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Short Report

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Use of Advance Care Planning Codes Among Transgender Medicare Beneficiaries

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Abstract

Purpose: We examined the use of advance care planning (ACP) among Medicare beneficiaries who were identified as transgender.
Methods: This study is a cross-sectional analysis of Medicare claims from 2016 to 2018, comparing ACP visits between transgender and other beneficiaries.
Results: Beneficiaries identified as transgender were slightly more likely than those who were dual eligible for Medicaid and Medicare, and the remaining fee-for-service Medicare population, to have received a claim for ACP. However, racial and ethnic differences exist and transgender beneficiaries were more likely to receive an ACP claim from hospice/palliative care clinicians compared with primary care clinicians relative to other beneficiaries.
Conclusions: Differences in ACP provision may exacerbate disparities in access to ACP benefits faced by transgender patients.

Keywords: aging, end-of-life concerns, Medicare, transgender

Introduction

People who are transgender face higher levels of social stigma and associated psychological distress,[1] as well as a higher burden of disabilities and chronic conditions despite similar rates of health care utilization, compared with people who are cisgender.[2,3] In May 2021, the Biden administration updated a policy in the Affordable Care Act (ACA) to ensure that the federal government provides protections for people who are transgender from discrimination by health care providers that receive federal funding.[4]

Ideological debates and court challenges over the interpretation of forbidding discrimination ''based on sex'' meant that protections for transgender people did not go into effect when the ACA was originally passed. In 2018, a survey found that 66% of people who are transgender expressed concern that their quality of health care would be negatively affected based on their gender identity.[5]

Adults who are transgender may be well positioned to benefit from advance care planning (ACP), a process that aligns and documents preferences for care with treatment received. Given that transgender adults have reported high levels of concern specifically related to aging and long-term care,[5] ACP may be especially important for transgender people.[6] Research has shown that ACP is positively associated with the quality of end-of-life care, satisfaction with patient and surrogate communication,[7] and is more effective in achieving patient preferences than written documentation alone.[8,9]

Engaging in ACP in an outpatient setting, before serious illness, can help patients and surrogates prepare for decision making with clinicians.[10] In this study, we characterize use of ACP billing codes among Medicare beneficiaries who have been identified as transgender using claims data.

Methods

Cohort

We performed a retrospective claims analysis comparing rates of ACP visits between Medicare beneficiaries who are transgender and those who are cisgender. Beneficiaries

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with continuous fee-for-service (FFS) Medicare coverage between 2016 and 2018 were identified using the standard 20% FFS sample. Inpatient, outpatient, skilled nursing facility, hospice, home health agency, durable medical equipment, and carrier files were searched. As transgender people are more likely to be younger[11] than other Medicare beneficiaries and qualify based on disability rather than age,[12] all beneficiaries of age 18 years or older were included. Among beneficiaries who died during the study period, data were included from 2016 until date of death.

Beneficiaries were divided into one of three groups: Transgender beneficiaries were defined using ICD-10 codes described by Ewald et al.[13] (F64.2-Gender identity disorder of childhood, F64.1-Gender identity disorder in adolescence and adulthood, F64.8-Other gender identity disorders, F64.9-Gender identity disorder, unspecified, Z87.890-Personal history of sex reassignment). The algorithm identifies beneficiaries seeking transgender-related care, and due to the specificity of ICD codes, it is unlikely that many cisgender people would be included. This approach relies on diagnosis codes and not self-reported gender identity, as Medicare does not ask this information of beneficiaries. Thus, an indeterminant number of transgender beneficiaries, including those who are not seeking related treatments, may be misclassified, and not be captured by this approach.

The remaining beneficiaries were assigned as follows: dual-eligible beneficiaries were defined as those with at least 1 month of Medicaid dual eligibility during the study period. This group was included for comparison due to some demographic similarities to transgender beneficiaries when compared with cisgender general FFS Medicare beneficiaries. Both transgender and dual-eligible beneficiaries tend to have lower incomes, which can lead to barriers to care.[11] If a beneficiary was identified as both transgender and dual eligible, they were assigned to the transgender group. Finally, all remaining beneficiaries who were not identified as transgender or dual eligible were grouped into the remaining FFS Medicare population. This analysis was reviewed by the MassGeneralBrigham Institutional Review Board (IRB) and deemed not human subjects research.

Outcomes

The outcome of interest was documentation of a billed ACP visit using Medicare ACP current procedural terminology (CPT) codes. Medicare introduced two new payment codes for ACP discussions between patients and clinicians effective January 1, 2016. CPT code 99497 and add-on code 99498 (for each additional 30 minutes of ACP) are separately payable under the Medicare Physician Fee Schedule. These codes are used to report face-to-face services between a physician or other qualified health care professional and a patient, family member, or surrogate in counseling and discussing advance directives (ADs), with or without completing relevant legal forms. These codes can be billed on the same day and can be repeated on subsequent visits. A visit is defined as at least one ACP CPT claim during the study period.

Data analysis

Proportions of transgender beneficiaries who were billed for ACP were compared with cisgender beneficiaries, and also with dual-eligible Medicaid and Medicare beneficiaries, as transgender people are more likely to be low income compared with cisgender adults.[11] Beneficiaries who were identified in both transgender and dual-eligible groups were excluded from the dual-eligible group.

Covariates included age (<65, 65–74, 75–84, and 85+ years), sex (limited in Medicare claims to male and female and, therefore, not a reliable designation among the transgender group), race (non-Hispanic White, non-Hispanic Black, Asian/Pacific Islander, Hispanic, Other), and region (midwest, northeast, south, west).

Among providers who are qualified to bill for ACP, we also examined which physician specialty (including acute care, general medicine, geriatric, hospice and palliative care, medical oncology, psychiatry, and surgery) and role (clinical nurse specialist-CNS, physician/medical doctor-MD, nurse practitioner, physician assistant) provided the service. Billing rates were calculated per 10,000 claim lines.

Results

We identified 3610 beneficiaries as transgender during the period of study (2016 or start of FFS coverage until 2018 or death). Among our sample, 6.0% were billed for ACP at any time during the study period, including 7.3% of transgender beneficiaries, compared with 6.2% of cisgender dual-eligible and 6.0% of cisgender FFS Medicare beneficiaries ($p < 0.001$) (Table 1). Consistent across groups, older beneficiaries were more likely to be billed for ACP (among those 85 years and older, 13.2% transgender, 9.7% dual eligible, and 9.1% FFS Medicare). ACP billing was fairly consistent across groups by region, with transgender beneficiaries more likely to be billed in the south compared with cisgender counterparts.

There was more variation in ACP across groups by race and ethnicity, with Asian/Pacific Islanders (8.5%, 8.7%, 7.1%), most likely to be billed for ACP across transgender, dual-eligible, and FFS Medicare beneficiaries. Beneficiaries of Hispanic ethnicity were more likely to be billed for ACP in the transgender and dual-eligible groups compared with cisgender FFS Medicare (7.6%, 6.6%, 5.4%, respectively). However, non-Hispanic Black transgender beneficiaries were less likely to be billed for ACP than either dual-eligible or FFS Medicare non-Hispanic Black beneficiaries (5.5%, 5.9%, 6.0%) (Table 1).

Across beneficiary groups, hospice and palliative medicine clinicians submitted ACP claims at the highest rate per 10,000 claim line, whereas general primary care providers submitted the most total claims by specialty. Rates were relatively higher in hospice and palliative medicine providers among the transgender group than among the dual-eligible or FFS Medicare beneficiaries (518.7, 327.4, and 339.8 per 10,000 claim lines). (Table 2)

Discussion

We examined differences in the rates of ACP Medicare billing and found that transgender beneficiaries were slightly more likely to have claims for ACP than other Medicare beneficiaries. Still, the use of ACP codes remains low across all groups. Results also suggest that some patterns of ACP use may

Table 1. Advance Care Planning Claim Utilization by Beneficiary Characteristics for Transgender, Dual-Eligible, and Fee-for-Service Medicare Beneficiaries

	Transgender		*Dual eligible*		*FFS Medicare*	
	Total	*Had ACP*	*Total*	*Had ACP*	*Total*	*Had ACP*
Eligible beneficiaries	3610	7.3%	1,439,069	6.2%	5,391,465	6.0%
Age (years)						
<65	1480	4.1%	665,321	3.3%	645,658	2.4%
65–74	946	7.3%	321,910	6.3%	2,284,590	5.2%
75–84	730	10.4%	245,279	8.8%	1,615,922	7.1%
85+	454	13.2%	206,559	9.7%	845,295	9.1%
Missing	—	—	—	—	—	—
Total	3610	7.3%	1,439,069	6.2%	5,391,465	6.0%
Median (quart. range)	69 (25)	75 (18)	67 (23)	74 (19)	73 (13)	77 (13)
Mean (SD)	64.8 (18.2)	73.5 (14.6)	65.6 (17.1)	73.2 (14.3)	74.5 (9.7)	77.6 (9.0)
Sex[a]						
Male	1847	6.7%	604,232	5.1%	2,484,303	5.6%
Female	1763	8.0%	834,836	6.4%	2,907,162	6.4%
Missing	—	—	—	—	—	—
Total	3610	7.3%	1,439,069	6.2%	5,391,465	6.0%
Race						
Non-Hispanic White	2838	7.7%	895,582	5.5%	4,590,753	6.1%
Non-Hispanic Black	400	5.5%	252,230	5.9%	349,166	6.0%
Asian/Pacific Islander	[b]	8.5%	70,072	8.7%	96,687	7.1%
Hispanic	212	7.6%	176,612	6.6%	204,288	5.4%
Other	[b]	[b]	44,573	4.3%	150,571	4.6%
Missing	—	—	—	—	—	—
Total	3610	7.3%	1,439,069	6.2%	5,391,465	6.0%
Region						
Midwest	744	4.6%	308,934	3.2%	1,247,480	3.3%
Northeast	852	7.3%	289,277	6.9%	943,749	7.0%
South	1173	9.0%	533,726	7.5%	2,169,099	7.1%
West	836	7.7%	306,126	6.6%	1,004,841	6.3%
Other	[b]	[b]	319	7.5%	14,319	1.1%
Missing	[b]	[b]	687	3.6%	11,977	1.6%
Total	3610	7.3%	1,439,069	6.2%	5,391,465	6.0%

[a]Sex: this variable is not a reliable designation among the transgender group.
[b]Number too small to report.
ACP, advance care planning; FFS, fee-for-service; quart. range, quartile range; SD, standard deviation.

exacerbate disparities in access to known benefits of ACP such as completion of ADs and congruence between patients and family members, experienced by transgender beneficiaries.

Among those who do receive ACP, data indicate that Black transgender beneficiaries receive the lowest rates of ACP. This is notable because people of color (including people who are Black/African American, Asian/Pacific Islander, multiple race, or Hispanic/Latinx ethnicity) who are transgender have described poor health care experiences and discrimination that intersect gender identity and race.[14,15] A review of ACP interventions designed for racial and ethnic under-represented groups found that tailoring approaches for these patients can have significant and positive effects on ACP-related outcomes.[16]

Although uptake of ACP is low generally, the importance of engaging in these discussions may be especially salient for some groups that have been historically marginalized by the health care system. However, to our knowledge no interventions have been described that address the ACP needs of transgender people of color.

Furthermore, an examination of which providers are billing for ACP suggests that transgender beneficiaries may be more likely to receive late ACP, as these individuals were more likely to have received an ACP claim from a hospice/palliative care provider compared with primary care relative to other beneficiaries. A qualitative analysis found that nurses reported more difficulties in engaging in ACP with sexual and gender minority patients,[17] indicating that transgender adults may be less likely to receive this service as part of routine care, before serious illness.

Among older adults, transgender people were less likely to have appointed health care power of attorney, or have a will or living will, compared with cisgender people.[18,19] As older transgender adults are also less likely to report having an available caregiver,[20] earlier ACP may be especially pertinent in this group.

Our findings suggest at least two strategies to be considered. A number of models[16] exist to promote engagement and participation in ACP between clinicians and under-represented groups. These approaches may be adapted, refined, and informed by the experiences of transgender patients to address racial disparities at the intersection of gender identity. Furthermore, primary care practices and clinicians should be aware of discrimination concerns among

Table 2. Advance Care Planning Claim Utilization by Provider Specialty and Role for Transgender, Dual-Eligible, and Fee-for-Service Medicare Beneficiaries

	Transgender		*Dual eligible*		*FFS Medicare*	
	ACP claims	*Rate per 10,000 claims*	*ACP claims*	*Rate per 10,000 claims*	*ACP claims*	*Rate per 10,000 claims*
Provider specialty						
Acute care	32	7.3	5065	4.7	11,649	6.0
General	340	17.1	119,957	21.1	410,823	23.7
Geriatric	10	39.8	3239	51.2	9042	66.5
Hospice and palliative care	18	518.7	4163	327.4	8807	339.8
Medical oncology	4	1.0	2037	2.8	8124	2.2
Psychiatry	0	0.0	97	0.2	159	0.4
Surgery	0	0.0	560	0.6	638	0.2
Other	164	1.9	49,376	2.3	123,211	1.9
Total claims	568	—	184,494	—	572,453	—
Unique beneficiaries with ACP	265	—	84,100	—	324,345	—
Provider role						
MD	432	4.4	141,618	5.7	471,747	6.2
NP	117	20.9	36,721	22.7	86,555	28.2
PA	19	6.9	5025	7.2	10,986	5.5
CNS	0	0.0	514	15.2	1778	41.3
Other	0	0.0	616	0.2	1387	0.2
Total claims	568	—	184,494	—	572,453	—
Unique beneficiaries with ACP	265	—	84,100	—	324,345	—

CNS, clinical nurse specialist; MD, medical doctor; NP, nurse practitioner; PA, physician assistant.

transgender patients and promote an environment of nonjudgmental care,[6] and provide training in ACP issues specific to transgender people.

Limitations

The findings from this study should be interpreted within the context of the limitations of a claims analysis. The ICD-10 algorithm used may not identify many transgender beneficiaries, and Medicare does not ask patients to self-report gender identity. Furthermore, the sex variable is limited to male and female, and could represent either sex assigned at birth or gender identity (if officially changed in Social Security Administration documents). Finally, although the ACP CPT codes capture discussions that were billed for, uptake of the code has been slow[21] and many discussions likely occur in clinical settings that are not reflected in the billing data, and the quality of ACP discussions cannot be ascertained from claims.

Conclusion

ACP may offer an opportunity to mitigate experiences of discrimination and disparate outcomes faced by transgender individuals at the end of life. Alignment of patient preferences with treatment can alleviate concerns among these adults regarding aging and long-term care. However, current patterns of ACP service use in claims data indicate that thus far, this opportunity has not been realized.

Authors' Contributions

A.J.R. contributed to the conception/design and acquisition and interpretation of data. A.M. contributed to the design and analysis and interpretation of data. R.S.S. contributed to the design and interpretation of data. C.C., K.L., and H.G.P. contributed to the design. J.S.W. contributed to the conception/design, acquisition, and interpretation of data. All coauthors were responsible for critical revision of the study, final approval of the version to be published, and agree to be accountable for all aspects of the study in ensuring that questions related to the accuracy or integrity of any part of the study are appropriately investigated and resolved.

Disclaimer

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