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MEDICAL NARRATIVE

Lessons from a Transgender Patient for Health Care Professionals

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Abstract

It is not uncommon for transgender patients to avoid sharing information about their identity and medical history with health care professionals, due to past negative experiences within health care settings. Professionals who show sensitivity to the topic and express care about health record documentation can increase a transgender patient's trust. There are many opportunities to increase transgender health literacy, including consultation, conferences, webinars, books, and articles focused on transgender health care. It's critical for professionals to listen closely to individual patients' stated needs. This article shares one transgender patient's encounters and experiences within health care settings and offers lessons on how health care professionals can be more inclusive, respectful, and responsive to the needs of transgender patients.

Major Life Transitions

In the spring of 2005, I prepared for two major life transitions. The first was finishing graduate school and leaving academia to enter the workforce. The second was coming out as a transgender man—a person assigned female at birth but who identifies as male. My professional and personal lives quickly collided when I embarked on the critical medically assisted parts of my transition and found that many health care professionals were not trained to care for transgender patients. To compensate for clinicians' gaps in knowledge, I began to specialize in transgender health education.

Lessons Learned

After doing this work for over a decade, I share several important lessons about what I've learned as a patient and educator, with the goal of trying to cultivate health professionals' and students' understanding of how to be a helpful and responsive clinician for transgender patients.

Lesson 1: Understanding transgender health means understanding risks faced by transgender people. Coming out as transgender to health care professionals carries substantial risk for emotional and physical harms. A 2011 survey of

nearly 6,500 transgender respondents found that 19 percent of transgender patients were denied access or treatment due to their identity in a clinician's office, 28 percent were harassed or disrespected, 2 percent were physically assaulted in hospital settings, and 50 percent reported having to teach their clinicians about the care they needed [1]. The risk for suicide and substance abuse is also disproportionately high among transgender people [2], with 41 percent reporting having attempted suicide at least once in their lifetime [1]. Although these numbers are unrelated to coming out as transgender to clinicians, they could possibly be reduced by training health professions students and professionals about the health needs of transgender people and how their vulnerabilities can be exacerbated (including in health care settings) by social determinants, such as pervasive social and cultural discrimination.

Lesson 2: A health care professional's humility can be a source of relief to an anxious patient. The first health care professional I came out to was my therapist of six years. I began treatment with her because of an eating disorder, and over the years I had grown up and changed before her eyes. However, coming out to her as transgender made me anxious. I predicted she would invalidate my identity and link it to my eating disorder. I feared she would stop seeing me as a patient and refuse to write the letter I needed to begin hormone therapy and undergo chest surgery (removal of breasts). Although clinicians can conduct mental health assessments of patients before medically assisted transition therapies, many request a mental health assessment and referral letter from a mental health practitioner before moving forward with treatment in accordance with current practice guidelines [3]. Many people in the transgender community feel that this requirement puts mental health practitioners in the position of gatekeepers [4] to their physical transition, causing further distress.

When I came out, though, her response was one that any health care professional can learn from and use: "I have never worked with someone who is transgender, but I am willing to learn." I felt relief upon hearing her nonjudgmental tone and sensing her humility and openness. I knew then that she would not reject me or my identity. I could rely on her to listen, learn, and be a source of support.

Lesson 3: Transgender patients are not all alike and need different things from health care. Each transgender patient has a different story and different needs—including general health care that are unrelated to their transition status. In regards to medically assisted components of a transition, some transgender patients seek numerous interventions, others want only some interventions, and still others seek no medical assistance for their transitions [5]. Transgender

identities and needs exist on a spectrum, and attempting to classify, generalize, or routinize them is not always helpful.

After I overcame my fear of coming out to my therapist, I was ready to find health care professionals to help me pursue the medically assisted parts of my transition. This meant finding a surgeon who could complete chest surgery and a clinician who could prescribe and monitor hormone therapy. (For transgender men, the hormone prescribed is testosterone, regardless of their anatomy. For transgender women, the hormone prescribed is estrogen, and if testes are retained, anti-androgens.) Each person's transition journey and timeline will be different. I chose to have chest surgery first because I did not want my body to begin to masculinize on hormone therapy and still have breasts. I also had the financial resources through a loan to move forward with surgery, but for many patients, even those with health insurance, lack of sufficient insurance coverage, lack of specific coverage for gender-affirming care, or the high cost of such care can prevent them from accessing the care and therapies they need [6].

Lesson 4: There is not a single right way to transition and not a single way to order events that need to happen for patients making transitions. I found a chest surgeon through an online support group for transgender men. During my consultation, the surgeon sat down in front of me and asked, "Are you currently living as a man?" I responded, "No." He then said, "Are you currently on hormones?" I also responded, "No," while handing him the letter from my therapist. He glanced over it and said, "Okay, I just want you to know that once I remove your breasts, I cannot put them back on." In this situation, I did not present to the surgeon with the narrative he was expecting. My story differed from those he had heard from other trans male patients because I was not living as a man [7]. I was not on testosterone. I was pre-transition. For me, the chest surgery (an early step in my transition) and where I went from that point had yet to be determined. Each patient will have different reactions to the approach and language used by their clinicians. While some patients might have been offended by my surgeon's comment about taking my breasts off, I felt relief because I knew he was confirming me as a patient, even if I didn't strictly follow the clinical perception of a transition timeline at that time, namely, that patients must be living as the gender to which they would like to transition or that patients are pursuing hormonal therapy to promote their transition.

Lesson 5: Patients should not be required to conform to health care professionals' conceptions of what men and women are, have, or don't have. A week after my chest surgery, I was sitting in front of a family practitioner. My chest was bound in ace wrap bandages with drains pinned to my button-up shirt. I was seeing her for an initial consultation before beginning another important part of my transition for

which I needed medical assistance, hormone therapy. During our conversation she asked if I was going to have a phalloplasty, a surgery that uses skin grafts to create a full-size penis. I told her that I was not, since I didn't feel it was a necessary part of my transition or self-definition.

Two weeks later, I received a call from her office saying she was canceling my appointment to begin hormone therapy and that I needed to see her for a second consultation. As I sat in her office again, she told me she felt I had doubts about my transition. In her exact words: "I've never met a trans man who didn't want a penis." I spent an hour convincing her that she was committing what's referred to in the psychology literature as "the phallus fallacy" [8]—one product of gender binary thinking—that is, acceptance of the oversimplification that everyone is either and only male or female, which prompts some to believe that men are men because they have penises. That is, I had to convince her that, despite her belief in the clinical significance of my lack of penis envy, I was ready to move forward with hormone therapy without a penis. Finally, a week later, I received my first testosterone injection, but I no longer trusted her to meet my health care needs. Subsequently, I sought care elsewhere, somewhere I didn't have to work so hard to get what I needed.

Lesson 6: When personal pronoun usage mistakes happen (and they will), apologize sincerely, and move on. When working with transgender patients, it is only a matter of time before a wrong name or pronoun slips out. Mistakes happen; we are human. What divides a forgivable error from offensive disregard is how the mistake is handled. A colleague of mine offered an example of how to handle "misgendering," or what could be perceived as misgendering. During a busy day at his clinic, he was seeing a transgender woman who had recently undergone a vaginoplasty procedure (the creation of a vaginal canal using inverted penile tissue or a colon graft). She had scheduled the appointment to have him examine her stitches and check for signs of infection. Running late, he popped his head into the exam room where she was waiting with a friend, and said, "Hey guys, I apologize for running behind. I'll be in shortly." As he closed the door, a moment of panic rushed over him; he realized he had just used the term "guys" with two transgender women. Instead of ignoring it or silently hoping they wouldn't be offended he opened the door again and said, "Sorry … ladies, I'll be in shortly." Both of the women laughed and showed their appreciation that he had noticed and revised his message.

Lesson 7: Challenge uses of demeaning references ("he/she," "it," or other slang) to transgender patients. Over the years, I've found there are many people in health care who do not understand or support transgender identities. For these reasons, transgender people are often gossiped about in health care settings.

This gossip can include asking inappropriate questions about a transgender patient's identity, joking or commenting about a patient's body or appearance, and using slang or the wrong pronoun or name when referring to a patient.

It is critical that health care professionals demonstrate leadership on this issue by expressing respect for transgender patients' vulnerabilities and standing up for patients when this kind of unprofessional and aggressive behavior is taking place in care settings [9]. By informing perpetrators of inappropriate and offensive speech, and by making clear that their actions are insensitive and sources of potential harm to patients, health care professionals can help establish safer and more nurturing environments for all patients [10], including transgender patients.

Lesson 8: Being transgender might not be relevant to a particular clinical encounter, but references to a patient's gender identity in a health record can be relevant to all subsequent clinical encounters that patient has. Ten years after I started my transition I scheduled an appointment with a spinal specialist. I did not mark that I was transgender on the patient intake form, but I did indicate that I had undergone a mastectomy and hysterectomy. As the physician assistant went through my intake form, he confusedly asked, "Oh, you've had a mastectomy and hysterectomy?" I responded by saying, "Yes, I am trans." He replied, "Oh … well … bless your heart."

I felt uncomfortable and unsure how to interpret this "blessing." We continued the exam, and nothing else about my being transgender was mentioned. After receiving the medical report that I had requested, however, my discomfort with this office turned into rage. Throughout the report I was referred to not as "Ryan," "he," or "male," but instead as a "pleasant 35-year-old transgender individual." To make matters worse, there were multiple places in the report where I was referred to as "she." I don't know whether this episode of misgendering documentation was intentional, but it certainly had, and can still have, consequences for me.

Lesson 9: Take care not to "out" patients who aren't "out" to everyone: ask patients about which information to document in their health records and preserve confidentiality. The health record documentation episode was and is important, not only because it was and is an instance of misgendering, but because the content of this encounter in my health record was then sent to my referring health care professionals and thus can be accessed by other health care professionals. That part of my health record effectively "outs" me as transgender, including to health care professionals with whom I might not have chosen to share that information about myself.

It is not uncommon for transgender patients to avoid sharing information about their identity and medical history with health care professionals because of past negative experiences within health care settings. Professionals who show sensitivity to transgender patients' risks and needs and demonstrate awareness about what is appropriate to document in a health record can increase a patient's trust. When patients trust you as a health care professional enough to come out as transgender, express respect for their trust. Showing respect includes discussing what should and should not be placed in health records, particularly correspondence to other clinicians or third-party payers.

Lesson 10: Transgender health literacy requires ongoing education and training. Like any area of medicine, in transgender health, standards of care [3] and best practice guidelines are continually being updated. As a professional who works with transgender patients, I find it is important to stay up-to-date on current research and literature pertaining to transgender identities. With new research, policies, and guidelines, past recommendations can get outdated and become unnecessary. For example, when I began training in transgender health care, it was recommended that transgender men undergo a hysterectomy within two to five years after beginning hormone therapy to avoid increased cancer risk [11]. More recent research, however, reveals that hormone therapy does not increase cancer risk or mortality [12], so it's no longer recommended that patients on hormone therapy undergo a hysterectomy unless medically necessary [3].

There are many opportunities to increase transgender health literacy among clinicians, including consultation [13], conferences [14], webinars [15], books, and articles focused on transgender health care. It's also critical for health care professionals to listen closely to individual patients' stated needs and to further support growth of knowledge about and experience in working with transgender patients.

Conclusion

These lessons have hopefully offered insight into unique issues that transgender patients confront when seeking health care services. Clinicians who practice cultural humility by listening to patients' needs and addressing their personal limitations through respectful conversations create safer environments that will hopefully deepen patients' trust and lead to better care.

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