



Documented Pronouns in Adolescents and Young Adults with Type 1 Diabetes

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Abstract

Introduction: Adolescents and Young Adults (AYA) living with Type 1 Diabetes (T1D) confront multifaceted challenges that are further compounded for LGBTQ+ (lesbian, gay, bisexual, transgender, queer, or other gender-expansive) identifying individuals. Studies have shown higher rates of T1D in those who identify as Transgender and Gender-Diverse (TGD). TGD individuals encounter stigma and bias in healthcare settings, which may delay access to essential care. Documenting Sexual Orientation and Gender Identity (SOGI) is crucial for tailored healthcare. Improved SOGI documentation has been associated with better mental health outcomes and more affirming care experiences for TGD individuals. This study investigates pronoun documentation and its associations with sociodemographic and clinical factors in AYA with T1D.

Methods: A retrospective chart review at Children's Hospital Los Angeles (September 2022 to March 2024) analyzed pronoun documentation among AYA with T1D. Associations with glycemic control and sociodemographic factors were evaluated using Fisher's exact, Welch's t, and Wilcoxon rank-sum tests.

Results: Of 1493 AYA with T1D, 25 (1.67%) had non-matching pronouns (pronouns which did not match documented legal sex), 754 (50.50%) matched their legal sex, and 714 (47.82%) had missing pronoun data. Pronoun reporting was more common among Latine individuals, those with public insurance, those under age 21, and those who received care at the main hospital. Non-matching pronoun use was associated with increased diabetes technology use.

Conclusion: Despite efforts to improve paediatric SOGI data collection, disparities in pronoun documentation persist for AYA with T1D. Enhanced documentation practices are needed to improve healthcare outcomes for TGD individuals with T1D.

Keywords: Paediatrics; Sociodemographic; Healthcare; Adolescents

Introduction

Effective management of Type 1 Diabetes (T1D) is essential to prevent acute and chronic complications [1,2]. Recent advancements in T1D care, such as Continuous Glucose Monitoring (CGM), insulin pumps, and Automated Insulin Delivery (AID) systems, facilitate achieving target Hemoglobin A1c (HbA1c) levels [3-5]. Despite these innovations, Adolescents and Young Adults (AYA, 16-25 years old) with T1D still face challenges. For instance, although mean HbA1c has decreased from 9.2% to 8.6% on average in AYA with T1D, they continue to have difficulty meeting the American Diabetes Association goal of a HbA1c less than 7% [3,4,6]. Youth with T1D can experience acute complications, such as severe hypoglycemia and Diabetes-Related Ketoacidosis (DKA), and chronic microvascular and macrovascular complications [1].

In parallel with these clinical challenges, recent research has shed light on healthcare disparities in access to care and treatment for T1D, especially for those who identify as LGBTQ+ (lesbian, gay, bisexual, transgender, queer, or other diverse identities). Transgender And Gender Diverse (TGD) AYA face more barriers to accessing essential healthcare, including mental health and social support, due to economic and systemic biases [7,8]. LGBTQ+ AYA experience higher rates of depression, psychological distress, and suicide risk compared to their non-LGBTQ+ peers [7,10]. Additionally, they are more likely to face harassment, violence, and rejection from family and others, exacerbating risks related to food insecurity, substance abuse, and displacement [8]. As a result,

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patients who identify as TGD are less likely to present for routine care and rate their overall health more poorly than their cisgender peers [9]. This avoidance of care is compounded by fear of judgement and mistreatment related to gender identity and expression [9]. Emerging evidence suggests a higher prevalence of T1D in TGD populations, [11-14] including a nine-fold increase among adolescents diagnosed with Gender Dysphoria (GD) compared to all other adolescents [12]. This underscores the role of clinician bias and healthcare underutilization [15].

Biases held by clinicians towards TGD individuals may reduce care quality and widen disparities [16,17]. Consequently, TGD AYA with T1D may be less likely to receive the personalized care they need. In a recent study involving eight adolescents with T1D and TGD (average HbA1c = 9.0%), five individuals showed an initial improvement in their glycemic control after a single TGD-supportive clinic appointment [12]. While further research is needed, these findings suggest person-centered, TGD-supportive care may positively influence diabetes outcomes. However, this unique group faces unexplored challenges, including psychosocial stressors related to gender identity that impact the effectiveness of care and increase susceptibility to T1D complications. Thus, a clearer understanding of the intersection of gender identity and T1D in AYA is essential for developing inclusive interventions.

Guidelines for paediatric SOGI collection remain limited [18]. Although the Health Resources and Service Administration recommended in 2016 that all Electronic Health Records (EHR) certified under the Office of the National Coordinator of Health Information Technology must be able to record SOGI data, a large-scale review of 1367 US sites - primarily Federally Qualified Health Centers (FQHCs) and community clinics serving mostly AYA found that most centers do not collect sufficient data [19]. While most centers reported some collection of sexual orientation (1028, 75.2%) and gender identity data (1099, 80.4%), 77.1% of all sexual orientation data and 62.8% of all gender identity data were missing [19]. Encouragingly, a more recent study from the T1D Exchange showed some progress, with 82% of paediatric centers and 65% of adult centers caring for people with T1D documenting patient pronouns [20]. To address this gap, gold hammer and colleagues proposed paediatric-specific pronoun collection guidelines, emphasizing the integration of SOGI questions into routine care, use of pronouns by clinicians, inclusion of SOGI questions on patient registration forms, and staff training to foster safe and inclusive environments [18]. These recommendations highlight the urgent need for standardized and universally implemented guidelines for SOGI data collection.

Improving SOGI data collection is an essential first step in addressing the challenges faced by TGD AYA with T1D. Pronouns are essential for expressing gender identity, which is a deeply personal aspect of self that may or may not align with societal expectations or sex assigned at birth. For TGD AYA, the use of pronouns that match their gender identity is a powerful affirmation of their sense of self and shows that their identity is valued and respected [21]. Most TGD AYA desire their asserted pronouns to be documented in EHR and used by all healthcare members [21]. In support of this practice, Russell and colleagues found that correct name and pronoun use were associated with a 71% reduction in severe depression, a 34% decrease in suicidal ideation, and a 65% reduction in suicidal behaviour [22]. Therefore, understanding the implications of respecting patient pronouns and integrating gender affirming practices in T1D management is essential for promoting the well-being, dignity, and rights of all patients.

Beyond individual clinical care, systematic pronoun documentation enables population health surveillance, healthy equity monitoring, and identification of structural barriers that affect sexual and gender minority youth with chronic conditions [18].

Given the need for more inclusive care, it is essential to investigate the intersection of gender diversity and T1D in AYA. This descriptive, cross-sectional study aims to investigate pronoun documentation within the EHR and the presence of non-matching pronouns (pronouns which do not match documented legal sex) among AYA with T1D at a paediatric diabetes care center in the United States. Additionally, this study examines the sociodemographic factors associated with the documentation of pronouns and evaluates how pronoun use relates to diabetes management.

Materials and Methods

Participants

A retrospective chart review was conducted at Children's Hospital Los Angeles, including both the main hospital and affiliated satellite clinics, from September 1, 2022, to March 1, 2024. AYA were eligible for this study if they were between the ages of 10-26 years, with a documented diagnosis of T1D for at least 6 months.

Terminology

In this study, "legal sex" refers to the sex documented in the EHR, which typically reflects the sex listed on legal documents (e.g., birth certificate or government-issued ID). This may or may not correspond to the individual's sex assigned at birth or gender identity. Because EHR systems do not routinely store sex assigned at birth separately from legal sex, we used legal sex as the reference point for determining whether documented pronouns were "matching" or "non-matching." In addition, the gender-inclusive term *Latine* is used to describe individuals of Latin American origin or descent.

Procedures

Data were extracted from the EHR using a standardized form, which captured demographics, clinical presentation, diagnostic tests, treatments administered, and clinical outcomes. Reviewers were trained to ensure consistency of data collection. Discrepancies between data elements were resolved whenever possible by consensus among reviewers (e.g., ethnicity reported by the patient is substituted for multiple conflicting EHR entries). The study was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki. This study and waiver of informed consent were approved by the Institutional Review Board at the institution (Study # CHLA-22-00316).

Data analysis

Descriptive statistics were used to summarize rates of pronoun documentation in the EHR, as well as rates of non-matching pronouns documented in the EHR, across demographic and clinical variables. Categorical data was evaluated using Fisher's exact tests; differences in clinical test data were evaluated using Welch-corrected t-tests; due to significant skew, T1D duration was evaluated using Wilcoxon rank-sum tests. P values less than 0.05 were considered statistically significant. All analyses were conducted using Stata/SE 14.2 (College Station, TX, USA).

Results and Discussion

Amongst 1493 AYA with T1D who attended appointments between February 2022 and March 2024, pronoun data was

Table 1: Demographic and Clinical Characteristics by Pronoun Documentation.

n (row %) or Mean (SD)	Pronouns Present in EMR		P Value
	Yes	No	
T1D Patients Total N=1493	779 (52.18)	714 (47.82)	
Age Group			
Under 10 years	0 (0)	1 (100)	<0.0001
10-13 years	177 (51.60)	166 (48.40)	
14-17 years	375 (57.60)	276 (42.40)	
18-20 years	209 (50.61)	204 (49.39)	
21 years and over	18 (21.18)	67 (78.82)	
Race/Ethnicity			
Asian or Pacific Islander	19 (52.78)	17 (47.22)	<0.0001
Black or African American	36 (65.45)	19 (34.55)	
Latina/o/e or Hispanic	355 (65.26)	189 (34.74)	
Non-Hispanic white	138 (47.59)	152 (52.41)	
Multiracial	15 (51.72)	14 (48.28)	
Unknown/Declined to state	216 (40.07)	323 (59.93)	
Insurance			
Private (HMO/PPO)	241 (38.81)	380 (61.19)	<0.0001
Public (Medi-Cal/CCS/SSI)	538 (61.70)	334 (38.30)	
Location			
Main Hospital	711 (58.91)	496 (41.09)	<0.0001
South Bay Clinic	25 (71.43)	10 (28.57)	
Other Community Clinics	43 (17.13)	208 (82.87)	
T1D Regimen			
CGM & Insulin Pump	321 (50.31)	317 (49.69)	<0.0001
Insulin Pump only	18 (36.73)	31 (63.27)	
CGM only	261 (56.86)	198 (43.14)	
Fixed/Flexible Injections	173 (55.63)	138 (44.37)	
Unknown	6 (16.67)	30 (83.33)	
T1D Duration (years)	0.71 (2.61)	1.50 (3.78)	<0.0001
Hemoglobin A1c	8.37 (2.70)	8.10 (2.15)	0.38
Thyroid Stimulating Hormone	1.72 (1.03)	5.03 (35.67)	0.32
LDL Cholesterol	100.60 (26.91)	96.13 (34.32)	0.36

documented for 779 individuals (52.18%) and was not documented for 714 individuals (47.82%; see Table 1). Twenty-five individuals (25/1493, 1.67%) had documented non-matching pronouns (those not aligning with their documented legal sex), while 754 individuals (754/1493, 50.50%) had matching pronouns (those consistent with their documented legal sex).

Pronoun documentation

Pronoun documentation was significantly associated with several demographic and clinical characteristics. Individuals with T1D who identified as Latine (355/544, 65.26%) or Black and/or African American (36/55, 65.45%) documented pronouns most frequently, while individuals who identified as white were less likely to have documented pronouns (138/290, 47.59%; P<0.0001). Reflecting incomplete record-keeping, individuals of unknown race were also the least likely to have pronouns documented (216/539, 40.07%). Additionally, individuals covered by public insurance were more

Table 2: Demographic and Clinical Characteristics by Pronoun Use.

n (column %) or Mean (SD)	Pronouns Matches Legal Sex		P Value
	Yes	No	
Pronouns Documented n=779	754	25	
Pronouns Used			
He/Him/His only	422 (55.97)	7 (28.00)	<0.0001
She/Her/Hers only	332 (44.03)	1 (4.00)	
They/Them/Theirs only	0 (0)	9 (36.00)	
He/Him/His, They/Them/Theirs	0 (0)	1 (4.00)	
She/Her/Hers, They/Them/Theirs	0 (0)	7 (28.00)	
Age Group			
Under 10 years	0 (0)	0 (0)	0.44
10-13 years	169 (22.41)	8 (32.00)	
14-17 years	365 (48.41)	10 (40.00)	
18-20 years	203 (26.92)	6 (24.00)	
21 years and over	17 (2.25)	1 (4.00)	
Race/Ethnicity			
Asian or Pacific Islander	19 (2.52)	0 (0)	0.42
Black or African American	35 (4.64)	1 (4.00)	
Latina/o/e or Hispanic	347 (46.02)	8 (32.00)	
Non-Hispanic white	131 (17.37)	7 (28.00)	
Multiracial	14 (1.86)	1 (4.00)	
Unknown/Declined to state	208 (27.59)	8 (32.00)	
Insurance			
Private (HMO/PPO)	229 (30.37)	12 (48.00)	0.08
Public (Medi-Cal/CCS/SSI)	525 (69.63)	13 (52.00)	
Location			
Main Hospital	692 (91.78)	19 (76.00)	0.02
South Bay Clinic	24 (3.18)	1 (4.00)	
Other Community Clinics	38 (5.04)	5 (20.00)	
T1D Regimen			
CGM & Insulin Pump	307 (40.72)	14 (56.00)	0.01
Insulin Pump only	18 (2.39)	0 (0)	
CGM only	254 (33.69)	7 (28.00)	
Fixed/Flexible Injections	171 (22.68)	2 (8.00)	
Unknown	4 (0.53)	2 (8.00)	
T1D Duration (years)	0.67 (2.50)	1.99 (4.87)	0.32
Hemoglobin A1c	8.71 (2.05)	8.53 (1.99)	0.67
Thyroid Stimulating Hormone	1.98 (3.20)	2.02 (1.20)	0.9
LDL Cholesterol	95.77 (30.30)	102.33 (34.99)	0.41

likely to have documented pronouns (538/872, 61.70%) compared to those with private insurance (241/621, 38.81%; P<0.0001).

Age at the time of appointment was associated with missingness of pronoun data, as individuals over age 21 were least likely to have documented pronouns (18/85, 21.18%), while other age groups documented at similar rates (51% - 58%; P<0.0001; see Table 1). Age at the time of appointment was also related to the location of service, as older patients were more likely to be seen at satellite clinics instead of the main hospital. However, even after accounting for

clinic location, a clear trend emerged. Attendees of appointments at the main hospital (711/1207, 58.91%) and one satellite clinic (25/35, 71.43%) documented pronouns more frequently than patients who attended appointments at any other center (where 3%-23% of patients documented pronouns; $P < 0.0001$). While pronouns were documented less frequently for adult patients (ages 21+) and more frequently by adolescent patients overall, the rates of documentation significantly differed between the main campus and most satellite clinics.

Duration of T1D at the time of chart review was significantly associated with pronoun documentation, as individuals who had no documented pronouns had been diagnosed with T1D for twice as long on average (1.50 years versus 0.71 years for those with documented pronouns; $P < 0.0001$). No significant differences were observed in clinical test values including HbA1c, Thyroid Stimulating Hormone (TSH), and lipid profiles between individuals with documented pronouns and those who did not have documented pronouns.

Pronoun use

Most individuals with documented pronouns in this review (754/779, 96.79% of those with pronoun data) had documented pronouns consistent with their legal sex, while 25 individuals (25/779, 3.21% of those with documented pronouns) had documented pronouns that did not align with their documented legal sex (Table 2). Pronoun usage did not significantly vary across age or racial/ethnic groups, although most individuals who use pronouns that do not match their documented legal sex were younger than 18 years.

Most of the individuals who reported using pronouns that do not match their documented legal sex received care at the main hospital (19/25, 76%; $P = 0.02$). Although pronoun documentation was less frequent at most satellite clinics, a larger proportion of those asked used pronouns that do not match their documented legal sex (6/68, or 8.82%; compared to 19/692, or 2.75%, at the main hospital).

Among individuals with T1D who had documented pronouns, those with non-matching documented pronouns reported significantly greater use of both CGM and insulin pump (14/25, 56%) than those with documented pronouns consistent with legal sex (307/754, 40.72%; difference: -15.28%, $P = 0.01$). Notably, they also had longer T1D duration (1.99 years versus 0.67 years; difference: -1.32, $P = 0.32$) and less frequent use of public insurance (13/25, 52%; versus 525/754, 69.63%; difference: +17.63%, $P = 0.08$) than those who had documented pronouns consistent with legal sex, although these differences were not significant. In addition, there were no significant differences in terms of HbA1c, TSH, or lipid profiles between those who use non-matching versus matching pronouns (Table 2).

This study provides a comprehensive analysis of pronoun use among AYA with T1D at a paediatric diabetes care center, highlighting significant disparities based on demographic and clinical characteristics. Our findings underscore the importance of integrating pronoun documentation into routine care for AYA with T1D which has critical implications for both individual clinical care and population level health equity monitoring.

Pronoun documentation and non-matching pronoun use

The most notable finding is inconsistency in pronoun documentation, with nearly half of the participants lacking documented pronouns. This gap points to a significant area for improvement in healthcare documentation practices. It remains

unclear whether the number of individuals in the current study who reported using non-matching pronouns (1.67%) accurately represents the proportion of TGD individuals in the larger patient population. Some TGD youth may intentionally withhold pronoun information to protect themselves from potential stigma or discrimination in clinical settings. Disclosure may be perceived as unsafe, particularly when trust in providers is low or when family members are present. The entire healthcare environment not just structured EHR fields – must be evaluated and restructured as needed to support safe and affirming disclosure [23].

Respectful pronoun documentation supports affirming care and engagement. Collection depends on EHR capacity, staff comfort, patient willingness, and caregiver support. Similar inconsistencies in gender identity documentation have been noted among paediatric primary care clinics, suggesting documentation is a broader problem found across healthcare settings [24]. Siqueira and colleagues demonstrated that targeted interventions in a paediatric emergency department, including EHR updates, staff education, and a toolkit for assessing gender-related support needs, improved pronoun documentation from 13.8% to 47.8% [25]. Strong leadership support further reinforced the importance of using correct names and pronouns, demonstrating the effectiveness of these initiatives.

Sociodemographic disparities in pronoun documentation

The present study identified significant sociodemographic disparities in pronoun documentation. Latine (see Terminology section for definition) and Black and/or African American individuals were more likely to have documented pronouns compared to their non-Latine and non-Black counterparts. The exact reason is unclear without additional research, but increased pronoun documentation may be attributable to a supportive cultural environment or effective outreach and education programs. Conversely, individuals of East Asian ancestry were even less likely to have documented pronouns, highlighting a potential area for targeted intervention to ensure inclusivity. The under-documentation of SOGI data by East Asian AYA has also been reported by Parmar and colleagues, highlighting the need for culturally sensitive approaches to improve documentation practices [26].

Pronoun documentation also differed by insurance status, with those covered by public insurance more likely to have documented pronouns than those with private insurance. This disparity may reflect healthcare access differences, requiring further study. Pronoun documentation also varied significantly by the location of service. Patients seen at the main hospital and one satellite clinic (South Bay, serving the communities of Long Beach and Torrance) were more likely to have documented pronouns (59.41% and 62.79%, respectively) compared to those seen at other centers, where documentation rates ranged from 2% to 23%. This pattern may be attributed to differences in institutional policies, staff training, and the emphasis placed on inclusive practices in various healthcare settings. The main hospital and South Bay satellite clinic may have more robust protocols or greater awareness regarding the importance of pronoun documentation, resulting in higher rates of documentation. Lower documentation at some satellite clinics suggests a need for standardized policies and training. Structured fields to collect gender identity and pronouns are recommended additions for EHRs, which may help address disparities by standardizing documentation across sociodemographic groups [27].

Impact of Non-Matching Pronouns on Diabetes Management

Individuals with documented pronouns that did not match their legal sex were found to have significantly greater usage of CGM and insulin pumps, and less frequent usage of multiple daily injections. This finding suggests that TGD individuals whose gender identity is affirmed within the healthcare setting might also be more proactive in managing their diabetes. Additionally, these individuals had been diagnosed with T1D for a longer duration on average, which might suggest a higher level of familiarity and comfort with diabetes technology over time. Clinicians who prioritize gender and pronoun documentation foster more inclusive care and may be more likely to engage all patients in conversations about diabetes technology. Prior studies have found that affirming TGD AYA's names and pronouns in the EHR is associated with better health outcomes, supporting our hypothesis that gender identity affirmation may enhance proactive diabetes management [21].

As expected, no significant differences in clinical test values were observed between individuals with documented pronouns and those without documented pronouns, reflecting a lack of association between pronoun documentation and glycaemic control. In the current study, small sample size precluded an examination of the impact of documentation of non-matching pronouns on clinical outcomes. However, pronoun recognition contributes to well-being and long-term outcomes [22]. The Trevor Project's 2020 survey highlights that LGBTQ+ youth who have their pronouns respected by most people in their lives attempt suicide less frequently than those whose pronouns are not respected, illustrating the profound impact of pronoun recognition on mental health [10].

Addressing implicit and explicit biases

Missing pronoun documentation reflects implicit and explicit bias, clinician knowledge gaps, or insensitivity, all of which may affect T1D care. These biases may deter TGD AYA from seeking necessary care, further exacerbating health disparities. Addressing these biases requires systemic changes, including comprehensive training of healthcare team members on gender diversity and the specific challenges faced by TGD individuals with T1D. Training should emphasize the importance of correct pronoun use and the impact of psychosocial factors on diabetes management and health outcomes. Furness and colleagues describe a collaborative quality improvement initiative that successfully transformed primary care practices to be more inclusive for LGBTQ+ patients, offering a model for other healthcare settings to follow [28].

Limitations

This study has several limitations, including its retrospective design and reliance on EHR for data collection, which may introduce formulaic biases (e.g., limited demographic categories) or inaccuracies in collected data. The lack of pronoun documentation for nearly half of the AYA with T1D could lead to incorrect assumptions about many patients' identities and care needs. The use of legal sex in the EHR, which may or may not reflect a patient's assigned sex at birth, complicates the interpretation of non-matching pronouns. Additionally, the limited sample size may affect the generalizability of the findings. The study is also susceptible to selection bias, as it only includes participants who sought care at a single institution. Future research should address these limitations by employing larger, more diverse samples and prospective study designs evaluating systemic changes in documentation practices.

Conclusion

This comprehensive analysis of pronoun documentation among AYA with T1D reveals important disparities based on demographic and clinical characteristics. Consistent with previous research on the documentation of SOGI, nearly half of the subjects in the present study were missing pronoun data in the EHR, highlighting a data gap. Healthcare organizations must train healthcare team members on gender diversity and the specific challenges faced by TGD individuals with T1D, as well as the importance of correct pronoun use. By providing more inclusive care, clinicians and healthcare systems can meet the unique needs of this population, ultimately improving healthcare experiences and outcomes for TGD AYA with T1D.

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