Identifying Medicare Beneficiaries Accessing Transgender-Related Care in the Era of ICD-10

Erin R. Ewald, ScM,[1] Paul Guerino, ScM,[2] Christina Dragon, MSPH,[3] Alison M. Laffan, PhD,[1]
Zil Goldstein, NP,[4] and Carl Streed Jr., MD, MPH[5]

Abstract

Purpose: The study purpose was to describe trends in the size and demographics of the population of transgender Medicare beneficiaries identified using International Classification of Diseases (ICD) Clinical Modification codes over time. We also assessed how the change from ICD, Ninth Revision (ICD-9) diagnosis codes to ICD, 10th Revision (ICD-10) diagnosis codes in October 2015 has affected the ability to identify transgender beneficiaries within claims data.

Methods: We used Medicare Fee-for-Service claims within the Centers for Medicare & Medicaid Services Chronic Conditions Data Warehouse from 2010 through 2016 to identify transgender beneficiaries. We linked these data to Medicare enrollment records to study demographic trends.

Results: Within the Medicare program, the number of beneficiaries identified as transgender through claims data in each year has increased from 2088 beneficiaries in 2010 to 10,242 beneficiaries in 2016 (a 390% increase). The highest numbers of transgender beneficiaries were identified in 2015 and 2016, which coincide with the change to ICD-10. Similarly, more beneficiaries were identified as transgender in the 12 months after the change to ICD-10 ($N = 8733$) than in the 12 months before ($N = 4857$).

Conclusion: Given that a first and critical step to better understand and eliminate health disparities and deliver culturally competent care is to identify and characterize the population of interest, this study provides an innovative view into how the change to the ICD-10 coding system affects the ability to study a transgender cohort within Medicare claims data.

Keywords: administrative data, ICD-10, Medicare, transgender

Introduction

IDENTIFYING AND CHARACTERIZING populations of interest is a first and critical step to better understand and eliminate health disparities and to provide culturally competent care.[1] For transgender individuals, whose gender identity differs from their sex assigned at birth, this can be especially difficult due to experiences of discrimination from society at large and within health care settings in particular.[2] Administrative data predominantly support a gender binary system, in which patients are only provided with the option to select male or female as their gender. As such, gender nonbinary, gender nonconforming, and transgender individuals are fre-

quently overlooked or left invisible within these data. This issue could be addressed by providing a two-step gender question, which allows a person to select both their current gender identity and the sex they were assigned at birth.[3] Although many transgender individuals are willing to have their gender identity included in the electronic health record (EHR) despite prior experiences of discrimination,[4–9] many of the data remain incomplete,[10] and developing novel methods of identifying transgender patients within currently available data has become a priority.[11]

National surveys have recently begun to include gender identity questions, but many of these surveys focus on specific topics such as tobacco use and substance abuse.[12,13]

[1]Health Care Evaluation Department, NORC at the University of Chicago, Bethesda, Maryland.
[2]American Hospital Association, Chicago, Illinois.
[3]Center for Drug Evaluation and Research, U.S. Food and Drug Administration, Silver Spring, Maryland.
[4]Transgender and Gender Non-Binary Health, Callen-Lorde Community Health Center, New York, New York.
[5]Section of General Internal Medicine, Center for Transgender Medicine and Surgery, Boston University School of Medicine, Boston Medical Center, Boston, Massachusetts.

Although this research[14–16] can reveal disparities in self-reported health issues, it cannot provide data on the broader health care experience of transgender individuals, including health care utilization, diagnoses, or health outcomes, such as the effects of hormone therapy[17] or cancer survivorship.[18]

Because Medicare beneficiaries are not asked about their gender identity and/or transgender status in a systematic way, there is no definitive information in administrative data that can identify transgender beneficiaries. In addition, beneficiaries can change their recorded sex in Medicare claims data as they transition; however, there is no indication in the data whether that information has been updated. Thus, the recorded sex variable in Medicare claims is an unreliable indicator of gender identity as it does not differentiate between sex assigned at birth and current gender identity.

Although there are limits to what claims data can reveal,[19] pairing claims with EHR data has revealed that gender minority Medicare beneficiaries experience more disability and mental illness compared with non gender minority beneficiaries.[20] Prior research using Medicare Fee-for-Service (FFS) claims data has identified a method to identify transgender beneficiaries receiving gender-affirming care and examine chronic disease burden and patterns of disparities among Medicare beneficiaries.[21,22]

Identifying transgender patients in administrative data can be challenging because diagnosis codes only identify people who receive transgender-related medical care, not all patients of transgender experience. In addition, gender is not captured using the recommended two-step method of patient-reported sex assigned at birth and current gender identity.[23] Previous studies have used combinations of medical claims, EHRs, and patient surveys to identify transgender beneficiaries, but many rely primarily on diagnosis codes recorded in administrative data.[3,22,24,25] At the time of this submission, prior research has used diagnosis codes from the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) to identify cohorts of transgender Medicare FFS beneficiaries and veterans.[21,22,24–27]

Implementation of the 10th Revision, Clinical Modification (ICD-10-CM) on October 1, 2015, provided the first update to the International Classification of Diseases (ICD)-based billing system in the United States in 30 years, adding codes that allow for more diagnostic specificity.[28] Methods established using ICD-9 need to be updated and reassessed to understand how future analyses would be affected. With this in mind, we aimed to investigate how the change from ICD-9 to ICD-10 has affected the ability to identify and characterize transgender patients seeking transgender-related care.

Methods

Data source and study population

To identify transgender beneficiaries seeking transgender-related care, we used Medicare FFS claims records accessed through the Centers for Medicare & Medicaid Services (CMS) Chronic Conditions Data Warehouse (CCW). We searched all Medicare records from 2010 through 2016 for ICD-9 and ICD-10 codes related to sexual and gender identity conditions or states (Table 1). The Institutional Review Board at NORC at the University of Chicago approved this study.

TABLE 1. CROSSWALK OF ICD-9 AND ICD-10 CODES

Description	ICD-9	ICD-10
Trans-sexualism	302.5	N/A
	302.51	
	302.52	
	302.53	
Gender identity disorder of childhood	302.6	F64.2
Gender identity disorder in adolescence and adulthood	302.85	F64.1
Other gender identity disorders	N/A	F64.8
Gender identity disorder, unspecified	N/A	F64.9
Personal history of sex reassignment	N/A	Z87.890

In October 2016, ICD-10 code definitions were updated to include transsexualism (F64.0); however, as this occurred outside the time frame of our study, we did not include F64.0 in this crosswalk.

Descriptions for codes in both ICD-9 and ICD-10 are listed in the table with ICD-10 wording; ICD-9 descriptions are worded slightly differently, per (1) gender identity disorder in children and (2) gender identity disorder in adolescents or adults.

ICD-9, International Classification of Diseases, Ninth Revision; ICD-10, International Classification of Diseases, 10th Revision.

For the period before October 2015, we used ICD-9 codes for trans-sexualism (302.50—trans-sexualism with unspecified sexual history, 302.51—trans-sexualism with asexual history, 302.52—trans-sexualism with homosexual history, and 302.53—trans-sexualism with heterosexual history), gender identity disorder in children (302.6), and gender identity disorder in adolescents or adults (302.85) to identify transgender beneficiaries, as described in a previous article.[21] To identify equivalent ICD-10 codes, we used the CMS General Equivalence Mapping tool, using the code definitions for the period of October 2015 through September 2016.[29] Based on this tool, we identified transgender beneficiaries served after October 1, 2015, using ICD-10 codes for gender identity disorder in adolescence and adulthood (F64.1), gender identity disorder of childhood (F64.2), other gender identity disorders (F64.8), gender identity disorder, unspecified (F64.9), and personal history of sex reassignment (Z87.890).

We searched all Part A and Part B claims and classified beneficiaries as transgender if they had a claim on which one of the transgender-related diagnosis codes appeared in any recorded code position. From these claims, we then identified unique beneficiaries using the beneficiary identification numbers in the Medicare enrollment files provided by CMS. As discussed in previous articles,[21,22] we acknowledge that this method may lead to an unknown amount of misclassification; however, recent studies have shown that claims-based identification of transgender beneficiaries is well aligned with clinician note data from EHRs that classify patients as transgender.[30] It is unlikely that many nontransgender beneficiaries are being identified as transgender using this algorithm due to the specificity of ICD codes and the caution that providers exercise when recording these codes.

Transition to ICD-10

To study changes in the size and demographic composition of the transgender Medicare population after transition to ICD-10, we created a cohort of transgender beneficiaries in the year before and the year after the switch to ICD-10. We refer to the year before transition to ICD-10 (October

2014 through September 2015) as year preswitch, whereas the year after transition to ICD-10 (October 2015 through September 2016) is referred to as year postswitch. For analyses comparing the years pre- and postswitch, the population was limited to those who had continuous FFS Medicare coverage throughout this 24-month time frame and incurred at least one claim in the year preswitch and at least one claim in the year postswitch.

Analytic methods

Summary statistics and cross-tabulations of beneficiaries identified with the ICD-9 and ICD-10 diagnosis codes were performed on the data. Data on beneficiary age, race/ethnicity, dual Medicare and Medicaid eligibility status, and current reason for Medicare entitlement are reported as of the analysis year and are based on CMS standardized measures.[31] In Medicare records, race and ethnicity are combined into a single parameter with seven mutually exclusive categories: White, Black, Hispanic, American Indian/Alaska Native, Asian/Pacific Islander, Other, and Unknown.[32] A beneficiary is determined to be dually eligible in a given year if they have one or more months of dual Medicare and Medicaid eligibility within that year. An unadjusted generalized linear model was used to test for linear trends in demographic characteristics from 2010 to 2016; results were considered significant where $p < 0.05$.

Cohen's unweighted kappa statistic (κ) was also calculated to determine the reliability between the two diagnosis code-based methods of identifying transgender beneficiaries; this statistic is appropriate for comparing two methodologies that separate out observations into two categories, as we have in this analysis.[33,34] All analyses were performed using SAS, version 9.4 (SAS Institute Inc., Cary, NC).

Results

Since 2010, both the overall and annual numbers of Medicare beneficiaries identified as transgender from claims have been increasing (Fig. 1). From 2010 to 2016, 17,713 unique beneficiaries were identified as transgender with at least one applicable ICD-9 or ICD-10 diagnosis code on a claim. We observed a 390% increase in the number of beneficiaries

identified as transgender from claims from 2010 ($N = 2088$) to 2016 ($N = 10,242$); this rate far outpaces the 19.5% growth seen in the general Medicare population over the same time period (data not shown).

From 2010 to 2016, we observed significant trends for age, dual eligibility, and current reason for entitlement (Table 2). Mean age increased from 49.9 years in 2010 to 58.5 years in 2016, and the percentage of dually eligible transgender beneficiaries decreased from 71.6% in 2010 to 56.1% in 2016. In 2016, more beneficiaries were eligible for Medicare based on age (45.0% compared with 17.6% in 2010) and fewer were eligible based on disability (54.3% compared with 81.6% in 2010). No significant trend in race/ethnicity was seen across these years.

We identified 4857 transgender beneficiaries (0.016% of all Medicare beneficiaries) in the year preswitch and 8733 transgender beneficiaries (0.029% of all Medicare beneficiaries) in the year postswitch (Table 3). Among beneficiaries in the year preswitch, the two most common diagnoses that appeared on one or more claims were 302.85 (gender identity disorder in adolescents or adults) and 302.50 (trans-sexualism with unspecified sexual history). Among transgender beneficiaries identified using ICD-10 codes, approximately half had F64.1 (gender identity disorder in adolescence and adulthood) and F64.9 (gender identity disorder, unspecified) recorded on one or more claims.

A new code for personal history of sex reassignment (Z87.890) was added in ICD-10 with no analog in ICD-9 codes. Nearly 23% of transgender beneficiaries (1998) in the year postswitch had at least one claim including this code (Table 3). For a majority (59.6% or 1191/1998) of these beneficiaries, Z87.890 was the only transgender-related code appearing on their claims. Those with only this code were older (mean 69.2, standard deviation 13.2) and more likely to qualify for Medicare based on age (73.2%) than the year postswitch group as a whole.

A total of 29,823,677 FFS Medicare beneficiaries incurred claims in both the years pre- and postswitch (Table 4). Across both time frames, we identified 10,204 beneficiaries as transgender. Overall, 3386 of 10,204 beneficiaries were identified as transgender in both time frames, whereas 6818 were identified in either the year preswitch alone ($N = 1471$) or the year postswitch alone ($N = 5347$). Cohen's

FIG. 1. Number of transgender beneficiaries identified with ICD-9 and ICD-10 diagnosis codes, annual and cumulative, 2010–2016. ICD-9, International Classification of Diseases, Ninth Revision; ICD-10, International Classification of Diseases, 10th Revision.
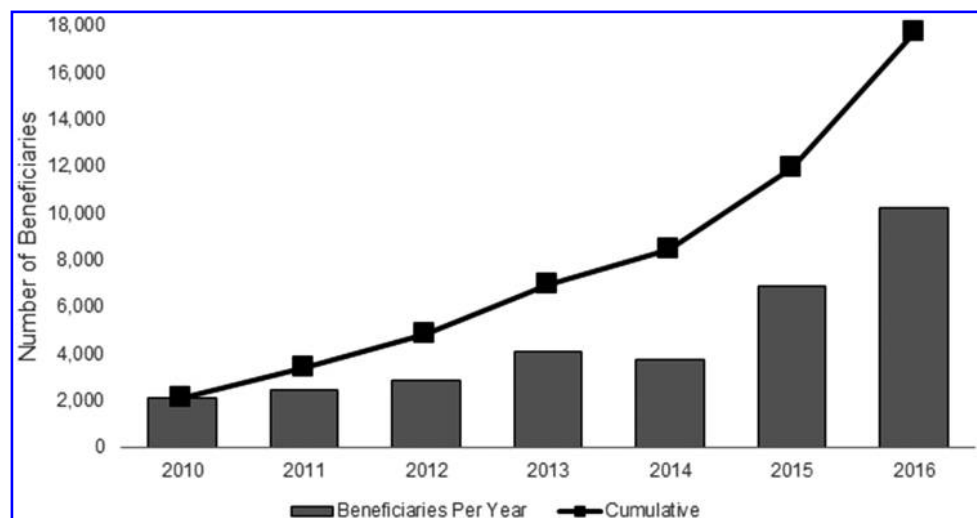
TABLE 2. CHARACTERISTICS OF TRANSGENDER BENEFICIARIES, 2010–2016

	Year						
	2010	2011	2012	2013	2014	2015	2016
N (% of total Medicare population)[a]	2088 (0.0042)	2443 (0.0047)	2826 (0.0053)	4101 (0.0074)	3722 (0.0066)	6888 (0.0067)	10,242 (0.017)
First occurrence N (%)[b]	2088 (100)	1348 (55.2)	1384 (49.0)	2155 (52.5)	1448 (38.9)	3513 (51.0)	5777 (56.4)
Mean age, years (SD)*	49.9 (15.2)	49.5 (15.0)	49.6 (15.3)	50.7 (15.4)	49.3 (15.3)	53.4 (17.1)	58.5 (18.3)
Dual eligibility*	1492 (71.6)	1752 (71.8)	2038 (72.2)	2853 (69.7)	2649 (71.2)	4416 (64.2)	5747 (56.1)
Reason for entitlement*							
Age	366 (17.6)	433 (17.8)	536 (19.0)	956 (23.3)	763 (20.5)	2178 (31.7)	4605 (45.0)
Disability	1702 (81.6)	1985 (81.4)	2261 (80.1)	3100 (75.7)	2932 (78.8)	4650 (67.6)	5553 (54.3)
End-stage renal disease	6 (0.3)	5 (0.2)	4 (0.1)	17 (0.4)	11 (0.3)	28 (0.4)	43 (0.4)
Disability/end-stage renal disease	11 (0.5)	16 (0.7)	21 (0.7)	24 (0.6)	16 (0.4)	26 (0.4)	35 (0.3)
Race/ethnicity							
White	1687 (80.9)	1932 (79.2)	2193 (77.7)	3143 (76.7)	2870 (77.1)	5355 (77.8)	8044 (78.6)
Black	254 (12.2)	331 (13.6)	416 (14.7)	640 (15.6)	555 (14.9)	959 (13.9)	1368 (13.4)
Hispanic	71 (3.4)	73 (3.0)	100 (3.5)	127 (3.1)	123 (3.3)	256 (3.7)	333 (3.3)
American Indian/Alaska Native	22 (1.1)	27 (1.1)	27 (1.0)	47 (1.2)	43 (1.2)	62 (0.9)	92 (0.9)
Asian/Pacific Islander	27 (1.3)	41 (1.7)	38 (1.4)	72 (1.8)	52 (1.4)	77 (1.1)	118 (1.2)
Other	19 (0.9)	20 (0.8)	26 (0.9)	40 (1.0)	38 (1.0)	76 (1.1)	118 (1.2)
Unknown	5 (0.2)	15 (0.6)	22 (0.8)	28 (0.7)	41 (1.1)	97 (1.4)	163 (1.6)

Results are presented as N (%) unless otherwise noted. $*p < 0.05$ for trend from 2010 to 2016. Percentages may not total 100% due to rounding.

[a]N refers to the number of beneficiaries in any calendar year, 2010–2016, who were identified as transgender based on the algorithm. The percentage reported is the percentage of transgender beneficiaries among total Medicare beneficiaries in that year. With the exception of 2014, there are a small number of beneficiaries in each year with missing demographic data: 2010 (n = 3); 2011 (n = 4); 2012 (n = 4); 2013 (n = 4); 2015 (n = 6); and 2016 (n = 6).

[b]The first occurrence N refers to the number of beneficiaries who appeared in the 2010–2016 cohort for the first time in a given year and the percentage of total transgender beneficiaries in that year.

SD, standard deviation.

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Table 3. Distribution of Transgender ICD-9 and ICD-10 Codes Among Medicare Beneficiaries, October 2014 through September 2016

Description of ICD code	ICD-9 (October 2014 through September 2015)		ICD-10 (October 2015 through September 2016)	
	N = 4857	%	N = 8733	%
Trans-sexualism with unspecified sexual history	2013	41.5	N/A	N/A
Trans-sexualism with asexual history	65	1.3	N/A	N/A
Trans-sexualism with homosexual history	118	2.4	N/A	N/A
Trans-sexualism with heterosexual history	79	1.6	N/A	N/A
Gender identity disorder of childhood	1155	23.8	78	0.9
Gender identity disorder in adolescence and adulthood	3118	64.2	4466	51.1
Other gender identity disorders	N/A	N/A	418	4.8
Gender identity disorder, unspecified	N/A	N/A	4168	47.7
Personal history of sex reassignment	N/A	N/A	1998	22.9

Beneficiaries are able to have more than one transgender diagnosis code in each study period (i.e., diagnoses are not mutually exclusive). ICD-9 codes are counted for the year preswitch (October 2014 through September 2015); ICD-10 codes are counted for the year postswitch (October 2015 through September 2016). Descriptions for codes in both ICD-9 and ICD-10 are listed in the table with ICD-10 wording; ICD-9 descriptions are worded slightly differently, per (1) gender identity disorder in children and (2) gender identity disorder in adolescents or adults.

unweighted kappa statistic for reliability between the two study periods was 0.533 (95% confidence interval [CI] 0.522–0.544), indicating moderate agreement between the two methods. When beneficiaries with only the Z87.890 (personal history of sex reassignment) were excluded from the analysis, kappa results were similar (0.527, 95% CI 0.515–0.540).

Discussion

From 2010 to 2016, the number of Medicare beneficiaries identified as transgender based on diagnosis codes increased each year, and the cumulative number of transgender beneficiaries grew more than eightfold from 2010 to 2016. These data are consistent with findings from other studies,[35] including those conducted with patients in the U.S. Veterans Health Administration (VHA), which have found similar rates of growth in the number of transgender patients seen by VHA providers.[25] Furthermore, there was a near-doubling in transgender beneficiaries identified after the transition to ICD-10; however, there was evidence that the population was already growing before the change in the coding system.

We found that the characteristics of beneficiaries in each year changed over this time period as well, with an increase in mean age and decreases in the proportion of dually eligible beneficiaries and those qualifying for Medicare based on disability. Inclusion of the personal history Z87.890 ICD-10 code likely had an impact on the age increase as those only identified by that code in the postswitch period were older

than the rest of the study population. However, overall, transgender beneficiaries remain younger and more likely to be dually eligible than the general Medicare population.[36]

However, an increase in the *identification* of a population over time may not align with an increase in size of the existing population. These changes, both in the growth of the identified transgender Medicare population over time and the change in characteristics of transgender Medicare beneficiaries, may be reflective of an expansion of health care coverage to transgender beneficiaries for whom transgender-related care was previously unavailable, as well as an effect of an increased number of transgender beneficiaries coming out and subsequently being able to seek transgender-related care. Furthermore, the new ICD-10 code for personal history of sex reassignment (Z87.890) may make it easier for providers to document in the claims records patients who transitioned previously even if they are not currently seeking transgender-related care. As research on demographic trends among transgender patients over time is sparse, more investigation is needed to understand what is driving these trends.

Another factor that could have contributed to the increase in transgender beneficiaries in more recent years is policy changes at the federal level that affected transgender beneficiaries' access to Medicare coverage for transgender-related care. In May 2014, the U.S. Department of Health and Human Services reversed a ban on Medicare coverage of gender-affirming surgery, which had been in place since 1981.[37] A recent study supports this hypothesis, finding that Medicare coverage of gender-affirming surgery for

Table 4. Comparison of Beneficiaries Identified in Year Preswitch and Year Postswitch, 2014–2016

	Year preswitch		
	Transgender ICD-9 code	No transgender ICD-9 code	Total
Year postswitch			
Transgender ICD-10 code	3386	5347	8733
No transgender ICD-10 code	1471	29,813,473	29,814,944
Total	4857	29,818,820	29,823,677

transgender patients nearly tripled from 2012–2013 to 2014.[35] In addition, a federal ban on discrimination against patients based on gender identity was enacted in May 2016, in addition to many current and new state and local bans.[38,39] However, it is important to note that an injunction was put in place against the federal ban in December 2016.[40] Although beneficiaries previously might have been at risk of being denied coverage based on their gender identity or for seeking transgender-related care, these policy changes may have increased access to coverage and encouraged providers to increase usage of transgender-related codes. Furthermore, current standards of care[41] require a mental health evaluation before initiating many gender-affirming procedures[19]; the increase in transgender individuals accessing medical care is likely reflected in the growing number of those acquiring a new diagnosis code.[20,35]

In recent years, there has been a shift to the use of an identity framework rather than a disease framework to understand and indicate transgender status, and notably, gender identity disorder codes in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV), upon which the ICD-10 coding system is based, have been updated to gender dysphoria codes in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5).[42,43] This shift in framework for understanding transitioning and transgender status is not reflected in the current ICD-10 code definitions; however, health care professionals' understanding may be shifting with the next generation of physicians.[44–46] Awareness of transgender health among practicing physicians is not well characterized and is implied to be poor based on reports of transgender patients' experiences.[2] However, without a curricular mandate addressing transgender health and an identity framework in gender-affirming care, it is unlikely that we will see a uniform shift in physician practice just yet.[46–48] October 2015 through September 2016 saw many mainstream and affirming conversations about transgender people in the media[49–51]; however, it is not likely that the difference in acceptance and destigmatization would have enough impact on existing prejudice and stigma[52] to explain the near-doubling in the number of transgender beneficiaries identified in our analysis.

It is also important to note that the demographics of transgender beneficiaries notably changed at approximately the same time that ICD-10 codes were introduced. This points to the need for all researchers to critically examine their methods, diagnosis codes used, and potential effects of bias when creating populations before and after October 1, 2015. The implications are wide-ranging and would apply to all studies using ICD codes to identify populations or outcomes over time.

Using claims data to identify the transgender population is still a fairly novel method for researchers, although recent research in this area is promising.[21,22,24,27] However, using diagnosis codes found in claims data as a proxy for gender identity can also be limiting in understanding the individual behind the data. In some situations, claims data can be combined with other types of administrative records such as EHRs and surveys to further support the conclusion of identifying a person as likely transgender.[53] Given the relative lack of data about transgender individuals, especially transgender Medicare beneficiaries, the incremental inclusion of gender identity items on federal surveys and select state health assessments has been key to better identifying and serving this population.

Limitations

Our study has some notable limitations. First, our method to identify transgender Medicare beneficiaries using claims data likely undercounted the population as it depends on transgender individuals being able to access correctly coded gender-affirming care. However, our analysis provides a substantial step toward an accurate count. This can help inform health care providers that transgender Medicare beneficiaries exist in growing numbers, which could then lead them to seek additional training to make their practices more trans-affirming spaces, ultimately providing better access to quality care. Second, although we used an established algorithm to identify transgender beneficiaries, there will necessarily be misclassification because not all beneficiaries are seeking THE transgender-related care upon which the algorithm is based. Unreliable data on beneficiary sex means that we were unable to incorporate any additional relevant information beyond the diagnosis codes, likely resulting in an underestimate of transgender individuals seeking care. Third, differential coding practices will have affected our study. Diagnosis codes and billing practices change on an annual basis, and it is possible that some providers are using codes with updated definitions or are interpreting existing codes in different ways than the current definition.

An additional ICD-10 transgender-related code, F64.0 (transsexualism), was introduced in October 2016 and was not included in this study as it was outside of our study period; at the same time, the description of code F64.1 was updated from gender identity disorder in adolescence and adulthood to be defined as dual-role transvestism. Future ICD-10 algorithms used to identify transgender Medicare beneficiaries should include the F64.0 code and take into account any relevant additions or updates to code definitions.

Conclusion

Overall, this study provides a view into how the transition from ICD-9 to ICD-10 affected our ability to identify the transgender Medicare population over time and allows us to observe how this population is rapidly growing and changing over time. In particular, inclusion of a code for personal history of sex reassignment appears to have captured a group of beneficiaries not previously identified from health care claims before October 2015. As more data are collected both at the federal level and the provider level, it is essential that data on sexual orientation and gender identity are collected in a standardized way (e.g., as demographic data) to further efforts to better serve the LGBT community.

Acknowledgments

Disclaimer

The views expressed in this article are those of the authors and do not necessarily represent the views of the Centers for Medicare & Medicaid Services or the U.S. Department of Health and Human Services.

Author Disclosure Statement

No competing financial interests exist.

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Address correspondence to:
Erin R. Ewald, ScM
Health Care Evaluation Department
NORC at the University of Chicago
4350 East-West Highway, 8th Floor
Bethesda, MD 20814

E-mail: ewald-erin@norc.org

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