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Temporal Changes in the Size and Composition of Transgender and Gender Nonconforming Population in the Kaiser Permanente System, 2006 to 2014

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Temporal Changes in the Size and Composition of Transgender and Gender Nonconforming Population in the Kaiser Permanente System, 2006 to 2014

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Abstract

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By Willi Rechler

Background: Transgender and/or gender-nonconforming (TGNC) people are an understudied but sizable minority, and studies show that the size of the TGNC population is increasing. Current studies do not estimate the proportion of TGNC people in the general population. The present study utilizes existing transgender health research program at Kaiser Permanente. This study examines the temporal changes in the proportion TGNC people among individuals enrolled in three Kaiser Permanente sites, and to investigate whether the trends differ by age and geographic location, and by sex assigned birth status.
Methods: This study uses data from the Study of Transition Outcomes and Gender (STRONG), an electronic health record-based cohort of TGNC people enrolled in Kaiser Permanente in Georgia and California from January 2006 through December 2014. We calculated the proportion of TGNC individuals among all Kaiser Permanente enrollees by year and by site. The temporal changes in the assigned male at birth (AMAB)-to-assigned female at birth (AFAB) ratio according to participants' age were then examined. Group specific changes were studied for trend. The average age at index was calculated for each calendar year by AMAB/AFAB status. The slope was estimated as a regression coefficient representing an average annual change in the age of presentation.
Results: The proportions of STRONG cohort members among all enrollees increased at all sites. The regression analyses yielded slope estimates of 7.07 (95% CI: 6.77-7.38) for KPNC, 4.58 (4.22-4.94) for KPSC and 4.14 (3.55-4.73) for KPGA. From 2006 to 2014 the AFAB:AMAB ratio among members of all ages changed from 1: 1.67 to 1:1. The AFAB:AMAB ratio in the under 18-year age group changed from 1.0 in 2006 to 1.8 in 2014 (P-trend < 0.001). The average age at initial presentation significantly decreased, with an annual change of -0.98 years (95% CI: -1.34, -0.62) for AMAB and -1.38 years (95% CI: -1.90, -0.85) for AFAB.
Conclusions: This analysis shows that the proportion of individuals who identify as TGNC increased significantly at all Kaiser Permanente sites, and the TGNC population appears to be getting younger. The AFAB:AMAB ratio, especially in persons under 18-years of age, is changing as well.

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INTRODUCTION

Transgender and/or gender-nonconforming (TGNC) people are an understudied but sizable minority, representing between 0.1% and 2% of the US population (1). It is also estimated that approximately 150,000 of US adolescents between 13 to 17 years of age identify as TGNC (2). Recent studies show that the size of the TGNC population is increasing, this increase appears to be more evident in younger age groups (1, 2).

Another issue that requires attention is the changing demographic composition of the TGNC population. When evaluating temporal changes, there is no obvious age when an individual begins to identify as TGNC, as most studies are clinic-based and do not include individuals who do not seek out medical or surgical interventions (1). Several clinic-based studies have also shown that the ratio of persons assigned as male at birth (AMAB) to persons assigned female at birth (AFAB) has shifted over time from predominantly AMAB to roughly 1:1 and even predominantly AMAB in some age groups (3-5). Whereas clinic-based findings appear to be consistent, population-based studies addressing these changes are not available. Moreover, as reviewed elsewhere, clinic-based studies are not designed to estimate the proportion of the TGNC people in the general population because these studies typically do not have a well-defined sampling frame and therefore do not have accurate denominators (1, 6, 7). In the United States, high quality numerator and denominator data can be obtained from large integrated health systems that both provide care coverage and directly administer health services for their members (8, 9).

One such system is the Veterans Health Administration (VA), which is the largest integrated system in the United States with 1,255 health care facilities and serves 9 million enrolled Veteran patients each year (10). The VA data were used previously to estimate the overall number of TGNC veterans and to assess temporal changes in the size of TGNC population in the VA system(11-13). The disadvantages of VA data is that they include a limited number of children and young adults, and cannot readily distinguish between AMAB and AFAB veterans (14).

Another example of an integrated health system is Kaiser Permanente, which is the United States' largest nonprofit system with over 12 million members (15). Unlike the VA, the Kaiser Permanente systems provide care to a large number of children and adolescents pediatric patients, and employ a wide range of pediatric specialists (16). Previous research has shown that the proportion of TGNC people among Kaiser Permanente enrollees has been increasing, but a more detailed analysis of temporal changes is needed to understand population-level trends in both the size and the composition of TGNC population.

With these knowledge gaps in mind, the present study takes advantage of the exiting transgender health research program at Kaiser Permanente (4). The goal of this study is to examine the temporal changes in the proportion TGNC people among individuals enrolled in three Kaiser Permanente sites, and to investigate whether the trends differ by age and geographic location, and by AMAB/AFAB status.

METHODS

This study utilizes data from the Study of Transition Outcomes and Gender (STRONG), an electronic health record (EHR) -based cohort study of TGNC people enrolled in the Kaiser Permanente plans in Georgia, and in Northern and Southern California,." The STRONG cohort was ascertained using a stepwise methodology described in detail previously (4). Briefly, the first step involved an initial EHR search using relevant International Classification of Disease 9th edition (ICD-9) codes in combination with free text keywords indicative of TGNC status. Once the cohort candidates with ICD-9 codes or keywords of interest were identified, the second step was to confirm their TGNC status using a review of free text excerpts from the clinical notes. Following validation of eligibility the third step involved determining the participants' AMAB/AFAB status using evidence related to each person's natal anatomy, and history of sex specific treatment. This three-step methodology identified 6456 members with first evidence of TGNC status ("index date") between January 2006 and December 2014.

To examine the changes in the size of the TGNC population we first calculated the proportion of TGNC individuals among all Kaiser Permanente enrollees by year and by site. The population denominator in these calculations included all Kaiser Permanente members enrolled during STRONG ascertainment from January 2006 through December 2014. Only persons enrolled in a given year were included in both the numerator and the denominator. The results of these analyses were expressed as site- and calendar year-specific proportions (per 100,000 population) accompanied by the corresponding 95% confidence intervals (CI). The trends in the proportions of TGNC people were examined

using linear regression models where the regression coefficient represented an average annual change.

The STRONG cohort data were further analysed to evaluate the temporal changes in the AMAB-to-AFAB ratio according to participants' age. The cohort was divided into 5 age groups: under 18 years, 15-25 years, 26-35 years, 36-45 years, and over 45 years. The AMAB:AFAB ratio was calculated for each year within each age group. Age-group specific changes in the AMAB;AFAB ratio were examined using the Cochran-Armitage Trend Test.

We also investigated how age at initial presentation ("index date") changed over time. The average age at index date among STRONG cohort members was calculated separately for each calendar year by AMAB/AFAB status. The slope was estimated using linear regression with results expressed as a regression coefficient representing an average annual change in the age of presentation.

RESULTS

As shown in Table 1, 63% of all participants were from KPNC, 34% from KPSC and less than 3% from KPGA. With respect to race and ethnicity, 55% were non-Hispanic white, while black and Asian individuals each comprised about 8% of the study population, and 19% were Hispanic. AFAB subjects were younger (26% under 18 and 76% under age 36) compared to AMAB subjects (17% under 18 and 53% under 36). Nearly a third (30%) of AMAB cohort members were over the age of 45 compared to just 12% of AFAB participants.

Figure 1 shows that the proportions of STRONG cohort members among all Kaiser Permanente enrollees increased at all sites. In 2006 this proportion (per 100,000 total population) was 3.5 (95% CI: 1.9-6.3) in Georgia, 5.5 (95% CI: 4.8-6.4) in Southern California and 17 (95% CI: 16-19) in Northern California. In 2014 the corresponding proportions were 38 (95% CI: 32-45), 44 (95% CI: 42-46) and 75 (95% CI: 72-78) in KPGA, KPSC and KPNC respectively. These changes corresponded to statistically significant trends with the most pronounced slope (7.07; 95% CI: 6.77-7.38) observed at KPNC. The corresponding regression analyses for the other two sites yielded slope (95% CI) estimates of 4.58 (4.22-4.94) for KPSC and 4.14 (3.55-4.73) for KPGA. The composition of the TGNC population has also changed over time. In 2006, the AFAB:AMAB ratio among newly identified cohort members of all ages was approximately 0.6 (or 1: 1.67); by 2014 the same ratio was 1:1. When examined by age group, the change in the AFAB:AMAB ratio was especially evident in the under 18-year age group from 1.0 in 2006 to 1.8 in 2014 (P-trend < 0.001). The change was also

statistically significant in persons over 45 years of age (p=0.011), but in that age group AMAB individuals outnumbered AFAB persons throughout the observation period.

Figure 2 summarize the changes in age of initial identification (index date) and inclusion in the STRONG cohort during the study period. The average age at index date among AFAB cohort members was 33.9 years in 2006 and 25.8 years in 2014. For the AMAB participants, the age at index date decreased from an average of 42.3 years in 2006 to an average of 32.8 years in 2014. The differences corresponded to a statistically significant annual change of -0.98 years (95% CI: -1.34, -0.62) for AMAB and -1.38 years (95% CI: -1.90, -0.85) for AFAB.

DISCUSSION

This analysis shows that over time, the proportion of individuals who identify as TGNC increased significantly at all Kaiser Permanente sites, with the greatest change observed at KPNC. In addition, the TGNC population appears to be getting younger and show a marked change in the AFAB:AMAB ratio, especially in persons under 18-years of age

Our findings appear to be in agreement with previous studies (1-2). Meerwijk and Sevelius reviewed national surveys to estimate the proportion of individuals who self-identified as TGNC in the general population in the United States, and significant average increase of about 0.03% per year; the trend was particularly evident in younger survey participants (18-24 years of age)(17). More recently, Ewald et al. examined Medicare data and using diagnostic codes observed a more than four-fold increase in the proportion of TGNC beneficiaries from 4.2 per 100,000 in 2010 to 17 per 100,000 in 2016 (18). A similar diagnostic code-based study conducted using national Veterans Health Administration data also reported an increase in the proportion of TGNC veterans over a 10-year period starting in starting in 2002 (12.5 per 100,000) and ending in 2011 (22.88 per 100,000) (19).

Our finding are also consistent with previous reports that TGNC people appear to present to their health care providers at progressively younger ages For example, a 2016 study from Denmark found over 20 years, the age of initiating gender affirming treatment decreased from a median of 40 years in 1994 to a median of 27 years in 2015(20). Similar

declines in the median age of the first TGNC-related clinic visit were reported in the Netherlands (21).

The temporal changes in the AFAB: AMAB ratio observed in the Kaiser Permanente population were also reported in a study that used data from two referral clinics in Canada and the Netherlands (22). Another clinic based study conducted in the UK study showed a shift in the AMAB:AFAB ratio in adolescents from 1.6:1 in 2009 to 1:2.5 in 2016; the corresponding change was even more pronounced (from 5:1 to 1:1) in younger children (under 12 years of age) (3).

An important methodological feature that distinguishes our study from clinic-based research is the availability of system-wide data that offer a well-defined sampling frame (3, 5, 6). From this perspective, our study has the same advantages as the previously published studies that used Veterans Health Administration and Medicare data; however, unlike these other health systems-based studies, our analyses were not limited to diagnostic codes, included a wider range of ages, and were able to determine the AMAB/AFAB status of participants (12, 13, 18, 19, 23).

It is important to keep in mind that studies aiming to ascertain the proportion of TGNC people from medical records consistently report lower estimates compared to similar studies that rely on surveys (1, 7). For this reason, perhaps the most important weakness of our study is the limited ability to identify people who have not reported their TGNC

status to their health care providers. It is expected that our methodology is especially likely to miss people who identify as non-binary or report other gender diverse identities. Further, most people enrolled in integrated health care systems have health coverage and may not be representative of the TGNC population in the United States. On the other hand, a certain proportion of Kaiser Permanente members are enrolled in Medicaid plans, ensuring that at least some of the study participants come from populations with lower socioeconomic status.

These limitations notwithstanding, it is clear that our results confirm and extend previous observations regarding the increasing size and the changing characteristics of the TGNC population. It is difficult to conclude from these data that the proportion of people who can be characterized as TGNC is truly increasing; however, it is likely that the observed trends are affected by the sociopolitical and medical changes, and evolving social norms with differential impact across generations. Another contributing factor that may explain the observed results is the leading role of Kaiser Permanente in providing gender affirming care (24-26). For this reason, TGNC people may seek enrollment in Kaiser Permanente health plans to avoid stigma, decrease the likelihood of being misunderstood or misgendered, and gain access to better quality care.

The comprehensive TGNC care instituted at health plans such as Kaiser Permanente has yet to be adopted by the wider medical community. Prejudiced attitudes or poor knowledge of the subject may lead physicians to avoid caring for the TGNC patients. The majority of TGNC individuals seeking gender-affirming care report instances of

mistreatment by the medical system, and point out that during interactions with health care providers they encounter a pervasive lack of understanding of the issues facing TGNC patients (27). Given the sizeable and growing proportion of the TGNC people in the general population and the multitude of available therapies, there is an urgent need to incorporate TGNC health-specific training in both the medical school curriculum and the continuous education activities across a wide range of clinical disciplines.

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TABLES AND FIGURES

Table 1: Descriptive characteristics of TGNC people in the STRONG cohort

Participant Characteristics	**AFAB (N=2892)**		**AMAB (N=3475)**		**Overall (N=6367)***	
	Number	%	Number	%	Number	%
Study site						
KPNC	1831	63.31	1949	56.09	3842	59.51
KPSC	982	33.96	1431	41.18	2440	37.79
KPGA	79	2.73	95	2.73	174	2.70
Race-ethnicity						
Non-Hispanic White	1669	57.71	1828	52.60	3532	54.71
Non-Hispanic Black	256	8.85	248	7.14	510	7.90
Hispanic	503	17.39	710	20.43	1232	19.08
Asian	203	7.02	305	8.78	515	7.98
Other/unknown	261	9.03	384	11.05	667	10.33
Age groups (years)						
Under 18	745	25.76	588	16.92	1347	20.86
15-25	753	26.04	655	18.85	1431	22.17
26-35	707	24.45	600	17.27	1329	20.59
36-45	347	12.00	577	16.60	939	14.54
Over 45	340	11.76	1055	30.36	1410	21.84

*There are 89 people with unknown natal sex

Figure 1: Changes in the proportion of STRONG cohort members among all Kaiser Permanente members by site: 2006-2014

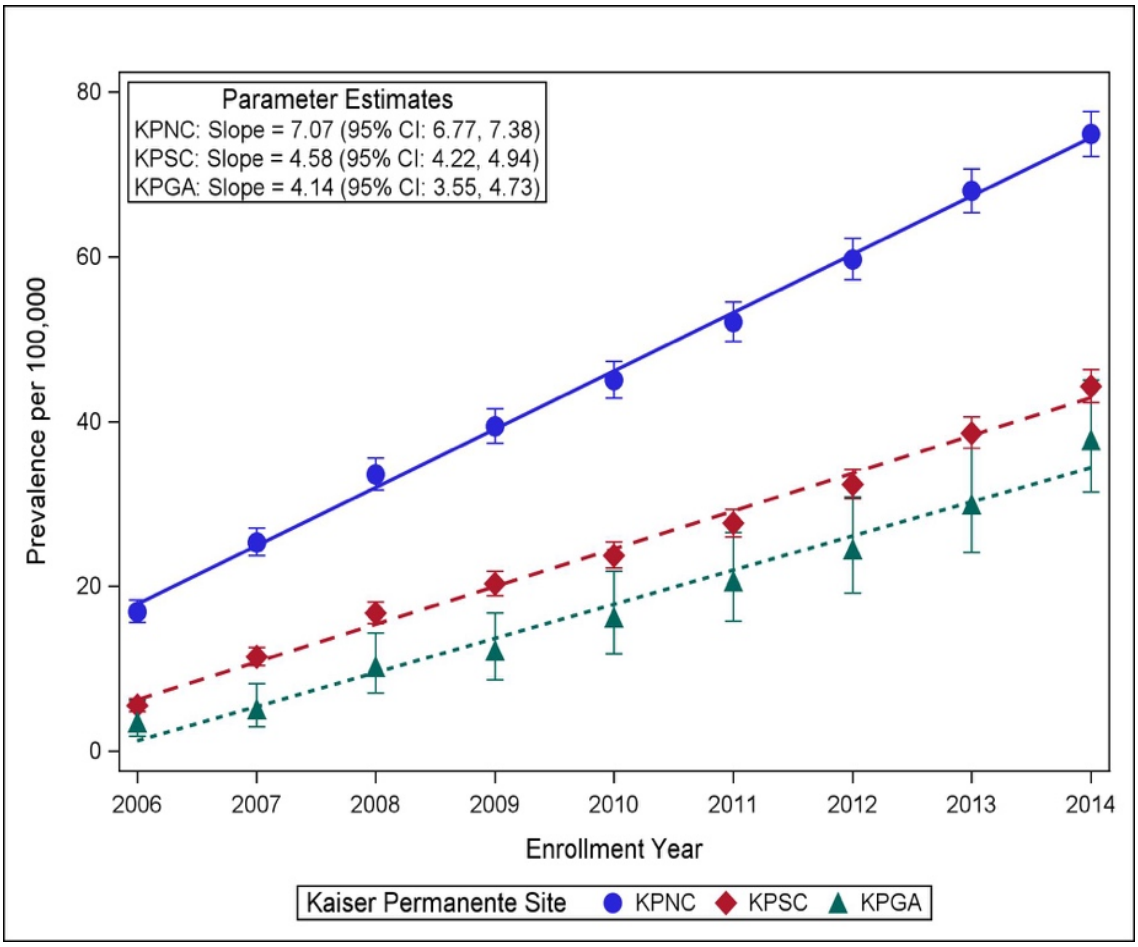

Table 2: Time trends in AFAB-AMAB ratio in the STRONG cohort

Age group	Calendar years	AFAB		AMAB		Ratio	Test for trend
		Number	%	Number	%		
Under 18 years	2006	40	5.37	41	6.97	1.0	<0.001
	2007	41	5.5	48	8.16	0.9	
	2008	66	8.86	61	10.37	1.1	
	2009	54	7.25	54	9.18	1.0	
	2010	57	7.65	63	10.71	0.9	
	2011	99	13.29	73	12.41	1.4	
	2012	114	15.3	82	13.95	1.4	
	2013	156	20.94	99	16.84	1.6	
	2014	118	15.84	67	11.39	1.8	
15-25 years	2006	57	7.57	44	6.72	1.3	0.3001
	2007	33	4.38	37	5.65	0.9	
	2008	63	8.37	47	7.18	1.3	
	2009	42	5.58	57	8.7	0.7	
	2010	57	7.57	51	7.79	1.1	
	2011	86	11.42	87	13.28	1.0	
	2012	118	15.67	103	15.73	1.1	
	2013	151	20.05	110	16.79	1.4	
	2014	146	19.39	119	18.17	1.2	
26-35 years	2006	80	11.32	68	11.33	1.2	0.7632
	2007	63	8.91	58	9.67	1.1	
	2008	60	8.49	53	8.83	1.1	
	2009	60	8.49	45	7.5	1.3	
	2010	55	7.78	55	9.17	1.0	
	2011	66	9.34	53	8.83	1.2	
	2012	95	13.44	78	13	1.2	
	2013	100	14.14	78	13	1.3	
	2014	128	18.1	112	18.67	1.1	
36-45 years	2006	63	18.16	117	20.28	0.5	0.1767
	2007	36	10.37	79	13.69	0.5	
	2008	48	13.83	65	11.27	0.7	
	2009	27	7.78	40	6.93	0.7	
	2010	21	6.05	52	9.01	0.4	
	2011	31	8.93	38	6.59	0.8	
	2012	32	9.22	56	9.71	0.6	
	2013	41	11.82	67	11.61	0.6	
	2014	48	13.83	63	10.92	0.8	
Over 45 years	2006	63	18.53	236	22.37	0.3	0.0112
	2007	41	12.06	152	14.41	0.3	
	2008	38	11.18	120	11.37	0.3	
	2009	21	6.18	102	9.67	0.2	
	2010	38	11.18	90	8.53	0.4	
	2011	33	9.71	97	9.19	0.3	
	2012	35	10.29	82	7.77	0.4	
	2013	41	12.06	69	6.54	0.6	

	2014	30	8.82	107	10.14	0.3	
All ages	2006	303	10.48	506	14.56	0.6	<0.0001
	2007	214	7.4	374	10.76	0.6	
	2008	275	9.51	346	9.96	0.8	
	2009	204	7.05	298	8.58	0.7	
	2010	228	7.88	311	8.95	0.7	
	2011	315	10.89	348	10.01	0.9	
	2012	394	13.62	401	11.54	1.0	
	2013	489	16.91	423	12.17	1.2	
	2014	470	16.25	468	13.47	1.0	

Figure 2: Changes in the age at initial presentation among STRONG cohort members by AMAB/AFAB status: 2006-2014