Comparing Sexual Orientation and Gender Identity Documentation Between Adolescent and Pediatric Primary Care Clinics

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ABSTRACT

PURPOSE: Recent literature suggests that sexual orientation and gender identity (SOGI) documentation is poor. We hypothesized that an adolescent clinic would have higher rates of SOGI documentation than a pediatric primary care clinic.

METHODS: We performed a single-center, retrospective, observational study of patients ages 10–26 presenting to the primary care or adolescent medicine clinics of a tertiary care hospital from 2019 to 2021. Electronic medical record (EMR) data were analyzed using Python and Stata/MP 16.1.

RESULTS: Patients in the adolescent clinic were five times more likely to have to have complete SOGI documentation compared to primary care. Gender diverse youth were over six times more likely to have a recorded sexual orientation than cisgender youth across both clinics.

CONCLUSION: Adolescent providers document SOGI more often than primary care providers. Sexual orientation information for cisgender patients remains poor across environments. This study emphasizes the need for ongoing provider education on SOGI documentation.

KEYWORDS: sexual orientation and gender identity, adolescent health, data privacy, confidentiality, transgender health

INTRODUCTION

Despite increased provider awareness regarding use of correct pronouns and gender identities, sexual orientation and gender identity (SOGI) documentation in the electronic medical record (EMR) has struggled to keep pace. There are nearly two million gender diverse youth (GDY) in the United States, including those who may identify as lesbian, gay, bisexual, transgender (LGBT).[1] This population has historically struggled to disclose their gender identity to healthcare providers due to fear of discrimination.[2] Yet it is critical that providers know a patient's gender identity, as misgendering an individual or using their non-chosen name can be emotionally harmful and undermine the patient provider relationship.[2] Adult LGBT clinic patients surveyed regarding SOGI questions overwhelmingly agree that it is not only appropriate to ask these questions, but very important.[3–6] Transgender youth have also indicated that asking gender identity questions is both important and expected, with a majority (79%) preferring EMR-wide documentation of chosen name and pronouns.[7,8]

SOGI information is important for individual patient care and also for public health and research initiatives seeking to improve the health of the gender diverse population, especially given that GDY are a vulnerable group disproportionately reported to suffer adverse outcomes.[9–11] On an individual level, documenting SOGI information helps providers order appropriate sexual health screening.[12] On a population level, improving SOGI documentation allows researchers to accurately identify this group of patients in order to illustrate disparities in insurance coverage, access to care, and outcomes.[2,9,10,13,14] Broadly, SOGI completion can enable clinics to cultivate a GDY patient registry, ensuring standardization of patient care, including: preventative healthcare screenings, sexually transmitted infection testing and treatment, mental health resources, and more.[3,15,16] These data, coupled with race and ethnicity data, would also allow improved understanding of racial disparities within LGBT health.[3]

In 2013, the World Professional Association for Transgender Health EMR Working Group released recommendations regarding how to appropriately solicit and document SOGI.[17] These recommendations focused the "two-step" approach, which first asks asserted sex, then birth sex. Guidelines suggested that EMRs should provide at least three fields to capture this data: legal sex, gender identity, and sex assigned at birth.[5,18] LGBT advocacy organizations also endorse SOGI documentation. For example, The Human Rights Campaign's Healthcare Equality Index factors organizations' documentation of SOGI into their Healthcare Equality Index scoring system.[19] The 2015 Centers for Medicare and Medicaid Services (CMS) and the Office of the National Coordinator for Health Information Technology recommended that all EMRs certified for Meaningful Use (a popular CMS incentive program) must include dedicated SOGI fields.[20] Subsequent studies have shown improved documentation after inclusion of a SOGI section in the chart.[21]

Despite this guidance, EMR SOGI information is rarely completed. When documentation does occur, it lacks

standardization both in terms of chart location and its entry as structured data.[11,22] In one survey, less than a third of clinics reported that their EMR supported structured SOGI documentation.[22] Even those with a dedicated SOGI section identified documentation rates of less than 50%.[21–25] One study examining data at an adolescent subspecialty clinic found rates of 84% following an EHR update, but most existing SOGI studies are done with adult data.[26] None that we could find appear to compare differences in documentation between types of pediatric clinics within an institution.

Our institution's EMR includes a dedicated "SOGI SmartForm" that includes structured information about the patient's sexual orientation, legal sex, gender identity, and sex assigned at birth, as well as pronouns and an organ inventory. The data entry form also includes standardized buttons for "transition steps," such as whether a patient has changed their legal name or sex, if they dress according to their gender identity, and if they plan to transition in the future.

In this study, we reviewed the frequency of pediatric SOGI form documentation at a gender-focused adolescent subspecialty clinic compared to a general primary care setting at our tertiary medical center. Given the gender-focused training of the adolescent subspecialty and the fact that this clinic provides gender affirming care, we hypothesized that the adolescent clinic would have higher rates of SOGI form documentation compared to the general primary care clinic. Our aim is to illustrate if and how often pediatric providers elicit this sensitive data in different settings.

METHODS

We performed a single-center retrospective observational study of patient medical records to evaluate type and frequency of SOGI documentation among GDY and cisgender youth across two outpatient medical settings. Our institution is in an urban center and both the primary care and adolescent clinics are affiliated with our academic hospital. The adolescent clinic provides primary care, as well as specialized eating disorder services and gender-affirming treatment. This study was approved by our health system's Institutional Review Board and a waiver of patient consent was obtained.

Population Selection

This study included patients aged 10 to 26 years presenting to the primary care (n = 5500) or adolescent medicine (n = 1870) clinics from March 6, 2019 (when our EMR's structured SOGI section was rolled out) through December 31, 2021. Qualifying adolescent medicine encounters required at least one visit with one of five subspecialty attending physicians certified in adolescent medicine. Patients who had multiple encounters were only counted once. Analyzed data was pulled from only the most recent encounter. A small portion (n = 140) of patients were seen in both adolescent and primary care clinic. Due to exposure to adolescent providers, they were included in the adolescent cohort.

Data Extraction & Analysis

Structured data were extracted from our institution's version of Epic EMR including basic demographic information, patient problem list, recorded gender, gender identity, sex assigned at birth, sexual orientation, transition steps, and organ inventory. Qualifying patients that did not have associated SOGI data were categorized as "No Data."

Gender diversity was identified using 1) problem list diagnoses E34.9 (Endocrine disorder, unspecified) or F64 (Gender dysphoria in adolescent and adult) under the international classification of diseases (ICD-10); or 2) if documented gender identity was "Transgender Male-to-Female," "Transgender Female-to-Male," or "Other;" or 3) if documented "gender identity" different than their "legal sex" or "sex assigned at birth." Patients were categorized as cisgender if they 1) had only "legal sex" documented in the EMR without associated transgender diagnoses; or 2) their "legal sex," "gender identity," and "sex assigned at birth" were congruent.

Sexual orientation categories included "Straight (not lesbian or gay)," "Don't know," "Bisexual," "Gay," "Something else," "Choose not to disclose," "Lesbian or Gay," and "Lesbian." For patients with multiple responses, if one of their orientation selections was "something else" or "don't know" they were classified as such. Patients with both "straight" and an LGB orientation were classified as LGB, and those with "bisexual" and "lesbian or gay" were classified as bisexual.

The distribution of all variables is described. Categorical variables are reported with frequencies and percentages. Odds ratios were estimated using simple logistic regression models and are reported with 95% confidence intervals (CI). Data were analyzed using Python 3.10 and Stata/MP 16.1.[27]

RESULTS

Chart review identified 7370 patients meeting inclusion criteria. Most patients (n = 5500) were seen in the primary care clinic, compared to 1870 in the adolescent clinic (**Tables 1a,b**).

Compared with all patients in the primary care clinic, patients in the adolescent clinic were five times more likely (16% vs. 4%, Odds Ratio (OR) = 5.0, 95% Confidence Interval (CI) [4.2, 6.1], p-value < 0.001) to have complete SOGI documentation (sexual orientation, legal sex, sex assigned at birth, and gender identity). Patients in the adolescent clinic were also nearly five times more likely to have a sexual orientation recorded than in the primary care clinic (16% vs. 4%, OR = 4.9, 95% CI [4.1, 5.9], p-value < 0.001). They were twelve times more likely to have a gender identity documented (41% vs. 5%, OR = 12.5, 95% CI [10.7, 14.5], p-value < 0.001).

Table 1a. Sexual orientation and gender identity demographic information of primary care and adolescent clinic populations

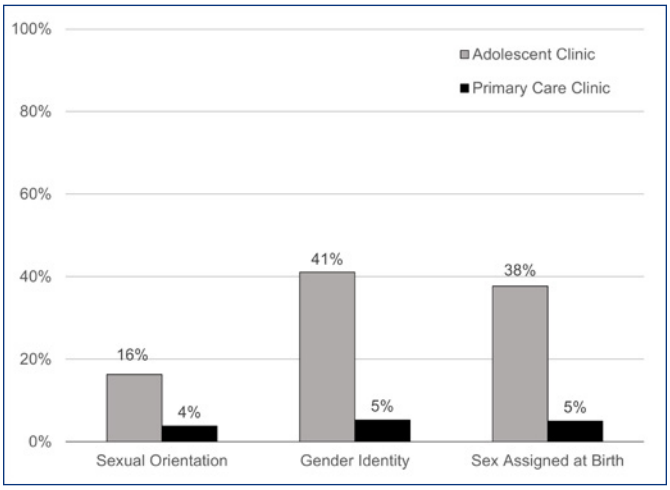
N = 7370	Primary care clinic (n=5500) n (%)	Adolescent clinic (n=1870) n (%)
Legal sex		
Female	2779 (50.5)	1349 (72.1)
Male	2720 (49.5)	517 (27.7)
Nonbinary	1 (0.02)	3 (0.16)
Unknown	0 (—)	1 (0.05)
Sex assigned at birth		
Female	182 (3.3)	529 (28.3)
Male	92 (1.7)	169 (9.0)
Choose not to disclose	3 (0.05)	7 (0.37)
Uncertain	0 (—)	1 (0.05)
No data	5223 (94.9)	1164 (62.3)
Gender identity		
Female	174 (3.2)	207 (11.1)
Male	98 (1.8)	213 (11.4)
Other	15 (0.27)	272 (14.6)
Transgender female/MTF	1 (0.02)	23 (1.2)
Transgender male/FTM	3 (0.05)	53 (2.8)
Choose not to disclose	1 (0.02)	1 (0.05)
No data	5208 (94.7)	1101 (58.9)
Sexual orientation		
Straight	136 (2.5)	101 (5.4)
Bisexual	34 (0.62)	81 (4.3)
Gay/Lesbian	14 (0.25)	21 (1.1)
Something else	8 (0.15)	56 (2.9)
Don't know	11 (0.20)	31 (1.7)
Choose not to disclose	7 (0.13)	16 (0.86)
No data	5290 (96.2)	1564 (83.6)
Pronouns		
She/her/hers	60 (1.1)	176 (9.4)
He/him/his	47 (0.85)	323 (17.3)
They/them theirs	12 (0.22)	74 (3.9)
No data	5381 (97.8)	1297 (69.4)
Transition steps documented		
No steps documented	5460 (99.3)	1521 (81.3)
≥1 step documented	40 (0.73)	349 (18.7)
Organ inventory		
No data	5421 (98.6)	1537 (82.2)
Data	79 (1.4)	333 (17.8)
Complete SOGI (sex assigned at birth, gender identity, and sexual orientation)	194 (3.5)	290 (15.5)

Table 1b. Race and ethnicity demographic information of primary care and adolescent clinic populations

N = 7370	Primary care clinic (n=5500) n (%)	Adolescent clinic (n=1870) n (%)
Insurance		
Private	2338 (42.5)	1277 (68.3)
Public	3098 (56.3)	573 (30.6)
No data	64 (1.2)	20 (1.1)
Race		
White	1179 (21.4)	1123 (60.1)
Black/African American	1709 (31.1)	231 (12.4)
Asian	118 (2.2)	36 (1.9)
American Indian/Alaskan Native	32 (0.58)	3 (0.16)
Native Hawaiian/Pacific Islander	12 (0.22)	1 (0.05)
Multi-racial	135 (2.5)	38 (2.0)
Other	2285 (41.6)	307 (16.4)
Unreported/refused	30 (0.55)	131 (7.0)
Ethnicity		
Hispanic/Latino	2819 (51.3)	373 (19.9)
Not Hispanic/Latino	2663 (48.4)	1364 (72.9)
Patient refused	5 (0.09)	34 (1.8)
Unknown	13 (0.24)	99 (5.3)

Figure 1. SOGI Documentation Across Clinical Settings

Sexual orientation and gender identity (SOGI) documentation rates in the adolescent clinic (n = 1870) compared to the primary care clinic (n = 5500).



All 7370 patients had a documented legal sex. However, sex assigned at birth was completed for only 13% of patients overall, with 38% completion in the adolescent clinic and 5% in primary care (**Figure 1**). Gender identity was complete for 14% of patients overall, with 41% in adolescent and 5% in primary care (**Figure 1**).

We identified 788 GDY patients receiving care in the adolescent clinic and 52 in the primary care clinic. Most GDY patients were identified by their ICD-10 code (97%), with 44% having a "trans" or "other" gender identity listed, and 76% with any discrepancy between gender identity fields (**Table 2**). Across both clinics, 94% of GDY patients had E34 in their problem list, with 46% having F64, and 44% who had both codes.

GDY patients in the adolescent clinic were twice as likely to have a recorded gender identity than GDY in primary care clinic (79% vs. 62%, OR = 2.4, 95% CI [1.3, 4.2], p-value = 0.004). The difference in sexual orientation documentation for GDY between the two clinics was insignificant. However, across both clinics, GDY were over six times more likely (24% vs. 5%, OR= 6.1, 95% CI [5.1, 7.5], p-value < 0.001) to have a recorded sexual orientation than cisgender youth.

For GDY patients, 63% had a documented chosen pronoun, and 40% had at least one documented transition step. The most documented step was "fashion aligned with gender identity" (87%) (**Table 3**).

Table 2. Gender identity by medical setting

N = 7370	Primary care clinic (n=5500) n (%)	Adolescent clinic (n=1870) n (%)
Gender diverse youth Yes	 52 (0.95)	 788 (42.1)
Among Gender Diverse Youth:	n=52	n=788
Trans via ICD-10 code[a]	39 (75.0)	768 (97.5)
E34, Endocrine disorder, unspecified	33 (63.5)	753 (95.6)
F64, Gender dysphoria in adolescent and adult	10 (19.2)	378 (47.9)
Stated gender identity "Trans" gender identity "Other" gender identity	 4 (21.1) 15 (78.9)	 76 (21.8) 272 (78.2)
Discrepancy in one or more SOGI[b] fields	29 (55.8)	613 (77.8)
Among Cisgender:	n=5448	n=1082
Gender identity data No gender identity data Full gender identity data Partial data	 5177 (95.0) 239 (4.4) 32 (0.6)	 934 (86.3) 139 (12.9) 9 (0.83)

a – International classification of diseases
b – Sexual orientation and gender identity

Table 3. Frequency of types of "transition steps" documented for gender diverse youth. Transition steps are a structured data entry option in our electronic medical record. Patients may have one or multiple steps documented.

n = 840	Primary care clinic (n=52) n (%)	Adolescent clinic (n=788) n (%)
Transition steps documented No steps documented ≥1 step documented	 43 (82.7) 9 (17.3)	 462 (58.6) 326 (41.4)
Preferred Name Aligned with Gender Identity	6 (11.5)	284 (36.0)
Fashion Aligned with Gender Identity	8 (15.4)	282 (35.8)
Future Transition Plans	2 (3.9)	56 (7.1)
Gender Identity (free text)	12 (23.1)	276 (35.0)
History of Medical/Surgical Intervention	3 (5.8)	104 (13.2)
Legal Name Aligned with Gender Identity	1 (1.9)	56 (7.1)
Legal Sex Aligned with Gender Identity	0 (—)	26 (3.3)
Sexual Orientation (free text)	4 (7.7)	42 (5.3)

DISCUSSION

Our results support our hypothesis that a gender-focused clinic will complete SOGI data at a higher rate than a non-specialty clinic. Despite the improved documentation rates in adolescent clinic compared to primary care, overall documentation completion rates of gender identity for all youth remain low at 14%, lower than other studies done in the field for adults and teens which have found rates between 35–46%.[15,22–24] Other SOGI-related fields, such as organ inventory and transition steps, were complete even less of the time, though we did not identify any known studies for comparison.

These overall low rates of SOGI structured documentation may stem from patients' and/or providers' perceived privacy concerns. Though there is a push to record SOGI data more often, and many GDY indicate they want these data recorded, the recent implementation of the 21st Century Cures Act in April 2021 means that most all patient data – including notes, lab results, and SOGI information – are readily viewable in online patient portals.[8,28] While this sensitive health information should be readily available to the patients, many remain concerned about who else is accessing these portals. Since implementation, several institutions reported that over 50% of adolescent accounts were accessed by a parent or guardian at least once.[29] This may give pause to providers caring for GDY, considering that surreptitious outing of these patients to their families could lead to serious physical and emotional harm.[29,30]

Higher documentation rates in the adolescent clinic probably stems primarily from that fact that this clinic is, in part, a medical home for gender-affirming care, including gender-affirming hormonal treatment. As such, this clinic is staffed by adolescent medicine providers who have received more advanced training in sexual health and gender health. Due to their specialty expertise, adolescent clinic providers encounter GDY more often than primary care pediatricians do. Almost half of this clinic's patients identify as GDY, compared to 4.5% nationally.[1] The adolescent clinic also schedules more time per patient visit than the primary care clinic does, which may contribute to the observed differences in SOGI documentation.

The ICD-10 code was the most common way we identified GDY – 97% of patients were identified using either E34 or F64. Utilizing billing codes is an imperfect but practical way of identifying transgender patients for chart review, which has been used by multiple previous studies.[23,31–33] Some codes used in similar adult studies, such as F65.1 "Transvestic Fetishism," or Z87.890 "Personal History of Sex Reassignment," were not present in our population. While the exclusion of the latter is likely due to the age, multiple interviews with gender-affirming care providers in our adolescent clinic revealed that providers prefer to use E34.9 "Endocrine disorder, other" for patients, as it is a less stigmatizing diagnosis. The use of E34.9 was specific

to providers in the adolescent clinic, who indicated they did not use this code for patients other than those in the gender program. Together, these codes captured more patients than gender identity fields would alone (**Table 2**).

Legal sex, which is completed at the time of hospital registration, was the only SOGI field that was consistently completed for all patients. Even when an additional gender field was complete, providers frequently did not fill all the GI categories. For instance, the documentation rate for sex assigned at birth lags behind other institutions at 13%, which has been recorded as high as 48%.[23] We posit that providers may not distinguish between legal sex and gender assigned at birth, and therefore consider documentation of legal sex to be sufficient. That said, in our state, there is a legal path for minors to change their legal sex from that which was assigned at birth. In addition, user workflow interface issues may lead providers to miss the entry field for these data altogether. To address the rates of incomplete gender identity information, institutions should consider prompting staff who are changing the patient's gender identity field to also enter or confirm the sex assigned at birth.

In this study, the odds of reporting sexual orientation were six times higher for gender diverse compared to cisgender youth. This may be due to providers being more likely to record sexual orientation for GDY because they feel it is relevant, or because they were more likely to have discussed SOGI generally. Overall, providers completely documented sexual orientation for 7% of patients; this is lower than prior studies, which noted 23–25% completion rate.[24,34] Around two-thirds of our patients with sexual orientation information identified as straight, much lower than the estimated national average of 97%, suggesting that most of the patients who had no sexual orientation recorded would likely have identified as heterosexual.[24] This may reflect a bias in healthcare providers who assume that patients are heterosexual and cisgender by default, and thus don't feel the need for documentation.[35] The lower rates of sexual orientation documentation compared to gender identity documentation may also reflect that patients tend to voluntarily share *only* their gender identity with their provider; patients may not disclose their sexual orientation if they think it is irrelevant to their chief complaint.[36]

Limitations

This retrospective observational study has several limitations. First, our analysis was limited to structured data. It is possible that some providers prefer to document SOGI data in unstructured formats due to workflow efficiencies or privacy concerns as described above. A future study could use natural language processing (a capability we did not have) to examine how frequently this data appears in free-text notes. Second, our method of GDY identification by ICD-10 code is subject to error, as patients may carry these diagnoses without identifying as gender diverse.[11,23] Moreover, ICD-10 codes likely do not capture the entire gender diverse patient population as many patients will not have a code associated with their chart. Though ICD-10 codes are a specific finding, their sensitivity is low, and are best used in combination with keyword, gender identity corroboration, and manual chart review – which we were unable to perform.[23,32] Third, due to limitations of data extraction from our EMR, our analysis was unable to capture changes to patients' SOGI documentation over time. In particular for adolescents, SOGI can be dynamic, illustrating adolescents' fluctuating identities.[3,11,12] Finally, we did not sort SOGI documentation by provider type – e.g., attending physician, resident physician, or advance practice provider. Given that prior studies have shown significant differences in social documentation between these groups, future study of provider-specific documentation patterns for each group will be key to guiding educational efforts.[37]

CONCLUSION

Structured documentation of SOGI remains poor across adolescent and primary care environments. However, adolescent clinic providers documented structured gender identity data more often than providers in the primary care clinic. Providers may enter SOGI information more consistently once they better understand the preferences of and benefits to the patient, such as encouraging use of chosen names, mitigating misgendering pronouns, and more consistently addressing their specific health needs (such as gender-affirming and/or customized sexual health care).[11,38] In addition, EMR solutions such as dedicated clinical decision support and improved user interfaces could improve documentation by prompting providers to complete the SOGI data in an efficient manner. Last, ensuring the privacy of SOGI data is vital to these patients' care and could lead to increased SOGI documentation. Overall, our study highlights the need for ongoing provider education on thorough SOGI documentation, as well as EMR interface improvements.

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