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### **ETHICS CASE**

## How Should Physicians Refer When Referral Options Are Limited for Transgender Patients?

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#### Abstract

Transgender people encounter many barriers to health care, and recommendations about where their treatment would best be offered can promote or thwart good care. This case examines the care setting from the perspective of a patient whose experiences with specialists have been negative. We argue that an ethos of harm reduction and informed consent, with a strong emphasis on continuity of care within a primary care setting, should guide questions about how to refer transgender patients to caregivers and to good care settings.

### Case

As a fourth-year medical student, Jasmine volunteers at a women's health clinic affiliated with her medical school. During her shifts at the clinic, Jasmine helps conduct initial patient interviews and physical exams and works with attending physicians—one of whom is Dr. Fan—to create care plans for her patients. On this afternoon, Jasmine sat down with a 29-year-old patient named Brianna.

Brianna told Jasmine that she had experienced recent episodes of nausea, which Brianna thought might be related to her hormone therapy. Brianna, who identifies as female but was birth-assigned male, began feminizing hormones five years ago. Brianna's hormone regimen is currently being managed by Dr. Maize, a specialist not affiliated with the clinic but known to the community.

"I've never had these symptoms before," Brianna said. Jasmine asked Brianna if she had told Dr. Maize about these recent symptoms. Brianna replied, "To be honest, I don't like spending much time at her office. I just try to show up for my check-ups, get my prescriptions, and leave." Brianna explained that, while at her appointments with Dr. Maize, she often catches the inconsiderate lingering stares of her staff. And on multiple occasions, Dr. Maize has said impolite things to her. During one visit, for example, Dr. Maize said to her, "Now that you've been doing well on hormones for a while, feminizing facial surgery could really help you complete 'the full look,'" which hurt Brianna and convinced her that Dr. Maize wasn't adept at making transgender patients feel comfortable. At the conclusion of Brianna's patient interview, Jasmine went to Dr. Fan, explained Brianna's discomfort with Dr. Maize, and asked if there were another specialist to whom they might refer Brianna for hormone therapy.

"I've heard similar complaints about Dr. Maize from other trans patients," Dr. Fan said, "but she's the only gender-transitioning hormone specialist in the area." Dr. Fan explained that there were specialists in a big city nearby who had better reputations for trans-friendliness, but they tended to be younger and less experienced with hormone therapy for gender transitions than Dr. Maize. "Since Brianna has her own share of preexisting health complications, from a strictly medical point of view, Dr. Maize could be the most qualified to care for her—but given Brianna's discomfort with her . . . I'm not so sure."

"So, what should we recommend to Brianna as her best referral option?" Jasmine asked Dr. Fan.

#### Commentary

While some strides have been made in social acceptance and legal equality for transgender people, there is still a need to address <u>stigma</u> and inequities in transgender health care [1, 2]. Access to gender transition-related care (e.g., gender-affirming surgery, hormones, and culturally competent mental health services) is a pressing and often unmet need for many transgender people, but it comprises only one component of their health care. Transgender patients' other health care needs are, in many respects, identical to those of cisgender (nontransgender) people. This case highlights the question of best referral practices for transgender patients, particularly when medically qualified specialists lack the knowledge or interpersonal skill needed to care well for transgender patients. In reflecting on Brianna's case, we will emphasize the importance of ensuring that transgender people stay within the care of professionals they trust for all their health care needs, with the goal of preventing harm and promoting continuity of care.

#### **Harm Reduction**

There is little empirical research on the outcomes of gender transition-related medical interventions [3]. This lack of data suggests a need for future study and a challenge to clinicians. In the absence of longitudinal evidence, <u>clinical practice guidelines</u>, such as the standards of care issued by the World Professional Association for Transgender Health (WPATH), call for harm-reduction approaches in confronting the pressing need to treat this patient population [4]. For example, in the case of patients whom the physician knows to have acquired hormones through the black market, Internet, or other means, this approach requires physicians to manage the patient's hormone regimen [4, 5] and provide a limited prescription for hormones (until a clinician who can prescribe long-term hormones is found) rather than refusing to prescribe [4], because it is likely that denial of

care will result in "continued independent treatment and possible harm" [6]. Efforts to reduce harm are intuitively necessary in cases of potential denial of care, but recent research has also started to focus on the need to reduce <u>emotional harm</u> to patients, in part because "emotional harms can erode trust, leave patients feeling violated and damage patient-provider relationships" [7]. Both physical and emotional harms should be considered in harm reduction efforts.

The principle of harm reduction is applicable in this case on both physical and emotional grounds and should guide whether and to whom Brianna is referred. The specialist, Dr. Maize, and her staff are experienced by Brianna to be "inconsiderate" and not "adept at making transgender patients feel comfortable," which, in turn, has resulted in Brianna minimizing and avoiding interactions with Dr. Maize and her staff. In the case, the patient-physician relationship can be understood to be causing two kinds of harm: emotional, since Brianna is uncomfortable and feeling pressure to seek unwanted medical intervention; and potentially physical, because she is reluctant to see Dr. Maize about her recent episodes of nausea. The scenario described above, in which transgender patients avoid medical care due to negative experiences, is neither hypothetical nor isolated [8]. In a survey of transgender people residing in Massachusetts, it was found that discrimination was associated with 24 percent of transgender patients postponing routine or preventative care and 11 percent postponing care that later resulted in emergency treatment [9]. Based on the model of harm reduction described above, Brianna should not be referred back to Dr. Maize, in order to avoid emotional harm, in particular.

#### Models of Transgender Care

Changes to referral practices are at the heart of a significant evolution in the medical treatment of transgender people. The most recent edition of the WPATH guidelines suggests—but no longer requires—that patients provide one or more letters of referral from a "gualified mental health professional [or] ... a health professional who is appropriately trained in behavioral health and competent in the assessment of gender dysphoria" prior to the provision of hormones [10]. The referring practitioner shares ethical responsibility for the provision of hormones with the prescribing physician, and the pre-letter-writing consultations are designed to confirm that the patient is both committed to transitioning (and therefore unlikely to regret the decision to initiate hormone therapy) and able to consent to the treatment [4]. In recent years, however, many centers that specialize in transgender medical care have moved to what is termed the "informed consent model" for initiation of hormone therapy [11, 12]. In this model, no referral letters are needed for hormone therapy, and pre-prescribing consultations are designed to ensure that the patient is fully aware of the "risks, benefits, alternatives, unknowns, limitations, [and] risks of no treatment" [13]. Although informed consent to endocrine treatment is not an issue for Brianna, the model of care that the informed consent pathway presents is helpful for thinking about where she is likely to receive the

best endocrine care. In contrast to the referral model, in the informed consent model, care is patient-initiated and fits within the primary care model of overseeing all aspects of care.

Through this lens, Dr. Maize's comment that "feminizing facial surgery could really help you complete 'the full look'" raises a red flag. Historically, the relationship between gender-nonconforming people and the medical establishment was fraught with mistrust and frustration, with psychiatrists serving as gatekeepers to desired care [14, 15]. Physicians believed that their patients lied to them in order to receive transitional treatment, while patients saw their physicians as paternalistic impediments, unwilling to offer medically necessary treatment or to acknowledge variations in gender identity from patient to patient [16]. An uneasy, and, for the most part, tacit, deal was struck. Patients would repeat a similar story to their doctors: they had been "trapped in the wrong body"; they had "always felt that way"; post transition they promised to be model heterosexual women (there are few recorded medical historical accounts of transgender men) [16]. In turn, physicians would work to provide "complete" transition, which combined available surgical techniques with hormone therapy and training in feminine behavior, one physician referring to it in a 1973 paper as a "charm school" for his transgender patients [17]. In the mid-twentieth century, the stakes were high because physicians had virtually complete authority to deny or grant access to patients seeking medical assistance with their gender transitions. For patients seeking medical interventions, the idea that there was such a thing as a "complete transition" or the "full look" was a convenient and necessary shorthand to legitimize transitional treatment. However, Dr. Maize's suggestion that Brianna undergo surgery to complete "the full look" suggests that she is still operating within this older, paternalistic model. Contemporary transitional care should be guided by the patient's sense of self, rather than the clinician's interpretation of gendered norms.

As our cultural <u>understanding of gender</u> has evolved to accommodate many different experiences of masculinity and femininity, clinical guidelines no longer require a binary expression of gender identity as a requirement for accessing care [18]. As a result, the idea that one's look must be "complete" is outdated and problematic. Because of the diversity of gender expressions and physical bodies among transgender people, there is not a standard set of surgical or endocrinal interventions that constitute an ideal or "complete" gender transition. Rather, informed consent to ensure a transitioning patient's self-determination should guide the course of medical assistance, when desired.

In considering whether and where to refer Brianna for hormone therapy, Dr. Fan and Jasmine could turn to the informed consent framework. It emphasizes patient knowledge—of transgender issues and of medical risks and benefits of potential treatments that clinicians can provide. By removing psychiatric gatekeeping

requirements, it also promotes continuity of care. Jasmine and Dr. Fan should prioritize referring Brianna to a physician that she trusts, ideally one already familiar with (or willing to be educated in) transgender medical care. Such a clinician can still, if needed, refer out to an endocrinologist in the event that Brianna's symptoms of nausea are found to be caused by her hormone therapy, while still maintaining responsibility for her hormone management.

#### A Common Problem in Transgender Health Care

Presuppositions about gender-transitioning hormones, as well as gender identity, constitute a potential blind spot for physicians in their care of transgender patients. Transgender and gender-nonconforming people report that one of the most frustrating aspects of being in a clinic for health care needs unrelated to gender transition is the myth of constant comorbidity. This is colloquially known as "trans broken arm syndrome" [19], the causal misattribution of unrelated medical problems to aspects of gender transition or transgender identity. The consequences of this phenomenon range from a misallocation of time resources—spending too much time taking the patient's history of transition-related intervention and failing to address the condition they came in for-to erroneous attempts to change the course or regimen of hormonal treatment [20]. While it is entirely possible that Brianna's symptoms are related to her feminizing hormones, the assumption that Brianna's hormone therapy is the cause of a symptom like nausea might be a red herring. Clinicians should exercise extreme caution before recommending that the patient stop hormone therapy on account of possible side effects, which can include unwanted physical changes, as well as emotional harms. Like any other medically necessary treatment for chronic or life threatening conditions, hormones should be actively monitored and maintained in a treatment plan, unless the patient wishes to stop taking them. More clinicians are needed who are well informed about transgender health issues as well as able to provide gender affirming care.

#### Transgender Patients' Access to Health Care: Common Barriers and Overcoming Them

Transgender people report encountering serious barrier and biases in health care [7]. Although large LGBT health centers do exist and disseminate educational materials beyond their specific patient populations [5, 21, 22], they are generally located in major cities and therefore too far for many people to travel for regular care. Surgeons who are experienced in gender-affirming procedures are also relatively few [23], and, as a result, patients might have no choice but to travel great distances for expensive procedures. This hardship has real financial impact on transgender patients and can remove them from their communities for postsurgery support. Additionally, health insurers have historically declined coverage of gender transition-related expenses, which required that procedures, such as mastectomy or hormone therapy, be paid for out of pocket unless physicians could find another way to bill for them that is unrelated to gender-affirming care [24]. Even though insurance plans are beginning to cover transition-related expenses, many transgender Americans remain uninsured and underinsured [8].

*Expanding access.* Despite these barriers to access, hormones as well as nonmedical gender-affirmation support can be provided within a patient's community and managed by a physician with whom the patient is most comfortable, even in a primary care setting. In fact, any physician, using tools and guidelines to help them gain competency, can manage hormone treatments for transgender patients. For example, the University of California, San Francisco's Center of Excellence for Transgender Health [5], the Fenway Institute at Fenway Health in Boston [21], and the Callen-Lorde Community Health Center in New York City [22] publish guidelines and instruction for clinicians. The UCSF guidelines state that "prescribing gender-affirming hormones is well within the scope of a range of medical providers, including primary care physicians" [13], and that "it is of similar difficulty to the monitoring of other similarly complex lab-monitored conditions managed by primary care providers" [25]. The Fenway approach (like the others) is "a philosophy of accessible, patient-centered care that views gender affirmation as routine part of primary care service delivery, not a psychological or psychiatric condition in need of treatment" [26]. This position doesn't mean that endocrinologists should not be involved in the provision of hormones, particularly in their roles as consultants. Rather, these guidelines allow clinicians more flexibility in weighing their own comfort and ability to provide effective care when deciding whether and how they will manage a transgender patient's care, instead of their particular specialty training overriding that decision.

A primary care-centered approach to the provision of hormones facilitates continuity of care. This continuity of care, wherein gender affirmation is a "routine part of primary care" [26], in turn can help to ameliorate "trans broken arm syndrome." Primary care physicians generally know their patients better than specialists and are familiar with many different aspects of their patients' health and well-being. They may prescribe hormones for transgender patients and are well-suited to monitoring them in the context of their overall health and well-being [5]. Primary care physicians who manage their patients' hormone therapy are better equipped to understand the therapy's effects—including what symptoms are unrelated to hormone therapy—than those who do not. Jasmine and Dr. Fan should help Brianna find a primary care physician.

#### Conclusion

In weighing referral options for transgender patients, clinicians should consider not only the experience potential specialists have in working with transgender people, but also their willingness and ability to develop care plans that reflect the wants and needs of the individual patient. These referral and care management decisions should be made to minimize physical and emotional harm, taking into account the cultural competence of the clinicians who might provide gender-affirming care, the importance of continuity of care, and the fact that, in many circumstances, it is not only acceptable but also, perhaps,

preferable that a primary care physician undertake hormone management. Ultimately, transgender patients need clinicians whom they feel safe and comfortable seeing regularly for all of their health care needs. The majority of medical care related to transgender health can be administered by any physician willing to research best practices and create a care plan that centers on an individual patient's health care needs and priorities.

#### References

- 1. Bradford J, Reisner SL, Honnold JA, Xavier J. Experiences of transgender-related discrimination and implications for health: results from the Virginia Transgender Health Initiative Study. *Am J Public Health*. 2013;103(10):1820-1829.
- 2. Hughto JMW, Reisner SL, Pachankis JE. Transgender stigma and health: a critical review of stigma determinants, mechanisms, and interventions. *Soc Sci Med.* 2015;147:222-231.
- 3. Fenway Institute. NIH Fenway Institute public comment on the health research needs of LGBTI populations. http://thefenwayinstitute.org/wp-content/uploads/public-comment-to-NIH-on-LGBT-health-research-November-18-2013-w-o-signatures.pdf. Published November 18, 2013. Accessed July 18, 2016.
- 4. Coleman E, Bockting W, Botzer M, et al. Standards of care for the health of transsexual, transgender, and gender-nonconforming people, version 7. *Int J Transgend*. 2012;13(4):165-232.
- 5. Deutsch MB, ed; University of California, San Francisco Center of Excellence for Transgender Health. Guidelines for the primary and gender-affirming care of transgender and gender nonbinary people. 2nd ed. http://transhealth.ucsf.edu/pdf/Transgender-PGACG-6-17-16.pdf. Published June 17, 2016. Accessed August 3, 2016.
- 6. Deutsch; University of California, San Francisco Center of Excellence for Transgender Health, 125.
- 7. Sokol-Hessner L, Folcarelli PH, Sands KEF. Emotional harm from disrespect: the neglected preventable harm. *BMJ Qual Saf*. 2015;24(9):550.
- Grant JM, Mottet LA, Tanis J, Herman JL, Harrison J, Keisling M. National transgender discrimination survey report on health and health care. National LGBTQ Task Force; 2010. http://www.thetaskforce.org/static\_html/downloads/resources\_and\_tools/ntd

s\_report\_on\_health.pdf. Accessed August 3, 2016.

- 9. Reisner SL, Hughto JMW, Dunham EE, et al. Legal protections in public accommodations settings: a critical public health issue for transgender and gender-nonconforming people. *Milbank Q*. 2015;93(3):484-515.
- 10. Coleman, Bockting, Botzer, et al, 181.

- 11. Deutsch MB. Use of the informed consent model in the provision of cross-sex hormone therapy: a survey of the practices of selected clinics. *Int J Transgend*. 2012;13(3):140-146.
- 12. Howard Brown Health. HBHC's revised THInC protocol. http://howardbrown.org/programs-services/transgender-health/revised-thincprotocol/. Accessed August 30, 2016.
- 13. Deutsch; University of California, San Francisco Center of Excellence for Transgender Health, 25.
- 14. Poteat T, German D, Kerrigan D. Managing uncertainty: a grounded theory of stigma in transgender health care encounters. *Soc Sci Med.* 2013;84:22-29.
- 15. Shane SM. *Assessing Transgender Attitudes Toward Health Care: Can These Attitudes Help Predict Health Outcomes?* [dissertation]. Philadelphia: Philadelphia College of Osteopathic Medicine; 2014.
- 16. Meyerowitz JA. Fierce and demanding drive. In: Stryker S, Whittle S, eds. *The Transgender Studies Reader*. New York, NY: Routledge; 2006:362-386.
- Fisk N. Gender dysphoria syndrome (the how, what, and why of a disease). In: Gandy P, Laub DR, eds. *Proceedings of the Second Interdisciplinary Symposium on Gender Dysphoria Syndrome*. Stanford, CA: Stanford University Medical Center; 1973:7-14.
- 18. American Psychiatric Association. Gender dysphoria. *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed. Arlington, VA: American Psychiatric Publishing; 2013:451-459.
- 19. Payton N. The dangers of trans broken arm syndrome. *PinkNews*. July 9, 2015. http://www.pinknews.co.uk/2015/07/09/feature-the-dangers-of-transbroken-arm-syndrome/. Accessed July 18, 2016.
- Bailey B. Off to the ER: will I be treated with dignity? *Huffington Post*. February 26, 2015. http://www.huffingtonpost.com/beck-bailey/off-to-the-er-will-i-be-treated-with-dignity\_b\_6754924.html. Updated February 2, 2016. Accessed July 18, 2016.
- 21. Makadon HJ, Mayer KH, Potter J, Goldhammer H. *The Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health.* 2nd ed. Philadelphia, PA: American College of Physicians; 2015.
- 22. Callen-Lorde Community Health Center. Protocols for the provision of hormone therapy. http://callen-lorde.org/graphics/2016/06/Callen-Lorde-TGNC-Hormone-Therapy-Protocols.pdf. Accessed August 3, 2016.
- 23. Kerri A. The trans problem not enough people are talking about. *Advocate*. August 23, 2016. http://www.advocate.com/commentary/2016/8/23/trans-problem-not-enough-people-are-talking-about. Accessed August 29, 2016.
- 24. Khan L. Transgender health at the crossroads: legal norms, insurance markets, and the threat of healthcare reform. *Yale J Health Policy Law Ethics*. 2011;11(2):375-418.

- 25. Deutsch; University of California, San Francisco Center of Excellence for Transgender Health, 32.
- 26. Reisner SL, Bradford J, Hopwood R, et al. Comprehensive transgender healthcare: the gender affirming clinical and public health model of Fenway Health. *J Urban Health*. 2015;92(3):587.

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