

## EDITORIAL

# Beyond anxiety: Autonomy and harm reduction approaches to DIY Hormone Replacement Therapy

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A researcher in a Hyderabad-based science institution, Roshni (*name changed to preserve anonymity*) started identifying as a transgender woman in 2018, and wanted to start her medical transition — the process by which transgender people seek to affirm and express their gender using medical interventions.

Medical transition involves combinations of endocrinological and surgical interventions following a psychiatric assessment for gender incongruence. The former, referred to as Gender-Affirming Hormone Therapy (GAHT) or Hormone Replacement Therapy (HRT), includes the administration of hormone blockers, and sex hormones and their analogues to align one's body better with their gender. Surgical interventions, on the other hand, include masculinising procedures like mastectomy (surgical removal of breasts), oophorectomy and hysterectomy (surgical removal of the ovaries and the uterus), phalloplasty (surgical construction of the penis), and feminising procedures like mammoplasty (surgical augmentation of the breasts), orchiectomy and penectomy (surgical removal of the testes and the penis), and vaginoplasty (surgical construction of the vulva and the vaginal cavity).

Roshni began her transition journey by scanning Wikipedia, which took her to research articles on the biochemistry, safety, and efficacy of drugs commonly used for HRT. Around the same time, transgender people had begun forming communities and discussing transitioning on social media platforms like Reddit. Despite having gathered the necessary information and feeling prepared to transition, she encountered two problems: the lack of a trans-affirmative endocrinologist, and the lack of money to afford such an endocrinologist, were she to find one. In addition, she had difficulty finding a psychiatrist who would assess and certify her gender incongruence — a prerequisite before an endocrinologist begins HRT, according to the *Indian Standards of Care for Persons with Gender Incongruence and People with Differences in Sexual Development/Orientation* published by the Association of Transgender Health in India [1]. "Most psychiatrists refuse to give the letter before 2-3 sessions and several expensive tests," she told me recently.

Under these constraints, Roshni started herself on birth control pills that had cyproterone (an anti-androgen) and ethinyl estradiol (a synthetic derivative of estrogen), despite knowing that "there were problems with safety"; she said. The combination of ethinyl estradiol and cyproterone is known to have an increased risk of blood clots as compared with a combination of cyproterone and estradiol, the naturally occurring form of estrogen [2,3]. Later, she shifted to the relatively safer and more effective combination of estradiol valerate and bicalutamide (another anti-androgen [4, 5]).

Roshni visited an endocrinologist only in 2021, who then put her on a prescription for a combination of estradiol valerate and leuprorelin (another anti-androgen and a safer alternative to bicalutamide, of which liver toxicity is a rare side effect [6]). Throughout her transition — before and after she began consulting the endocrinologist — she monitored her hormone levels and signs of potential toxicity through tests. Now, while she is not unhappy with her endocrinologist, she believes that the prescribed dosage is inadequate for her to achieve her transition goals. Therefore, she tells me, she "rarely" visits her endocrinologist except to have her prescription renewed once a year, lest pharmacies around get suspicious.

I start with Roshni's story, which I share here with her consent, since it illustrates a case of "Do-it-yourself Hormone Replacement Therapy" (DIY HRT) [7]. Also referred to as "self-administration of gender-affirming hormones" [8], "self-prescribing sexual hormones in gender affirmation" [9], and "nonprescribed hormone use" [10], DIY HRT is one of the two ways in which transgender people globally report attempting to transition without medical supervision, the other — and uncommon — way

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being DIY surgeries [11]. Despite the medical and social implications (described below), evidence suggests that the DIY way is common among transgender people around the world [7,9,10,11], and in India [12].

In this editorial, I discuss the implications of the prevalence of DIY HRT practices for transgender persons, the medical ecosystem, and the relationship between the two. Drawing upon the principles of harm reduction and patient autonomy, I recommend against blanket anxieties around DIY practices, instead suggesting simultaneous bolstering of efforts to bridge the gap between transgender people and medical practitioners, and the wide dissemination of HRT-related knowledge to transgender people, particularly those further marginalised by poverty and a lack of formal education.

## The DIY Way

The terms “DIY medicine” or “DIY medical endeavours” refer to instances where people administer medical therapies to themselves without professional supervision. In the past, researchers have documented several examples of DIY medicine, including brain stimulation, faecal transplantation<sup>1</sup> [13], 3D-printing prosthetic limbs, DIY orthodontics and dentistry, and invention of low-cost hearing aids and modification of existing ones, etc (see [7] for a review). Some researchers have argued that DIY medicine is a form of “citizen science” [7] — a term denoting the participation of the general public in scientific activities.

Evidence indicates that gender-transgressive communities around the world have historically self-administered medical procedures. For example, anthropologist Don Kulick’s ethnography of the *travestis*, a gender-transgressive community in Brazil, identified that most *travestis* self-administer copious amounts of feminising hormones as well as silicone injections — all in the absence of trained medical professionals [14]. In the Indian context, anthropologist Serena Nanda has documented the ritual castration process among the *hijras*, where certain *hijras* (called *dai ma*) performed the castration surgery on others<sup>2</sup> [15,16]. However, despite the historical prevalence of self-administering medical procedures among gender-transgressive communities, the DIY HRT movement appears to be of a markedly different order. Anecdotally, in my conversations around DIY transitioning, most transgender people showed interest in reading scientific and medical literature and were concerned regarding the safety of HRT regimens — an observation that has also been reported by previous journalistic reports on DIY transitioning [11].

## Why DIY?

DIY HRT acts as an alternative circumventing the barriers faced by transgender persons in accessing gender-affirming healthcare [9,11]. Reports suggest that transgender people face significant discrimination and gatekeeping within the medical ecosystem, including stigmatisation and pathologisation of their identities [9,11,17,18] and the violation of their bodily autonomy [19], which discourage them from approaching medical professionals. This apprehension is compounded by the anticipated risks of sexual and gender-based violence within the medical ecosystem [18]. Even when transgender persons are able to secure HRT prescriptions, they face gatekeeping, stigma, and discrimination from pharmacists [12], which compels them to turn to drugs not meant for transitioning (eg, birth control pills), or seek hormones from acquaintances [12].

Further, reports indicate that medical curricula globally lack discussions on transgender health [11], leading to a lack of medical practitioners trained in providing gender-affirmative services. In India, despite the 2019 Transgender Persons (Protection of Rights) Act mandating a review of the medical curriculum and the production of a manual for gender-affirmative surgeries [20], medical education in the country has remained ignorant of the health requirements of transgender persons. Earlier this year, when the competency-based medical education (CBME) curriculum was revised by the National Medical Council, it continued to list gender incongruence as a “disorder” and intersex conditions as “abnormalities” [21] — both outdated misconceptions.

In addition, a large number of transgender persons in India and around the globe live in precarious conditions, including homelessness, poverty, and lack of education and employment. Therefore, most find themselves unable to afford HRT under medical supervision, which is estimated to cost Rs 1000-3000 per month [12]. Even when government provisions claim to support transgender persons who seek to transition medically, through measures such as the Support for Marginalised Individuals for Livelihood and Enterprise (SMILE) scheme by the Indian Ministry of Social Justice and Empowerment, access to these provisions is limited by stringent requirements of transgender identity cards [22] that are hard to procure [23].

## Medical and social conundrums

Having summarised the major reasons for the prevalence of DIY transitioning among transgender people, I now focus on the key medical and social implications that this practice forces us to confront.

### Safety hazards

While research indicates that HRT is safe when monitored for safety risks [24], systematic studies of safety risks of hormone administration, particularly in the context of transitioning, are only beginning to surface. Evidence indicates that HRT may

increase the risk of blood clots, heart attacks, strokes, and breast cancer in transgender individuals, particularly transgender women on estrogen [3, 25, 26, 27]. Spironolactone, the testosterone blocker, may cause dehydration and negatively impact the kidneys in rare cases [28].

Further, testosterone use in masculinising HRT may worsen mental health conditions and increase the risk of estrogen-related cancers in some predisposed individuals, although evidence for the latter is unclear [24, 29]. Testosterone administration can also increase the risk of abnormally high levels of red blood cells [24], which, in turn, can lead to an increased risk of blood clotting, and, consequently, of strokes. Thus, the lack of medical supervision in DIY transitioning might mean that transgender persons on DIY HRT regimens are at an increased risk of these adverse effects. Even when transgender persons monitor potential toxic effects, the risk might remain since extensive monitoring of HRT-related adverse effects can be prohibitively expensive (for a complete list of recommended tests, see [1]).

### **Widening the gap within**

While there is evidence indicating that many transgender persons on DIY HRT demonstrate a rigorous knowledge of scientific and medical literature concerning HRT and its risks [7,12], access to this knowledge is structured by level of education and income [12]. For example, a Maharashtra-based study found that transgender women belonging to the traditional *hijra/kinnar* discipleship-kinship structure (ie, the *gharanas*) and engaged in occupations like sex work, ritual begging, and ritual blessing [15, 16, 30] relied largely on their *gurus* or *naiks* (leaders) for accessing HRT and had little knowledge of the medication; in contrast, transgender persons outside the *gharana* system got their knowledge about HRT from internet sources, which in some cases included scientific and medical literature [12]. Notably, the former group had lower income and education levels as compared with the latter [12]. That is, despite the prevalence of DIY HRT among transgender people in India, not all transgender people have equal access to the knowledge and resources required to identify and monitor safety risks; this puts those who are further marginalised by poverty and lack of education at a higher risk of side effects. Even as DIY HRT might be increasing the ambit of who is able to medically affirm their gender, it also perpetuates the rift between transgender women who are more privileged with respect to education and livelihood, and those who aren't.

### **Recommendations**

The *Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming People* by the World Professional Association for Transgender Health (WPATH), the global authority on transgender health, recognises HRT as a “medically necessary” intervention [31]. It also acknowledges DIY transition practices, noting that “[...] many TGD [transgender and gender diverse] people take non-prescribed hormone therapy” [31]. In a similar vein, the World Health Organization (WHO) in 2022 revised the *WHO Guideline on Self-Care Interventions for Health and Well Being* and recognised self-administration of gender-affirming hormones as a form of “self-care”, noting that “Transgender and gender-diverse individuals who self-administer gender-affirming hormones require access to evidence-based information, quality products and sterile injection equipment” [32]. It also recommends that healthcare providers be trained in the management of adverse effects arising from self-administration and argues for a harm-reduction approach while navigating self-administration of gender-affirming hormones [32], much like the WPATH *Standards of Care* [31] and other systematic studies on DIY HRT [9]. “Harm reduction” denotes practices that intend to mitigate risks associated with certain behaviours. For example, in the context of HIV/AIDS, harm reduction involves the distribution of condoms and single-use syringes to reduce the risk of HIV transmission through sexual and needle routes.

Despite potential health risks associated with DIY transitioning, recent research indicates that it is a “community-driven, accessible, and empowering practice” [33]. Further, many DIY practitioners participate in harm-reduction practices, including testing for toxic effects, self-organisation and mutual aid, and dissemination of information about hormone use [12,33]. Drawing upon the above-mentioned guidelines and studies, and centring the principle of harm reduction, I close with a few recommendations for medical practitioners as they begin navigating DIY transition practices among transgender persons in India. Broadly, the recommendations suggest that while transgender persons should be encouraged to seek medical expertise during their transition process to minimise risks, medical practitioners should be encouraged to communicate with transgender persons about their transition goals and take into consideration their access to medical resources while prescribing HRT regimens.

While implementing any of the recommendations below, it is important to involve transgender persons in all aspects and stages, including the core team, and right from the conception to the execution stages.

### **Knowledge co-creation on DIY transitioning in an Indian context**

Unlike the WPATH *Standards of Care*, the *Indian Standards of Care* document from the Association of Transgender Health in India [1] does not mention DIY HRT practices. Further, while some systematic studies in India have investigated barriers for

transgender persons in seeking gender-affirmative care [17] and the ways in which transgender people navigate these barriers, including DIY transitioning [12], large-scale systematic studies on the same are missing. This results in an incomplete picture of the prevalence of DIY transitioning practices within transgender communities in India.

In addition, more research is needed on how the access to and practice of DIY HRT is affected by intersecting axes of marginalisation and privilege, like caste, class, sexual orientation, geographical location, disability, etc. Future studies on DIY HRT would benefit from not taking an adversarial approach, which runs the risk of further antagonising transgender persons, and could, instead, focus on harm reduction of DIY practitioners, and bridging the gap between transgender persons and the medical ecosystem.

### ***Training and sensitisation of healthcare providers***

While self-medication is generally seen as risky [34], scholarship suggests that self-medication, at least in the context of minor illnesses, might be seen as promoting patient empowerment [34] and autonomy [35]. Blanket condemnation of self-medication in case of DIY HRT practices might lead to cementing of the adversarial relationship between the medical ecosystem and transgender persons. To avoid this, healthcare providers should be sensitised to DIY HRT practices and trained to handle potential adverse effects resulting from DIY HRT; for example, the curriculum guidelines from the Association for American Medical Colleges (AAMC) recommends that healthcare practitioners be trained to connect transgender people on DIY HRT to community-based groups for harm reduction [36].

Larger initiatives in training medical practitioners in transgender healthcare are also required and might motivate transgender persons to seek medical supervision during their transition processes. Recent initiatives like curriculum guidelines from the AAMC [36], and guidelines for implementation of transgender health programmes [37] and clinics [38] are steps in the right direction.

### ***Knowledge dissemination on gender-affirmative healthcare and harm reduction practices***

Drawing upon previous models of harm reduction (for example, in the case of alcohol and drug use), a widespread knowledge dissemination initiative should be executed focussing on different hormone regimens, their risks and benefits, and the necessary tests to monitor safety and side effects. Such an initiative should mobilise government resources, existing public dissemination platforms, medical professionals, transgender persons, and science and health journalists, among other stakeholders.

Community-driven initiatives that are led, conceived and executed by transgender persons must be encouraged and supported. One such community-driven initiative seeking to disseminate knowledge on HRT is *transfemscience.org*. Popular among transfeminine people (ie, people assigned male at birth whose gender identity is predominantly feminine), including those seeking to transition DIY, the online platform features content on HRT written by transgender people with other transgender people, medical providers, and those studying transgender health as its intended audience [39]. All articles on the platform have thorough discussions on efficacy, safety, tolerability, and pharmacology of the drug under review, and are heavily referenced with peer-reviewed medical literature.

### ***Advocacy to refurbish and strengthen government support for transgender healthcare***

Existing government support for transgender healthcare is both inadequate and inaccessible. These initiatives should be reconsidered in consultation with transgender persons and medical professionals with expertise in transgender health. In addition to making HRT more readily available to transgender persons (for example, through the Informed Consent Model documented in the WPATH *Standards of Care*), testing facilities to monitor adverse effects must be made available.

The WPATH *Standards of Care* defines the Informed Consent Model as one that “[...] prioritizes the TGD [Transgender and Gender-Diverse] adult as the decision maker with the HCP acting as an advisor, barring serious contraindications” [31]. This model, thus, does away with the requirement of psychiatric referral before endocrinologists can begin transgender people on HRT. Reports indicate that the informed consent model might enable transgender persons to begin HRT the same day they visit the clinic for their first consultation, significantly bringing down the waiting time [11].

## **Conclusion**

The recommendations above seek to make safe and evidence-based gender-affirmative care available to a large number of transgender persons. Overall, this editorial advises against adversarial approaches to DIY HRT practices, instead suggesting that the medical ecosystem centre frameworks of patient autonomy and harm reduction while working towards developing and deploying transgender healthcare programmes.

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### Notes:

<sup>1</sup>Faecal transplantation aims to provide relief to individuals with *Clostridium difficile* infections, Crohn's Disease, etc, by replenishing eroded gut microbiota. According to media reports, absence of doctors trained in or willing to perform faecal transplants leads a large number of patients to take the DIY approach, where people seek faecal matter from a close relative, liquidise it using kitchen blenders, and then use enema kits to deliver to their colon [13].

<sup>2</sup>However, in a later ethnography of the hijras, anthropologist Gayatri Reddy remarks that most hijras appeared to be seeking castration services from medical professionals and not from the dai ma, although getting castrated at the hands of the latter was seen as more respectful [16].

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