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Identifying Gender Minority Patients' Health and Health Care Needs In Administrative Claims Data

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Abstract

Healthcare utilization patterns for gender minority Medicare beneficiaries (transgender or gender non-binary persons) are largely unknown. We identified gender minorities using a diagnosis-code algorithm and compared them to a 5% random sample of beneficiaries from 2009–2014 for mental health and chronic diseases, preventive and mental healthcare use, hospitalizations, and emergency department visits. Gender minority beneficiaries experienced more disability and mental illness than non-gender minorities. Adjusting for age and mental health, gender minorities used more mental healthcare. Adjusting for age and chronic conditions, they were more likely to be hospitalized and to visit the emergency department. There were several small but significant differences in preventive care use. Findings were similar for disabled and older cohorts. These findings underscore the need to capture gender identity in health data in order to better address health needs for this population.

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Introduction

Rigorous studies describing gender minorities' (transgender or gender non-binary persons) health and healthcare use are scarce (1–10) despite being a National Institutes of Health disparity population.(11) Despite being recently added to 7 federal studies during the Obama administration, gender identity information is still not routinely collected in administrative databases, electronic health records (EHRs), or most federal surveys,(2, 12, 13) and is often measured inconsistently across studies.(3) Disabled and/or elderly gender minorities are especially vulnerable to high health burden and reduced healthcare access.(1, 2)

Gender minority research to date shows elevated physical and mental illness compared to cisgender peers (people who identify with their gender assigned at birth),(2, 5–8, 14) particularly in older and/or disabled groups.(13) Thirty nine percent of gender minorities have a disability, compared 15% of people nationally.(15) Half of older adult gender minorities, and over 80% of disabled gender minorities under age 65, received depression treatment.(13) About 40% of gender minorities, and over 60% of those experiencing assault, attempt suicide.(5, 16) Gender minority persons face social burdens including discrimination in healthcare(including lower insurance coverage rates(17)), employment, housing, and reduced social support.(5) Even those with Medicare coverage often lack access to covered hormone therapy services (14%) and to gender-affirming surgery (28%; not covered prior to 2014).(15) Up to 1/3 (18) of gender minorities lack a regular primary care provider, compared to less than 1/5 of cisgender people.(17) Twenty eight percent experience verbal harassment in medical settings(5) and 50% have to educate their doctors about gender minority care.(5, 19) Older adult gender minorities lack social support but fear accessing health services more than cisgender elders.(20) These realities contribute to delaying medical care.(21)

We used the Center for Medicare and Medicaid's (CMS') high-specificity algorithm to identify gender minority patients (13, 22) in 2009–2014 Medicare claims, and compared them to a 5% random sample of non-gender minority beneficiaries on: mental healthcare use (outpatient, inpatient, and psychotropic medication use), preventive care (flu shots, use of routine physical exams, and annual wellness visits), physical health hospitalizations, and emergency department use. Prior work has focused on single years and primarily on chronic condition data;(13) we use 6 years of data to present one of the first national analyses modeling healthcare service use for gender minorities in Medicare.

Study Data and Methods

We compared 2009–2014 yearly cross-sectional claims datasets for all gender minority beneficiaries and a 5% random sample (a standard research analytic cohort provided by CMS) of non-gender minority beneficiaries using the Inpatient, Outpatient, Skilled Nursing Facility, Home Health, Carrier, and Part D Event Files. The Master Beneficiary Summary File captured enrollment, demographic information, and chronic and/or potentially disabling conditions.

We identified gender minority beneficiaries using CMS' recently published algorithm.(13) In each year, we **identified** beneficiaries using the following ICD-9 codes: 302.50–302.53 (Transsexualism), 302.6 or 302.85 (Gender Identity Disorder in children/adults). Beneficiaries were **validated** in each year by identifying multiple such records within the same year or prior/subsequent years or having hormone therapy.(23) We created a comparison group of non-gender minority beneficiaries from the 5% random sample who were not captured by the gender minority algorithm, and had at least 1 claim in the year studied. Although these individuals are not identified in the gender minority algorithm, they are also not confirmed to be cisgender. Therefore, we describe these individuals as “non-gender minority” beneficiaries. We required that beneficiaries have a claim to ensure engagement in care.

Cohorts Studied

We included beneficiaries with continuous enrollment in Medicare parts A and B (and not Part C) for 12 months in each year studied. We excluded beneficiaries with End-Stage Renal Disease from the analysis, and compared gender minority and non-gender minority beneficiaries within each eligibility cohort (disabled or aged ≥ 65, based on their original entitlement reason). See Appendix for cohort size by year.(23)

Healthcare Utilization

Mental healthcare utilization (outpatient visits, psychotropic medication use, inpatient visits) was extracted from event-based records. Outpatient visits included Part B Carrier Claim or Outpatient Claims records with a mental health diagnosis code (ICD-9 codes 291, 292, or 295–314 (24)) in the primary diagnosis location. Inpatient visits used these codes in either the admitting or primary location.(25) Psychotropic medications were identified using the Part D Event file and a psychotropic medication list from previously published Medicare analyses.(26)

Physical health hospitalizations were inpatient visits not meeting mental health hospitalization criteria described above. Emergency department (ED) visits were measured using the following revenue center codes in Outpatient Claims Revenue Center Files with paid amounts >\$0: 450, 451, 452, 456, 459, 0981.(27)

Preventive care indicators (annual flu shots, routine physical exam, or annual wellness visits) were selected because these services are recommended to all studied beneficiaries regardless of gender. Flu shots were captured using procedure codes described in prior literature(28) in any claim. Routine physical exams were captured using procedure codes 99381–99387 and 99391–99397 in any claim. Medicare “initial preventive physical exam” (IPPE; G0402) or “annual wellness visits” (AWV) (Initial - G0438, Subsequent - G0439) were also captured by procedure codes in any claim. Medicare IPPE and AWVs focus on preventive care and screenings only, and tend to be shorter than regular physical exams.(29)

Covariate Measures

We described beneficiary characteristics by cohort in the **first year** the beneficiary met inclusion criteria, including age, Medicaid dual eligibility, race/ethnicity, U.S. region, and chronic health conditions: any mental or physical chronic or potentially disabling conditions (see Appendix (23)), as well as indicators of multiple chronic conditions (25) (either physical or mental).

Statistical Analysis

Chi-squared tests compared baseline demographic and health status characteristics of gender minority and non-gender minority beneficiaries.

Mental healthcare use outcomes include outpatient visits (any visits; number of visits among those with ≥ 1 visit), psychotropic drug use (any), and inpatient visits (any visits; number among those with ≥ 1 visit). These models were adjusted for age (continuous) and mental health need (binary indicators for each mental health condition). Preventive healthcare use outcomes are annual rates of flu shots, preventive physical exams, and annual wellness visits, adjusting for age only. Other inpatient use (any visits; number among those with ≥ 1 visit) and ED use (any visits; number among those with ≥ 1) models were adjusted for age, chronic conditions (binary indicators for each mental or physical health condition), and multiple chronic conditions (continuous variable).

We captured differences adjusted for health need only, in line with the Institute of Medicine definition of disparities (30). Utilization models were nested at the beneficiary level and therefore account for both within- and between-subject variance. We used logistic regression models for binary outcome variables and generalized linear models for continuous outcomes (see Appendix for details(23)). We report predicted population margins (the marginal means for each group after adjusting for covariates).

In a sensitivity analysis for physical health hospitalizations, we excluded any beneficiaries with procedure codes for genital or breast surgery (See Appendix for list of codes (23)). Medicare denied coverage for gender affirmation surgeries prior to 2014, so we did not anticipate a change in the results.

Limitations

This study has several important limitations. First, CMS' claims-based gender minority algorithm includes patients who are currently in treatment, paid for by Medicare, related to their gender minority status or a medically assisted transition. It does not differentiate between the heterogeneity of gender identities and does not capture people who: do not have access to or do not want medical procedures related to their transition, whose providers may not use transgender-related ICD-9 codes to avoid potential for claims being denied, and persons receiving their transgender-related care through free clinics, online, or without claims-based payments. Second, reported estimates of utilization for gender minorities only represent those beneficiaries captured by the algorithm (who, by definition, are receiving medical care), and may therefore over-estimate use of medical services relative to gender

minority beneficiaries not receiving care. Third, we excluded gender-minority-related ICD-9 codes from mental healthcare use measures, although these claims may represent a mental health visit and are not always captured with another mental health diagnosis code. Fourth, Medicare claims can miss flu shots provided by employers, paid for out of pocket, or received at free clinics (28) (though they do capture retail clinic data). Fifth, we did not have information about supplemental Medicare coverage (Medigap plans), which may affect some healthcare utilization. Finally, mental healthcare use estimates exclude substance use claims. Due to recent policy changes, future analyses will be able to observe and report on claims for substance use.

Study Results

Description of Cohorts

Disabled gender minorities were more often under 65 years old than disabled non-gender minority peers ($p<0.0001$; Exhibit 1). Gender minorities were also slightly more likely to be white than non-gender minority peers, and less likely to live in the South (both $p<0.0001$).

Gender minorities were more likely to be dually eligible for Medicaid in both the disabled (72% vs. 47%; $p<0.0001$) and the aged cohort (17% vs. 11%; $p<0.0001$). Chronic physical conditions were similar for disabled gender minority and non-gender minority beneficiaries (78% vs. 77%, $p=0.8031$) but slightly higher in aged gender minority beneficiaries (91% vs 88%, $p<0.0001$). Gender minority beneficiaries had markedly higher mental health morbidity across both cohorts (78% vs. 46% in the disabled; 43% vs. 24% in the aged; both $p<0.0001$). More gender minority beneficiaries had multiple chronic conditions compared to non-gender minorities: 80% vs. 70% of disabled—and 84% vs. 75% of aged—beneficiaries had 2 or more chronic conditions.

Healthcare Utilization

Mental Healthcare Use (Outpatient, Inpatient, and Psychotropic Medications)

—After adjustment, 29.9% of disabled gender minority (vs. 18.3% of disabled non-gender minority beneficiaries) had 1 outpatient mental health visit. In the aged, 10.3% of gender minority (vs. 3.7% of non-gender minority) beneficiaries had 1 visit (both $p<0.0001$; Exhibit 2). Among those with 1 outpatient mental health visit, gender minorities had approximately 2–3 more visits in each cohort (both $p<0.0001$): 9.4 vs. 7.0 visits annually (disabled), and 6.8 vs. 4.0 visits annually (aged). Relatively speaking, gender minority beneficiaries had 34% and 70% more visits in the disabled and aged groups, respectively. In the disabled cohort, 56.2% of gender minority and 50.3% of non-gender minority beneficiaries used a psychotropic medication. In the aged cohort, 23.2% of gender minority and 18.6% of non-gender minority beneficiaries used a psychotropic medication (both $p<0.0001$).

In the disabled cohort, 1.0% of gender minority and 0.6% of non-gender minority and beneficiaries had a mental health hospitalization ($p<0.0001$). In the aged cohort, 0.15% of gender minority and 0.09% of non-gender minority beneficiaries had a mental health

hospitalization ($p=0.0361$). Number of mental health hospitalizations among those with at least one did not differ for gender minority vs. non-gender minority beneficiaries.

Preventive Care Measures—After adjustment for age, disabled gender minority beneficiaries were more likely to receive an annual flu shot (41.3%) than non-gender minorities (37.2%; $p<0.0001$, Exhibit 3). Receiving a flu shot was more common in the aged sample (55–56%), and similar for gender minority and non-gender minority beneficiaries. Having a routine physical exam annually was somewhat less common for disabled gender minority beneficiaries (3.7%) compared to non-gender minority beneficiaries (4.0%; $p=0.0302$). Routine physical exams were also rare in the aged cohort, and did not differ by gender identity.

Annual wellness visits were similar in the disabled cohort (between 5.5–5.7 visits), but significantly higher for gender minority beneficiaries (11.1%) in the aged cohort compared to non-gender minority beneficiaries (9.6%; $p=0.0147$).

Other Inpatient Use and ED Visits—After adjusting for age, all chronic or potentially disabling conditions, and number of chronic conditions, more gender minority beneficiaries had a physical health hospitalization (Disabled: 13.3% of gender minority vs. 12.3% of non-gender minority beneficiaries, $p=0.0039$; Aged: 13.5% of gender minority vs. 10.5% of non-gender minority beneficiaries, $p<0.0001$; Exhibit 4). This difference was not attenuated in the sensitivity analysis. Gender minority beneficiaries were also more likely to have an ED visit (Disabled: 40.8% in gender minority vs. 35.5% in non-gender minority beneficiaries, $p<0.0001$; Aged: 27.0% of gender minority vs. 20.3% of non-gender minority beneficiaries, $p<0.0001$). Among the aged with 1 physical health hospitalization, gender minority beneficiaries had about 0.7 more hospitalizations annually (1.53) than non-gender minority beneficiaries (1.45; $p=0.0211$). This result also remained stable in the sensitivity analysis. Of all beneficiaries with 1 ED visit, disabled gender minorities had nearly 24% more ED visits annually (2.6 visits) compared to disabled non-gender minority beneficiaries (2.1 visits; $p<0.0001$). The difference in the aged cohort was significant as well, but represented a smaller relative difference (1.7 visits for gender minority vs. 1.5 visits for non-gender minority beneficiaries, $p<0.0001$).

Discussion

Our findings, that gender minority Medicare beneficiaries had higher mental illness and mental health utilization, and higher ED and hospitalization rates, adds to limited knowledge of healthcare use among gender minority populations. Small observed differences in flu shots and routine primary care do not suggest a lack of access for identified gender minority beneficiaries compared to peers. Our results contrast somewhat with recent findings from survey data in a subset of U.S. states showing no difference in prevalence of chronic diseases or depressive disorders.⁽¹⁷⁾

The finding that differences in utilization of mental health, emergency, and hospital care persist after adjusting for age and the presence and number of mental health and/or physical health chronic conditions likely indicates other mechanisms for health burden among the

gender minority cohort, or higher severity of existing conditions. Chronic conditions in Medicare databases likely do not fully capture the level of health need. Future studies may benefit from comparisons within disease-specific or severity-adjusted subgroups.

Higher mental health need for gender minorities has been documented elsewhere (5, 16) and as posited by the Minority Stress Theory, may be explained by the distress generated from the unique forms of discrimination faced by minorities (here due to gender identity and/or expression). (31) These “minority stressors,” including gender-related victimization and discrimination, are associated with increased mental distress among gender minorities (32–34) as well as suicidal ideation.(35)

Many factors widely reported in survey data that influence healthcare need and access are not measured in administrative claims. These include direct discrimination by healthcare providers toward gender minority individuals, which can lead those individuals to delay needed care (5) 4 times as often as those not report such discrimination.(21) Other psychosocial risk factors such as a lack of social support, stable housing, or employment (5) may likewise impact care seeking.

Gender minority patients identified in Medicare claims are primarily disabled, and therefore over-represented in a population with relatively lower flu shot rates and preventive primary care use in this analysis, and other preventive care use in prior literature (36, 37). They also appear to have more frequent contact with the healthcare system, which may partially explain higher flu shot rates relative to peers. Preventive primary care may play a larger role for Medicare beneficiaries in the future as CMS continues experimenting with pay-for-performance models and value-based purchasing. Many other preventive screenings, such as breast and prostate cancer screenings, are important for gender minority patients to receive, but difficult to study accurately in claims data without information about sex assigned at birth and gender transitions.

Healthcare data availability for gender minorities may be improving. Since 2015, EHR Meaningful Use incentive programs require the capacity to record structured gender identity information,(38) an essential step toward understanding and reducing health disparities for gender minority populations.(2, 39, 40) But many still do not record gender identity, despite the fact that the vast majority (90%) of patients say they would share this information even in emergency settings.(41) These analyses add valuable information to a sparse research literature about gender minority Medicare beneficiaries, even as policies around health coverage for transgender individuals evolve rapidly.(42) The Affordable Care Act (ACA) extended health insurance protections to gender minority patients through Section 1557 (43) and HHS recently extended nondiscrimination policies to include gender identity.(44, 45) In 2014, Medicare reversed a ban on gender affirmation surgery.(46) However, against a backdrop of efforts to “Repeal and Replace” the ACA, legal and policy experts believe that “a revision of Section 1557 regulations to exclude protections for gender identity and transgender services seems likely.”(47)

As federal priorities shift, so do policies around collection of sexual orientation and gender minority data in federal surveys. Some of these changes have been reversed (or proposed

changes reconsidered) under the current Administration.(48) Decisions about what questions to include have also successfully been influenced by public commentary: HHS retained a sexual (but not gender identity) question in the National Survey of Older Americans due to comments received. (49)

The findings of this analysis in the context of prior literature and the current policy environment bolster the importance of studying gender minority populations across different data sources to better understand their health and healthcare needs.

Conclusion

This analysis demonstrates the large disability and mental health burdens for gender minority beneficiaries, as well as high rates of mental healthcare service use in that population. Furthermore, higher rates of emergency care use among gender minorities than non-gender minority beneficiaries may signal relatively higher unmet need, and reflects a need for more action to study and mitigate potential drivers of morbidity for this population.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Exhibit 1**Characteristics of Continuously Enrolled Medicare Beneficiaries By Cohort, 2009–2014**

	Original Eligibility: Disabled		Original Eligibility: Aged	
	Non-Gender Minority	Gender Minority	Non-Gender Minority	Gender Minority
Age				
<65	74%	93%	0%	0%
65–74	19%	6%	56%	58%
75–84	6%	<1%	30%	25%
85+	2%	<1%	15%	17%
Medicaid Dual Eligibility				
Yes	47%	72%	11%	17%
No	53%	28%	89%	83%
Race/Ethnicity				
Unknown	<1%	<1%	<1%	<1%
Non-Hispanic White	70%	73%	84%	88%
Black (or AA)	18%	16%	7%	4%
Other	<1%	1%	1%	1%
Asian/Pacific Islander	1%	2%	2%	2%
Hispanic	8%	8%	5%	4%
AI/AN	1%	1%	<1%	<1%
Region of the U.S.				
South	42%	27%	39%	31%
West	16%	27%	18%	26%
Northeast	18%	23%	19%	23%
Midwest	24%	23%	24%	20%
Other Region ^d	<1%	<1%	<1%	<4%
Chronic / Potentially Disabling Conditions:				
Any Mental Health Conditions	46%	78%	24%	43%
Any Physical Health Conditions	77%	78%	88%	91%
Number of Conditions				
1 or more	85%	93%	89%	93%
2 or more	70%	80%	75%	84%
3 or more	55%	67%	60%	72%
4 or more	42%	55%	45%	59%
5 or more	31%	44%	32%	48%
6 or more	23%	36%	23%	38%
7 or more	17%	38%	16%	28%
8 or more	12%	33%	11%	22%

	Original Eligibility: Disabled		Original Eligibility: Aged	
	Non-Gender Minority	Gender Minority	Non-Gender Minority	Gender Minority
9 or more	9%	17%	8%	17%

SOURCE: Authors' analysis of Medicare Research Identifiable (RIF) data files from 2009–2014.

NOTES: All comparisons between Gender Minority and Non-Gender Minority beneficiaries significant at the $p < 0.001$ level, other than “Any Physical Illness” in the Disabled cohort (which is not significant). Demographic information is from the first year that beneficiaries met inclusion criteria. Beneficiaries are categorized as aged or disabled based on their original reason for entitlement in Medicare. Non-gender minority patients are from a 5% random sample of Medicare Beneficiaries in each year, with at least 1 claim, and who are not identified as gender minorities. All beneficiaries in Disabled and Aged cohorts are continuously enrolled in Medicare parts A and B (and not Part C) for 12 months in each year studied. Inclusion criteria for non-gender minority patients also included at least 1 non-pharmacy claim in the year studied. Excludes Beneficiaries with End Stage Renal Disease. AA is African American. AI/AN is American Indian/Alaskan Native.

^a Other Regions includes Puerto Rico, U.S. Virgin Islands, American Samoa, Guam, Other U.S. Possessions, as well as beneficiaries with listed locations as Canada & Islands, Africa, Central America & West Indies, Europe, Mexico, Oceania, and the Northern Marianas Islands.

Exhibit 2

Mental Healthcare Use for Gender Minority Beneficiaries Compared to Non-Gender Minority Beneficiaries, Adjusted for Age and Mental Health Conditions

	Original Eligibility: Disabled		Original Eligibility: Aged	
	Non-Gender Minority	Gender Minority	Non-Gender Minority	Gender Minority
Any Outpatient MH visit (%)	18.3	29.9 ****	3.7	10.3 ****
Any Psychotropic Fills (%)	50.3	56.2 ****	18.6	23.2 ****
Any Inpatient MH Visit (%)	0.6	1.0 ****	0.09	0.15 **
Outpatient MH visits (Mean) (Any OPMH>0)	7.0	9.4 ****	4.0	6.8 ****
Inpatient MH visits (Mean) (Any IPMH>0)	1.5	1.6	1.2	1.2

SOURCE: Authors' analysis of Medicare Research Identifiable (RIF) data files from 2009–2014.

NOTES: Results are predicted population marginal means. MH is Mental Health; OPMH is Outpatient Mental Health; IPMH is Inpatient Mental Health. Models are adjusted for age (continuous) and mental health chronic or potentially disabling conditions (as binary indicators).

**
p<0.05,

p<0.001 for significant difference between Gender Minority group vs. Non-Gender Minority group.

Exhibit 3**Preventive Healthcare Use for Gender Minority Beneficiaries Compared to Non-Gender Minority Beneficiaries Adjusted for Age**

	Original Eligibility: Disabled		Original Eligibility: Aged	
	Non-Gender Minority	Gender Minority	Non-Gender Minority	Gender Minority
Annual Flu Shot (%)	37.2	41.3 ****	55.5	55.6
Any Routine Physical Exam (%)	4.0	3.7 **	3.5	3.6
Any Annual Wellness Visit (%)	5.7	5.5	9.6	11.1 **

SOURCE: Authors' analysis of Medicare Research Identifiable (RIF) data files from 2009–2014.

NOTES: Results are predicted population marginal means. Models are adjusted for age (continuous).

**
p<0.05

p<0.001 for significant difference between Gender Minority group vs. Non-Gender Minority group.

Exhibit 4**Non-Mental Health Hospitalizations and Emergency Department Use for Gender Minority Beneficiaries Compared to Non-Gender Minority Beneficiaries Adjusted for Age and Chronic or Disabling Conditions**

	Original Eligibility: Disabled		Original Eligibility: Aged	
	Non-Gender Minorities	Gender Minorities	Non-Gender Minorities	Gender Minorities
Any Physical Health Hospitalizations (%)	12.3	13.3***	10.5	13.5****
Any ED Use (%)	35.5	40.8****	20.3	27.0****
Number of Physical Health Hospitalizations Among those with Any (Mean)	1.6	1.7	1.45	1.53**
Number of ED Visits Among Those with Any (Mean)	2.1	2.6****	1.5	1.7****

SOURCE: Authors' analysis of Medicare Research Identifiable (RIF) data files from 2009–2014.

NOTES: Results are predicted population marginal means. Models are adjusted for age (continuous), binary indicators of all chronic or potentially disabling condition flags, and a count for the number of chronic conditions (continuous). ED is Emergency Department.

p<0.01,

p<0.001 for significant difference between Gender Minority group vs. Non-Gender Minority group.