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Agreement between Medical Records and Self-Reports: Implications for Transgender Health Research

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Abstract

Purpose: A key priority of transgender health research is the evaluation of long-term effects of gender affirmation treatment. Thus, accurate assessment of treatment receipt is critical.

Methods: The data for this analysis came from an electronic medical records (EMR) based cohort of transgender individuals. A subset of cohort members were also asked to complete a self-administered survey. Information from the EMR was compared with survey responses to assess the extent of agreement regarding transmasculine (TM)/transfeminine (TF) status, hormone therapy receipt, and type of surgery performed. Logistic regression models were used to assess whether participant characteristics were associated with disagreement between data sources.

Results: Agreement between EMR and survey-derived information was high regarding TM/TF status (99%) and hormone therapy status (97%). Lower agreement was observed for chest reconstruction surgery (72%) and genital reconstruction surgery (83%). Using survey responses as the “gold standard”, both chest and genital reconstruction surgeries had high specificity (95% and 93%, respectively), but the corresponding sensitivities were low (49% and 68%, respectively). A lower proportion of TM had concordant results for chest reconstruction surgery (64% versus 79%

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for TF) while genital reconstruction surgery concordance was lower among TF (79% versus 89% for TM). For both surgery types, agreement was highest among the youngest participants.

Conclusions: Our findings offer assurance that EMR-based data appropriately classify cohort participants with respect to their TM/TF status or hormone therapy receipt. However, current EMR data may not capture the complete history of gender affirmation surgeries. This information is useful in future studies of outcomes related to gender confirmation therapy.

Introduction

An important priority in transgender health research is the need to better understand short- and long-term outcomes of gender affirming therapy [1]. It is expected that transgender people who undergo hormonal or surgical interventions may have fewer mental health problems and experience better quality of life. On the other hand, gender affirmation therapy may be associated with adverse effects, which may include increased incidence of certain hormone-related cancers, hematologic problems, and cardiovascular and metabolic disease [2]. Although biologically and clinically plausible, these beneficial and adverse effects remain poorly understood, and require rigorous study [3, 4].

Most of the unanswered research questions about the effects of gender affirmation therapies cannot be addressed via clinical trials because randomizing participants to receiving or not receiving the desired therapy is not ethical. Moreover, many of the outcomes of interest may require very large sample sizes and prolonged follow up, which may not be feasible in a randomized trial. For all the above reasons, many of the existing knowledge gaps can only be addressed via large scale observational studies that involve systematic identification and follow up of participants representing the full range of gender affirmation treatments. A critical methodological challenge in conducting these types of observational studies is accurate determination of treatment receipt.

In general, comprehensive medical records, particularly those from integrated health systems, have been proven to be the gold standard for treatment ascertainment in observational studies [5]. The increasing availability of electronic medical records (EMR) facilitates research because receipt of treatment can be ascertained from standardized codes [6]. In the case of gender affirmation therapy, however, the accuracy and completeness of EMR data remain questionable [6, 7]. The concern about the validity of EMR-derived data on gender affirmation data is often attributed to the decentralized nature of transgender care. The fact that gender affirmation is often not covered under many health plans forces some transgender patients to seek treatment outside of their insurance [6, 8]. Consequently, it can be argued that self-reported data may serve as a better source of gender affirmation therapy data than data ascertained from medical records. These considerations notwithstanding, the frequency and extent of disagreement between self-reports and medical records as alternative methods for evaluating history of hormone therapy and gender affirmation surgeries have not been examined in a systematic fashion.

Another methodological challenge facing EMR based studies of transgender people is the need to accurately distinguish between transfeminine (TF) and transmasculine (TM) participants. As TM and TF individuals are different with respect to treatments, risk factors,

and outcomes, accurate classification is fundamental for both research and quality of care monitoring. The determination of TF or TM status presents a methodological challenge because the available demographic data can reflect sex recorded at birth or gender identity, without specifying which is which [9]. While TM/TF status can be assessed by asking two questions about their sex recorded at birth and gender identity [10], reliance on self-report requires contact with individual participants and is subject to non-response, which reduces sample size and increases the risk of selection bias.

The present study compares EMR-derived and self-reported data from the on-going longitudinal study of transgender people enrolled in three integrated healthcare systems. Our goal is to examine the frequency and determinants of disagreement between self-reports and EMR as alternative methods of determining TM/TF status and ascertaining receipt of gender affirmation therapy.

Methods

Study Data & Population

The present study utilizes EMR-based information and survey responses pertaining to transgender individuals enrolled in the “Study of Transition, Outcomes & Gender (STRONG)”. The STRONG cohort includes transgender people who are members of three Kaiser Permanente (KP) health plans located in Georgia (KPGA), Northern California (KPNC) and Southern California (KPSC). The study was conducted in partnership with Emory University, which served as the coordinating center. All activities were reviewed and approved by the Institutional Review Boards (IRB) of the four participating institutions. The three KP organizations are members of several research consortia; they use similar EMR systems, and have comparably organized databases with identical variable names, formats, and specifications across sites [7].

The methods of the STRONG study are described in detail elsewhere [7, 9]. The cohort was ascertained by searching the EMR to identify all KP members whose records indicated evidence of transgender status. The subjects were considered potentially eligible if they had relevant International Classification of Diseases, Ninth Edition (ICD-9) codes, or if their clinical notes contained relevant transgender-specific keywords. Two trained reviewers independently reviewed the free-text notes to verify eligibility, determine TM/TF status, and assess gender affirmation treatment status. Disagreements among reviewers were adjudicated by a review committee that included two physician investigators and the project manager. Following adjudication, medical record numbers of eligible cohort members were linked to multiple data sources including diagnostic and procedural codes, laboratory reports, and pharmacy records.

After the EMR cohort was established, a subset of participants was invited to complete a survey focusing on the experience of life as a transgender person, health outcomes, gender affirmation treatment status, and demographic information. To be eligible to participate in the survey, the cohort members must have been 18 years of age or older, currently enrolled in one of the participating health plans, and have had at least one transgender-related ICD-9 diagnostic code as well as a text string confirming transgender status. Participants were

excluded from the survey if their evidence of transgender status was limited to mental health records, their Kaiser Permanente physicians did not provide consent for initiating the contact, or their responses to the survey's screening questions noted that gender identity was the same as sex recorded at birth. All initial invitations were sent via regular mail. To protect subject confidentiality the letter referred to the STRONG project as a "study of gender, identity and health." The letter included a website and a unique password linked to the Study ID. Subjects who did not respond to the initial invitation were sent up to two reminders.

TM/TF Status Ascertainment

The self-reported TM/TF status was determined based on a two-step question: first inquiring about participants' sex recorded at birth (on the birth certificate) and then asking about their current gender identity (male, female, transgender, or other). If the gender identity was different from the male sex recorded at birth, the participant was considered TF; if the gender identity was different from the female sex recorded at birth, the participant was considered TM.

The corresponding EMR-based information on TM/TF status was used to categorize study participants as TF or TM using several different approaches. First computer searches were used to identify specific keywords such as 'male-to-female', 'female-to-male' and TM- and TF-specific codes for gender affirmation procedures. During validation of study eligibility, the reviewers were instructed to review short text strings containing the relevant keywords to categorize each eligible person as 'male assigned at birth', 'female assigned at birth' or 'unclear'. For persons whose TM/TF status was unclear after the initial review and for persons with ICD-9 codes only, another free-text program was developed to search for keywords reflecting sex anatomy ('testes' or 'ovaries'), history of specific procedures (orchiectomy or hysterectomy) or evidence of hormonal therapy (estrogen or testosterone). Text strings containing TF- and TM-specific keywords were reviewed and differences between reviewers were adjudicated as discussed above.

Determination of Gender Affirmation Treatment Status

The self-reported gender affirmation treatment status was determined with survey questions about past and current therapies. Subjects were asked about their use of cross-sex hormones, and histories of chest and genital reconstruction surgeries.

The EMR-based data collection to determine gender affirmation used several approaches. During initial cohort validation and TM/TF determination, reviewers were instructed to check a box for 'Evidence of treatment' if the text strings provided an indication of receipt or referral for hormone therapy, surgery, or other relevant procedures to alter secondary sex characteristics. In addition to text string reviews, hormone therapy receipt was determined by linkages with pharmacy records using national drug codes. ICD-9, ICD-10 and Current Procedure Terminology (CPT) codes were used to ascertain histories of chest and genital reconstruction surgeries.

Data Analyses

The goal of the data analysis was to assess agreement between information on TM/TF status and gender affirmation therapy derived from the EMR and the corresponding information obtained from the survey. With respect to gender identity each person was characterized as survey- and EMR-based TM or TF. Similarly, each data source was used separately to assign each participant a 'yes' or 'no' value for hormone therapy, and for chest and genital reconstruction surgery.

The level of concordance for each parameter of interest was evaluated by calculating percent agreement, and a kappa statistic with a corresponding 95% confidence interval (CI). Kappa values of <0.20, 0.21–0.40, 0.41–0.60, 0.61–0.80, and >0.80 were interpreted as showing none to slight, fair, moderate, substantial, and near perfect agreement, respectively [11]. Sensitivities and specificities and corresponding 95% CIs were calculated using self-reported results as the gold-standard.

Multivariable logistic regression models were used to further examine the association between EMR/survey agreement and various self-reported participant characteristics obtained from the survey (age, race/ethnicity, education level). These models were only used in instances when the discordant results represented at least 10% of all observations. The independent variables in these models included TM/TF status, age, race/ethnicity, and education level. The results were expressed as adjusted odds ratios (OR) and 95% CIs.

To address the effect of survey non-response on study results, the logistic regression analyses were replicated using weighted models. The weights for the models represented inverse selection probabilities drawing from all invited participants. The selection probabilities were obtained from a separate logistic model, which included all STRONG cohort members who were invited to participate in the survey. The binary dependent variable in this model was response to the survey and independent variables included age, TM/TF status, race/ethnicity, education, study site and receipt of hormone therapy and gender confirmation surgery. All analyses were conducting using SAS 9.4 (SAS Institute, Cary, NC).

Results

As shown in Table 1, the analytic cohort included 640 people (320 TM and 320 TF) who answered all relevant survey questions. The TM and TF participants were similar with respect to race/ethnicity and educational attainment. Compared to TF participants, TM included a greater proportion of individuals under the age of 40 years (73% vs. 35%).

Table 2 shows the extent of agreement between EMR- and survey-derived data across the four parameters of interest: TM/TF status, hormone therapy, and chest and genital reconstruction surgery receipt. There was over 99% agreement with respect to TM/TF status (kappa = 0.98). Of the gender affirming therapies considered, the highest level of agreement (97%; kappa = 0.71) was observed for hormone therapy, followed by genital reconstruction surgery (83%; kappa=0.63). The lowest level of agreement was found for chest reconstruction surgery (72%; kappa = 0.44). Table 2 also shows that the specificities for all

four parameters of interest were over 0.90, whereas sensitives ranged from 0.49 for chest reconstruction surgery to 0.99 for TM/TF status.

Tables 3 and 4 examine factors associated with data discordance for chest and genital reconstruction surgery – the two parameters with less than 90% agreement between survey and EMR results. Compared to TF study participants members, TM participants were more likely to have discordant information regarding chest reconstruction surgery (OR: 2.41, 95% CI: 1.60–3.64). The association between TM/TF status and discordance of genital reconstruction surgery information was in the opposite direction but not statistically significant (OR=0.66; 95% CI: 0.40–1.09). For both types of gender affirming surgery, the likelihood of discrepancy between EMR and survey responses was greater for older participants compared to those younger than 30 years. By contrast, no discernable differences were observed with respect to race/ethnicity or level of education. The use of inverse probability weighting did not affect the associations between covariates and outcome meaningfully, although the confidence interval for the OR reflecting the association between TM/TF status and genital reconstruction surgery excluded the null value.

Discussion

In this study based on a relatively large sample of transgender people, EMR-derived TM/TF status and history of hormone therapy receipt were in substantial to near perfect agreement with self-reported survey information; however, the two data sources were more discordant with respect to history of gender affirming surgeries.

Using survey responses as the “gold standard”, both chest and genital reconstruction surgeries were ascertained from the EMR with reasonably high specificity, but the sensitivity of EMR-based surgical history was low. Thus, the observed data discordances are attributable primarily to the high proportion of missing surgical history information in the EMR.

The likelihood of disagreement between EMR and survey data varied across different groups of study participants. For chest reconstruction surgery, the disagreement was more evident among TM, while history of genital reconstruction surgery was more discordant among TF subjects. In addition, the disagreement with respect to both types of surgery was more evident among older study cohort members than in their younger counterparts.

The age-related differences with respect to presence and extent of data discordance are not surprising. As coverage of gender affirming surgeries at KP was implemented relatively recently, it is expected that a substantial proportion of older transgender enrollees underwent gender affirmation procedures elsewhere. The surgery-specific differences between TM and TF study participants are also consistent with expectations. Previous reports indicate that chest surgery is more common among TM relative to TF people while TF individuals are far more likely to seek genital sex reassignment surgery compared to TM subjects [12, 13]. It is important to keep in mind that chest reconstruction surgery is considered an essential step toward improving body image among TM persons [14, 15] whereas TF individuals can achieve visible breast augmentation by hormone therapy alone [16]. The differences in

genital reconstruction surgery may be explained by the greater technical difficulties and higher rate of complications associated with female-to-male relative to male-to-female genital reconstruction [17, 18].

We recognize that transgender people enrolled through an integrated health care system represent a cohort of persons with health insurance and access to specialized care. It is also important to keep in mind that the study survey was only sent to cohort members whose medical records included both relevant diagnostic codes and keywords and whose transgender care was not limited to mental health visits. These restrictions were necessary to avoid contacting persons who may not want to disclose their transgender status. It is possible that the disagreement between EMR and survey data may be different among those who did not meet criteria for inclusion. Finally, response to the survey was relatively low (33%), however this limitation was taken into consideration quantitatively by the use of inverse probability weighting.

Weighing against these concerns is the demonstrated ability to examine the possible extent of misclassification in a cohort of transgender subjects with detailed EMR data. Our findings offer assurance that EMR based data are unlikely to misclassify cohort participants substantially with respect to their TM/TF status or hormone therapy receipt. On the other hand, it is clear that the data source used in this study may not capture the complete history of gender affirmation surgeries. As many transgender patients now initiate and receive gender affirmation therapy exclusively within the KP system, the extent of agreement between EMR and self-report is expected to increase over time. Recent efforts to incorporate the Sexual Orientation and Gender Identity module in the KP EMR will make identification of transgender people more efficient and accurate. In the meantime the data generated in this analysis can be used to ascertain the extent of information bias and permit quantitative analysis to account for misclassification of key variables.

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Table 1.

Selected Patient Characteristics

Patient Characteristics	All Subjects n (%)	TM n (%)	TF n (%)
Age (years)			
Under 30	202 (32)	138 (43)	64 (20)
30–39	142 (22)	95 (30)	47 (15)
40–54	155 (24)	64 (20)	91 (28)
55 or Older	141 (22)	23 (7.2)	118 (37)
Race/ethnicity			
Non-Hispanic White	380 (59)	184 (58)	196 (61)
Non-Hispanic Black	19 (3.0)	13 (4.1)	6 (1.9)
Hispanic	129 (20)	65 (20)	64 (20)
Other	112 (18)	58 (18)	54 (17)
Education			
High School Graduate or Less	74 (12)	45 (14)	29 (9.1)
At Least Some College	230 (36)	97 (30)	133 (42)
College Graduate	191 (30)	101 (32)	90 (28)
Graduate/Professional School	145 (23)	77 (24)	68 (21)
Total	640	320	320

Table 2.

Measures of Agreement between EMR and Survey Data

		Survey					Survey		
		TM/TF Status					Hormone Therapy		
		TF	TM				Yes	No	
EMR	TF	318	3	321	EMR	Yes	588	3	591
	TM	2	317	319		No	19	30	49
		320	320	640			607	33	640
	Sensitivity =	0.99	95% CI: (0.97–1.00)			Sensitivity =	0.97	95% CI: (0.95–0.98)	
	Specificity =	0.99	95% CI: (0.98–1.00)			Specificity =	0.91	95% CI: (0.76–0.98)	
	Kappa =	0.98	95% CI: (0.97–1.00)			Kappa =	0.71	95% CI: (0.60–0.83)	

		Survey					Survey		
		Chest Surgery					Genital Surgery		
		Yes	No				Yes	No	
EMR	Yes	157	15	172	EMR	Yes	154	31	185
	No	166	302	468		No	73	382	455
		323	317	640			227	413	640
	Sensitivity =	0.49	95% CI: (0.43–0.54)			Sensitivity =	0.68	95% CI: (0.61–0.74)	
	Specificity =	0.95	95% CI: (0.92–0.97)			Specificity =	0.93	95% CI: (0.86–0.95)	
	Kappa =	0.44	95% CI: (0.38–0.50)			Kappa =	0.63	95% CI: (0.57–0.69)	

Table 3.

EMR and Survey Disagreement for Chest Reconstruction Surgery by Demographic Variables

Variable	Category	Discordant (%)		OR	(95% CI)	wOR*	(95% CI)
Gender Identity	TF (reference)	67	(20.9%)	1.00		1.00	
	TM	114	(35.6%)	2.41	(1.60–3.64)	2.41	(1.73–3.53)
Age (years)	Under 30 (reference)	40	(19.8%)	1.00		1.00	
	30–39	54	(38.0%)	2.37	(1.40–3.99)	2.15	(1.42–3.24)
	40–54	52	(33.5%)	2.42	(1.42–4.12)	2.30	(1.51–3.49)
	55 or older	35	(24.8%)	1.94	(1.05–3.59)	1.83	(1.12–2.97)
Race	Non-Hispanic White (reference)	115	(30.3%)	1.00		1.00	
	Non-Hispanic Black	5	(26.3%)	0.69	(0.23–2.02)	0.72	(0.28–1.84)
	Hispanic	28	(21.7%)	0.74	(0.45–1.21)	0.75	(0.50–1.11)
	Other	33	(29.5%)	0.92	(0.57–1.48)	0.96	(0.66–1.41)
Education	Some college or less (reference)	70	(23.0%)	1.00		1.00	
	College graduate or more	111	(33.0%)	1.17	(0.79–1.73)	1.19	(0.87–1.63)

* weighted odds ratio

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Table 4.

EMR and Survey Disagreement for Genital Reconstruction Surgery by Demographic Variables

Variable	Category	Discordant (%)		OR	(95% CI)	wOR*	(95% CI)
Gender Identity	TF (reference)	68	(21.3%)	1.00		1.00	
	TM	36	(11.3%)	0.66	(0.40–1.09)	0.67	(0.45–0.99)
Age (years)	Under 30 (reference)	18	(8.9%)	1.00		1.00	
	30–39	14	(9.9%)	0.98	(0.46–2.10)	0.94	(0.52–1.71)
	40–54	32	(20.6%)	2.10	(1.08–4.07)	2.15	(1.29–3.60)
	55 or older	40	(28.4%)	2.78	(1.37–5.61)	2.57	(1.48–4.46)
Race	Non-Hispanic White (reference)	70	(18.4%)	1.00		1.00	
	Non-Hispanic Black	3	(15.8%)	1.04	(0.28–3.84)	1.08	(0.35–3.35)
	Hispanic	18	(14.0%)	0.92	(0.51–1.66)	0.95	(0.59–1.51)
	Other	13	(11.6%)	0.61	(0.32–1.18)	0.67	(0.40–1.12)
Education	Some college or less (reference)	38	(12.5%)	1.00		1.00	
	College graduate or more	66	(19.6%)	1.47	(0.91–2.38)	1.43	(0.98–2.08)

*weighted odds ratio