other than HIV infection that might result in immunosuppression. There is also evidence in the literature to suggest that AIDS is underdiagnosed among elderly people (Weiler, Mungas, and Pomerantz, 1988; Ship and Wolff, 1989; Hinkle, 1991; Centers for Disease Control and Prevention, 1995). Together, the literature and our findings suggest that, at least for the period 1991-93, there is substantial underreporting of AIDS among people over 65.

Little is known about the incidence and manifestations of AIDS among elderly people. There is some evidence that older

¹² For information about the ACSUS survey, refer to Berk, Maffeo, and Schur (1993).

¹³ Trends observed in the data must be interpreted with care. Because the algorithm generally required multiple claims to establish AIDS, people who had AIDS and were enrolled in the Medicare program in a given year may not have been identified until the following year. The fraction of the population that remained unidentified could be expected to diminish over time. Hence, our 1992 and 1993 estimates of the number of Medicare beneficiaries with AIDS are likely to be more accurate than our 1991 estimate, and changes observed between 1992 and 1993 in the Medicare AIDS population are apt to reflect actual trends in the onset of AIDS and the enrollment of person with AIDS in the Medicare program better than changes observed between 1991 and 1992.

people with HIV infection are more often female and are more likely to have been infected through contaminated blood products than are younger people with HIV infection and AIDS (Ferro and Salit, 1990). Given the almost universal Medicare coverage among people over 65, this data set provides an important opportunity to explore the number of elderly cases, their demographics, and their patterns of service use.

One area where the algorithm raises concerns is for ESRD cases. Although the algorithm identified what appears to be a reasonable number of AIDS cases with ESRD, the length of Medicare enrollment for these ESRD cases seems too long, given what is known about mortality rates among HIV-infected persons who develop ESRD. Hence, the specificity of the algorithm for this group warrants further study.

Role of Medicare in AIDS Treatment System

The growing number of Medicare beneficiaries with AIDS and the corresponding increase in the share of people with AIDS who have Medicare coverage signal a changing role for Medicare in AIDS-related care. Our estimate of 21,000 Medicare beneficiaries with AIDS represents a tiny fraction of the almost 33 million Medicare beneficiaries, but accounts for about 12 percent of the people living with AIDS in the United States. Thus, Medicare is likely to play an increasingly important role in AIDS-related care, even if AIDS remains a relatively small financial issue from the perspective of the overall Medicare program.

Our findings suggest that total Medicare expenditures for AIDS-related care have been growing. In 1993, it appears that average Medicare expenditures per beneficiary month were about \$2,500. This sug-

gests that total AIDS-related Medicare expenditures in that year probably exceeded \$500 million. During the 3 years covered by our study, Medicare beneficiaries with AIDS received much of their care as inpatients. Correspondingly, costs are substantial, even considering that Medicare does not cover AIDS-related pharmaceuticals outside inpatient settings.

Recent improvements in treatments, particularly the introduction of protease inhibitors in December 1995, have cut mortality substantially for people with severe immunosuppression. Hirschel and Francioli (1998) cite several instances of substantial improvements in AIDS mortality after the introduction of protease inhibitors, including New York City which experienced a decline in AIDS mortality of 29 percent from 1995 to 1996 and a further decline of 44 percent by mid-1997. Palella et al. (1998) find that from 1994 to mid-1997, there was a 75-percent decline in deaths and a 73-percent decline in the incidence of AIDS-defining conditions among severely immunosuppressed patients in 9 large clinics treating AIDS patients. Furthermore, greater use of protease inhibitors appears to reduce the need for inpatient care while increasing the amount of outpatient care (Torres and Barr, 1997).

However, this success may not be shared equally by people with AIDS regardless of insurance coverage. Palella et al. (1998) report that people with AIDS who have Medicare or Medicaid coverage may be less likely to receive protease inhibitors and that they have correspondingly higher levels of mortality than do people covered by private insurance. This difference may reflect underlying differences in the clinics used by Medicare and Medicaid beneficiaries and the care provided at those clinics rather than features inherent in publicly-funded insurance. Nevertheless, it raises concerns, particu-

larly for Medicare beneficiaries, because Medicare does not cover outpatient pharmaceuticals. Indeed, one of the major AIDS-related issues for Medicare is how it can promote access to appropriate treatment for AIDS when it does not cover prescription medications, which are the primary treatment mode.

Future of Claims-Based AIDS Casefinding

The casefinding process described here offers policy analysts an important tool for understanding the care delivered to an increasing share of the AIDS population. It can help policymakers monitor how the various AIDS-related trends affect Medicare. It seems likely that increases in the number of AIDS cases and in the life expectancy of people with AIDS will lead to more Medicare beneficiaries with AIDS. At the same time, the new pharmaceutical treatments will shift the pattern of care toward more outpatient care and less inpatient care. It is too soon to know how these trends will play out and how they will affect Medicare expenditures, but the casefinding algorithm gives HCFA a convenient way to track enrollment, use, and expenditure patterns.

In order to be accurate, the algorithm must also keep pace with changes in coding and definition. For example, effective October 1, 1994, the distinct codes for HIV infection and AIDS (ICD-9-CM codes 042 to 044) were replaced with a single code for HIV disease (U.S. Department of Health and Human Services, 1994). Also,

if the decline in morbidity that Palella et al. found among people with severe immunosuppression continues, it will become more difficult to use our current casefinding approach which looks, in part, for evidence of AIDS-indicator conditions in order to identify AIDS cases. Finally, the expansion of Medicare managed care may further limit the future usefulness of casefinding methods unless Medicare can collect accurate encounter data.

These changes in illnesses and in diagnostic coding suggest that future casefinding efforts may have to focus more broadly on beneficiaries with HIV infection rather than just those cases with AIDS. This shift is probably appropriate and will help Medicare look more broadly at a population that requires a wide array of prophylactic and ameliorative treatments.

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