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Gender-affirming Treatment Patterns among Transfeminine People in Mumbai, India

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Bachelor of Science
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ABSTRACT

Gender-affirming Treatment Patterns among Transfeminine People in Mumbai, India

By Tu Khong

Background: While transgender health research in low- and middle-income countries may face numerous logistical and methodological difficulties, one notable exception is India, where transfeminine (TF) persons, sometimes referred to as "hijra," are officially recognized as the 'third gender'. Although the HIV epidemic in the TF community in India is relatively well described, other aspects of health in this population including the frequency and types of gender-affirming hormonal treatment (GAHT) are largely unknown.

Methods: This cross-sectional study was based on a survey of 201 TF individuals identified among members of hijra communes, as well as other transgender and gender-diverse persons receiving support and counseling at a research and advocacy organization in Mumbai, India. The main outcome variables were past and current GAHT use including feminizing hormone therapy (fHT) and various gender-affirming surgical procedures. Data analyses evaluated the frequency and distribution of GAHT with the study group. Determinants of fHT were examined using multivariable Poisson models.

Results: Among all study participants, 39% (n=79) denied receiving any GAHT, 35% (n=70) reported using 'improper fHT' (defined as non-prescribed and/or nonstandard hormone use), 11% (n=22) had castration alone, 8% had improper fHT in combination with castration (n=17), and only 7% (n=13) of individuals received appropriate fHT, as recommended by the current guidelines. Among 100 persons who reported using fHT, only 33 indicated that they obtained prescriptions for hormone medications. Factors associated with fHT receipt included at least some high school education and self-identification as transgender women as opposed to hijra or other non-binary categories. In the analyses evaluating factors associated with prescribed (as opposed to informally obtained) fHT, only education was related to the endpoint of interest. However, most results were accompanied by wide confidence intervals that usually included 1.0.

Conclusion: Based on these data, most TF people who use fHT receive their medications through informal means rather than by prescription. More importantly, only a small proportion of fHT users undergo treatment in accordance with current recommendations. These findings highlight the problem of inadequate access to guideline-concordant gender-affirming care among TF people in India.

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INTRODUCTION

Since its introduction into academic discourse in the 1960s,[1] the term "transgender" has evolved and has become widely used. Today, the terms "transgender" or "gender diverse" typically refer to the heterogeneous group of individuals whose gender identity, expression, or behavior depart from the societal gender norms associated with their biological sex.[2,3] Biological (natal) sex, which is determined and assigned at birth, is based primarily on the appearance of the external genitalia.[4,5] In contrast, gender identity is one's sense of being a man, a woman, neither, or both, which can be either stable or dynamic throughout a person's lifetime.[3,5-6] Although some transgender and gender diverse (TGD) persons do not describe themselves using binary definitions,[7,8] a person with a male sex assignment and conflicting gender identity is often referred to as transfeminine (TF), and conversely, a person with a female sex assignment and conflicting gender identity is described as transmasculine.[9]

According to a recent analysis of the Behavioral Risk Factor Surveillance System, 0.5% (approximately 1.3 million) of U.S. adults identify as TGD,[10] an estimate consistent with prior studies that reported a range between 0.4% and 0.6%.[11,12] While members of the TGD community represent a growing and increasingly visible population, transgender health is an emerging field with a myriad of unmet data needs.[13-15] For example, TF people receiving feminizing hormone therapy (fHT) have been shown to experience an increased risk of vascular events such as venous thromboembolism and ischemic stroke, but specific factors that may modify this risk are presently unknown.[16] In addition, TF people represent a population suffering from an exceedingly high burden of HIV,[17] which in turn may act as an independent risk factor for thromboembolic events.[18,19] Taken together, this evidence raises concerns about the possible interaction between fHT and HIV as synergistic determinants of cardiovascular morbidity among TF people.

The concern about the potential synergistic effects of fHT and HIV may be especially relevant in low- and middle-income countries (LMIC) where HIV control among TF persons is often inadequate[20] and where the recommended monitoring of hormone levels may not be possible.[21] While conducting TGD health research in LMIC may present numerous logistical and methodological difficulties,[22,23] one notable exception is India, where TF persons are officially recognized as the 'third gender'.[24,25] Locally known as hijra, TGD people typically migrate from their homes during adolescence to find peer support within hierarchal communes known as gharanas.[26] This social structure offers an excellent framework for identifying and following large cohorts of TF persons with variable HIV status and a diverse history of gender affirmation.

While the HIV epidemic in the TF community in India is relatively well described,[27-30] the frequency and types of gender-affirming hormone treatments (GAHT), including fHT and castration, in this population are largely unknown. The few available studies[31,32] are relatively small and focus primarily on participants' perceptions of care rather than details of GAT receipt.

With these considerations in mind, this pilot study aims to examine the patterns of GAT use among members of the TF communities in Mumbai, the largest city in Maharashtra, the Western Indian state with the highest number of people living with HIV in the country (nearly 400,000) and a large well-established TF community.[33,34] The long-term goal of this pilot study is to generate preliminary data for a broader research initiative investigating the interaction between HIV status and GAHT, especially fHT, as risk factors for thrombotic and cardiovascular disease in India.

METHODS

Recruitment of Study Participants

This cross-sectional study was based on a survey of 201 TF individuals. Candidates for inclusion in the survey were identified among members of hijra communes, and among persons

receiving care and counseling at Humsafar Trust, a local health care, research, and advocacy organization with extensive experience working with sexual and gender minority populations. Eligible participants for the cohort recruitment were: (1) self-identified as TF; (2) were at least 18 years of age; (3) resided in Mumbai; and (4) were able to speak and read Hindi or English.

The recruitment was stratified to include at least one-quarter of HIV-positive individuals. The HIV-positive survey participants (n=50) were identified among persons receiving anti-retroviral therapy at the Humsafar Trust clinic. If an eligible person expressed interest in participating, peer educators and outreach workers scheduled a recruitment and data collection appointment. Upon recruitment, the participants were asked to provide informed consent, and all study procedures were approved by the Humsafar Trust Ethics Committee and by the Institutional Review Board of the Emory University.

Data Collection

The study survey was administered by the Humsafar Trust research staff using portable tablets with RedCap interface. The survey was developed based on the previously used transgender health questionnaires. The data for the present analysis were obtained from several sections of the survey. The General Information section collected demographic data and inquired about each participant's self-described gender identity. The Medical Gender Affirmation section inquired if the participants ever used (or currently use) hormones for the purposes of gender affirmation, and if so, what type of fHT medications they received and when. Similar questions were asked to obtain information about gender-affirming surgeries (e.g., castration or vaginoplasty) or other procedures (e.g., laser hair removal or tracheal shave) aimed at changing secondary sex characteristics. Finally, the Lifestyle and Health section included questions on HIV status and history of HIV testing and also collected information on the use of tobacco products and alcohol.

Data Analyses

The main outcome variables of interest included receipt of any GAHT and receipt of fHT. Persons with a history of any GAHT were further subcategorized as receiving: 1) "improper fHT" alone (defined as non-prescribed and/or nonstandard hormone use), 2) castration alone, 3) improper fHT in combination with castration, and 4) appropriate fHT (defined as estradiol in combination with an anti-androgen therapy or estradiol alone for previously castrated individuals). Persons receiving fHT were further divided into two groups: those who received prescriptions for hormone medications and those who obtained hormones from other sources (e.g. shared with friends or purchased on the black market). For simplicity, we considered an individual who reported receiving at least one prescription by a physician for hormone medication under the "prescribed" group, since many study participants took a combination of prescribed and informal fHT.

The demographic variables in this study included age (≤24, 25-34, and 35+ years), and education (no formal schooling/not specified, less than high school, and at least some high school). Dichotomous lifestyle and health variables were current smoking and alcohol consumption (Yes vs. No), and HIV status (positive vs. negative). Finally, with respect to self-described gender identity, each participant was characterized as transwoman vs. hijra/other.

The distributions of demographic, health, lifestyle, and gender identity-related factors were compared across fHT receipt categories with results presented as counts and percentages. The proportions of GAHT subcategories among all study participants and persons who self-identify as transgender women were depicted using pie chart diagrams. Associations between various participant characteristics and fHT use were examined using multivariable Poisson models with results expressed as adjusted prevalence ratios (PR) and the corresponding 95% confidence intervals (CI). Two alternative Poisson models were used. The first model included all study participants and used any fHT use as the dependent variable. The second model was restricted to persons receiving

fHT and used prescribed medications as the outcome of interest. The data management was performed using Microsoft Excel and all statistical analyses were carried out using SPSS 29.0 for Windows (IBM Corp. Armonk, NY) and/or SAS 9.4 for Windows (SAS Institute, Inc., Cary, NC).

RESULTS

As shown in **Tables 1-2**, among 201 survey respondents, 100 individuals reported receiving fHT; and of those, only one-third (n=33) indicated that their therapy was prescribed by a health care provider. Compared with participants who were not on hormone therapy, persons receiving fHT were more likely to have at least some high school education (37% vs. 23%), and smoke cigarettes (39% vs. 28%) or consume alcohol (57% vs. 48%) at the time of the survey (**Table 1**). The proportion of participants who self-identified as hijra rather than transgender was lower among fHT users (10%) than among persons who denied receiving fHT (39%). Persons receiving fHT were also more likely to report a history of surgeries or other gender-affirming procedures; this difference was especially pronounced for top surgery (82% vs. 12%). When study participants receiving prescribed fHT were compared to those who obtained fHT from other sources (**Table 2**) the two groups differed with respect to proportions of persons with high school education (55% vs. 28%). By contrast, the differences in self-described identity and other characteristics, including surgical histories were less evident.

Figures 1A and 1B display the distributions of GAHT categories within the study population. Among all study participants (n=201), 39% (n=79) denied receiving any GAHT, 35% (n=70) reported using 'Improper fHT' (i.e. non-prescribed and/or nonstandard hormone use), 11% (n=22) had castration alone, 8% had Improper fHT in combination with castration (n=17), and only 7% (n=13) of individuals received appropriate fHT (**Figure 1A**). When the data were restricted to subjects who self-identified as "transgender women" (n=152), the proportion of persons receiving

improper fHT without castration was higher than in the overall study groups sample (43% vs. 35%); whereas the corresponding percentages for other GAHT categories were generally comparable.

Table 3 presents the results of the multivariate Poisson regression analyses evaluating the associations between various subject characteristics and fHT use. Compared to persons with no formal schooling, persons with at least some high school education were more likely to use fHT (PR=1.42) and receive an fHT prescription (PR=3.22); although both results were accompanied by a wide 95% CI that included 1.0. Survey respondents who self-identified as transgender women were more than twice as likely to receive fHT (PR=2.60; 95% CI: 1.47-4.60) but less likely to obtain fHT via prescription (PR=0.65; 95% CI: 0.21-2.06) compared to persons who self-identified as hijra or other. By contrast, age, HIV status, and lifestyle characteristics were not associated with fHT use or receipt of fHT prescriptions.

DISCUSSION

Since 2014, the Indian government has officially recognized TGD individuals as the 'third gender' demographic group.[35] Whereas TGD people represent a sizeable and relatively visible part of the general population in India, little is known about the patterns of GAHT use and health status in this group A proper examination of health issues facing TGD people in India requires systematic studies capable of enrolling and following large numbers of participants. The feasibility of such studies can be assessed through formative research intended to pilot-test recruitment of participants, develop and refine data collection methods, and obtain preliminary results.

In this pilot study of 201 TF individuals living in Mumbai, India we observed that while fHT use was highly prevalent among study participants, it was usually obtained through informal means rather than by prescription. Several previous studies of GAHT in trans women have likewise demonstrated a common pattern of self-prescription and acquisition of medications through alternative sources, most commonly via the internet.[36-38] In our study, notable sources of fHT

included online marketplaces, friends, and senior members (*gurus*) of the *hijra* communes. Furthermore, only a small percentage of fHT users in this study reported receiving treatment in accordance with current recommendations, as outlined by the World Professional Association for Transgender Health.[21]

In the United States access to hormone therapy and relevant insurance coverage for TGD persons is also difficult.[40-42] One recent U.S. study estimates that one-in-five of insured TGD respondents had their insurance claims denied.[42] Similarly, affordable and comprehensive gender-affirming health care may be inaccessible in the majority of European countries.[43] In LMIC, where resources are limited and research infrastructure often lacking, these health and healthcare disparities are even more pronounced.[22-23] Our findings are generally in agreement with the handful of studies documenting the high rates of informal fHT use in TF communities of LMIC, including the Philippines,[44] Thailand,[45-46] Nepal,[47] and elsewhere in India.[31-32]

To our knowledge, this is the first study to quantitatively evaluate treatment regimens, surgical history, and sources of hormone medications in a relatively large and diverse group of TF people in India, including those who self-identify as transgender in those who refer to themselves as *hijra*. Whereas past studies typically utilized qualitative methods (e.g., structured interviews followed by thematic analysis) to describe the health practices of *hijras* and were relatively small,[31-32] we sought to evaluate the frequency and types of gender-affirming hormone treatments, including fHT and castration, in a larger group through a detailed survey instrument.

We found that many survey respondents received fHT in the form of combined oral contraceptive pills rather than estradiol in combination with antiandrogens (or orchiectomy) as recommended by the current guidelines.[21] This is particularly alarming because oral contraceptives are often unregulated (with black box warnings), are not intended as a substitute for gender-

affirming hormone therapy, and can potentially pose major health risks.[48-49] A few studies from Thailand also found that combined oral contraceptives were the most common GAHT regimen for trans women,[46,50] while a smaller-scale study in India found that injections, specifically Progynova depot (estradiol valerate), were the most utilized fHT, followed by oral contraceptive pills.[32]

Another notable feature of the present study is the ability to distinguish between participants who identify as trans-women from those who refer to themselves specifically as *hijra*. While the two groups share certain characteristics, the *hijra* community encompasses a wide range of gender identities that may not align with Western concepts of transgender.[24-25,52] Our results indicate that the two groups may differ with respect to their sociodemographic characteristics, lifestyle, health status, and type and extent of GAHT use, and therefore may need to be considered as two separate categories of participants in future studies.

Perhaps the most important limitation of the present study is the cross-sectional design that precluded a more comprehensive evaluation of temporal relation and sequence of GAHT receipt over time. Further the relatively modest sample size limited statistical power of most analyses. As the data collection relied on self-report, the details of GHAT receipt may have been subject to inaccurate or incomplete recall.

These limitations notwithstanding, the present study served its purpose as the initial step in a planned long term research effort aiming to understand the various aspects of health status, and especially the GAHT use, among TGD people in India. Such research effort will likely require extended longitudinal follow up of a larger and more diverse cohort of TGD people with more detailed data collection capable of capturing GAHT medication combinations, doses, duration, and side effects in this population. The findings from this study also highlight the problem of inadequate access to and utilization of guideline-concordant gender-affirming care among TF people in India.

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Tables and Figures

Table 1. Descriptive characteristics of survey participants by fHT receipt

Participant characteristics	All respondents (N=201)		Receiving fHT (N=100)		Not receiving fHT (N=101)	
	N	%*	N	%*	N	%*
Age (years)						
≤24	80	39.8%	38	38%	42	41.6%
25-34	57	28.4%	32	32%	25	24.8%
35+	64	31.8%	30	30%	34	33.7%
Education						
Never attended school/Unspecified	34	16.9%	12	12%	22	21.8%
Less than high school	107	53.2%	51	51%	56	55.4%
At least high school	60	29.9%	37	37%	23	22.8%
Current smoker						
No	134	66.7%	61	61%	73	72.3%
Yes	67	33.3%	39	39%	28	27.7%
Current alcohol consumption						
No	96	47.8%	43	43%	53	52.5%
Yes	105	52.2%	57	57%	48	47.5%
HIV status						
Negative	151	75.1%	77	77%	74	73.3%
Positive	50	24.9%	23	23%	27	26.7%
Self-described identity						
Transgender woman	152	75.6%	90	90%	62	61.4%
Hijra and Other	49	24.4%	10	10%	39	38.6%
Presents as a woman in public						
No/Unspecified	41	20.4%	29	29%	12	11.9%
Yes	160	79.6%	71	71%	89	88.1%
Chest surgery (alone, or in combination with other surgeries/procedures)						
No	171	85.1%	82	18%	89	88.1%
Yes	30	14.9%	18	82%	12	11.9%
Genital surgery (alone, or in combination with other surgeries/procedures)						
No	153	76.1%	73	73%	80	79.2%
Yes	48	23.9%	27	27%	21	20.8%
Other procedures (alone, or in combination with other surgeries/procedures)						
No	166	82.6%	73	73%	93	92.1%
Yes	35	17.4%	27	27%	8	7.9%

* Column percentages
Abbreviations: fHT = femininizing hormone therapy; HIV = human immunodeficiency virus

Table 2. Descriptive characteristics of participants receiving fHT by source of medication

Participant characteristics	All fHT recipients (N=100)		Prescribed fHT (N=33)**		Informal fHT (N=67)	
	N	%*	N	%*	N	%*
Age (years)						
≤24	38	38%	13	39.4%	25	37.3%
25-34	32	32%	10	30.3%	22	32.8%
35+	30	30%	10	30.3%	20	29.9%
Education						
Never attended school/Unspecified	12	12%	2	6.1%	10	14.9%
Less than high school	51	51%	13	39.4%	38	56.7%
At least high school	37	37%	18	54.5%	19	28.4%
Current smoker						
No	61	61%	19	57.6%	42	62.7%
Yes	39	39%	14	42.4%	25	37.3%
Current alcohol consumption						
No	43	43%	16	48.5%	27	40.3%
Yes	57	57%	17	51.5%	40	59.7%
HIV status						
Negative	77	77%	25	75.8%	52	77.6%
Positive	23	23%	8	24.2%	15	22.4%
Self-described identity						
Transgender woman	90	90%	30	90.91%	60	89.6%
Hijra and Other	10	10%	3	9.09%	7	10.4%
Presents as a woman in public						
No/Unspecified	29	29%	7	21.21%	22	32.8%
Yes	71	71%	26	78.79%	45	67.2%
Chest surgery (alone, or in combination with other surgeries/procedures)						
No	82	18%	27	81.8%	55	82.1%
Yes	18	82%	6	18.2%	12	17.9%
Genital surgery (alone, or in combination with other surgeries/procedures)						
No	73	73%	24	72.7%	49	73.1%
Yes	27	27%	9	27.3%	18	26.9%
Other procedures (alone, or in combination with other surgeries/procedures)						
No	73	73%	27	81.8%	46	68.7%
Yes	27	27%	6	18.2%	21	31.3%

* Column percentages

** Participants who took both prescribed and non-prescribed medications, were included in the 'Prescribed fHT' group

Abbreviations: fHT = femininizing hormone therapy; HIV = human immunodeficiency virus

Figure 1A. Gender-affirming Care Patterns Among All Participants (n=201)

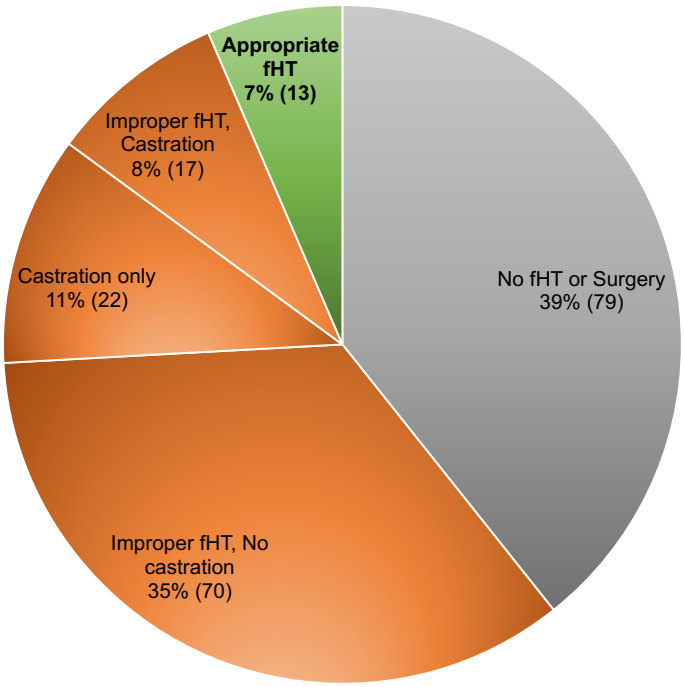

Figure 1B. Gender-affirming Care Patterns Among Self-Identified Transgender Women (n=152)

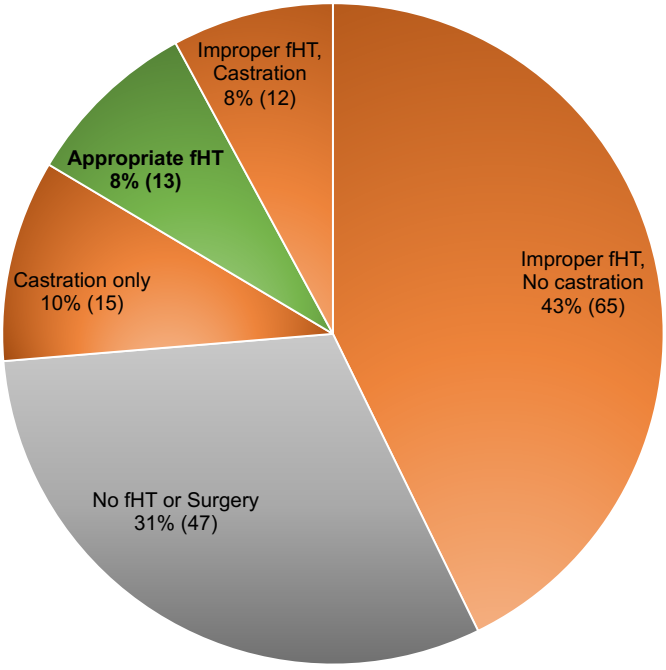

Table 3. Association of participant characteristics with fHT use (n=201) and fHT prescription receipt (n=100)

Participant Characteristics	PR (95% CI) for fHT use*	PR (95% CI) for prescribed fHT *
Age (years)		
≤24	1 (ref)	1 (ref)
25-34	1.23 (0.89 - 1.71)	0.99 (0.50 - 1.95)
35+	1.05 (0.74 - 1.48)	1.29 (0.64 - 2.58)
Education		
Never attended school/Unspecified	1 (ref)	1 (ref)
Less than high school	1.26 (0.78 - 2.02)	1.53 (0.39 - 5.94)
At least high school	1.42 (0.89 - 2.26)	3.22 (0.84 - 12.4)
Current smoker		
No	1 (ref)	1 (ref)
Yes	1.06 (0.79 - 1.42)	1.30 (0.67 - 2.51)
Current alcohol consumption		
No	1 (ref)	1 (ref)
Yes	1.16 (0.85 - 1.56)	0.78 (0.42 - 1.46)
HIV status		
Negative	1 (ref)	1 (ref)
Positive	0.96 (0.69 - 1.33)	1.07 (0.53 - 2.14)
Self-described identity		
Hijra and Other	1 (ref)	1 (ref)
Transgender woman	2.60 (1.47 - 4.60)	0.65 (0.21 - 2.06)

*Based on multivariable Poisson models; all variables listed in the table are included in each model

Abbreviations: fHT = femininizing hormone therapy; HIV = human immunodeficiency virus; PR = prevalence ratio; CI = confidence interval