Put Your Money Where Your Mouth Is: An analysis of medical school websites v. trans patient experiences

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Acknowledgments

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Literature Review & Background

- Most of the related research regards gaps in trans healthcare and various attempts at closing them
  - Provider knowledge gaps are a big problem because med schools do not necessarily weave considerations of trans people into the general curriculum where it would be relevant (Hana et al. 2021).
  - A 2020 review of ten trans-specific medical education programs reported that they were mostly elective, very short, or both, allowing medical students to disengage from the needs of the trans community at their discretion (Nolan et al. 2020).
  - It’s always, “How can we fit this in efficiently and quickly to cover our asses?” and not, “How can we weave queerness into the fabric of our curriculum?”

- Due to socioeconomic, academic, and bureaucratic barriers, there is a notable lack of doctors who are trans and/or nonbinary themselves.
  - Only 0.7% of matriculating medical students identify as transgender and/or nonbinary, even though 1-10% of Americans identify as transgender and/or nonbinary depending on the age group surveyed (Das 2020).
● A good body of scientific research discusses trans biology in common medical issues
  ○ Ophthalmology (Hollar et al. 2016), bone density (Walcott et al. 2022), reference ranges (Irwig 2021), reproduction (this one can be a bit problematic) (Moravek et al. 2020), cardiovascular risk (Shawsky et al. 2023) just to name a few

● Not much anthropological/sociological research names non-binary biology or trans people’s divergence from cissexist hegemonic medical norms and practices as a reason for these gaps in medical care
  ○ There is a lot of discussion about trans divergence from hegemonic gender norms in general
  ○ Elkins and King talk about sociology of trans bodies as not just transferring from one gender to the other but transcending gender altogether (1999)
I will argue that the counter hegemonic, non-binary aspects of trans healthcare are what is largely incomprehensible in the current medical culture.

- Medicine is a cultural system which currently relies on rigid ideas of binary, gendered bodies and their needs which influence how people perceive themselves, their bodies, and others (Martin 1987).

- Medical institutions need to account for the relationship between imposition and embodiment for trans bodies (applying same idea as “thickness of Black/racialized bodies” from Fassin (2021)).

  - Gender and biological expectations are ascribed onto bodies as a result of rigid and pathologizing systems which are simultaneously context-dependent, similarly to race.

  - Notably, trans people function differently inside versus outside medical contexts. Medical institutions often require and assume a binary gender onto their patients (similar to Fassin’s discussions of imposing racialization) which may affect how trans people construct themselves as patients, how they present themselves online, and what medical institutions learn (or do not learn) from interactions with trans patients, all of which are relevant questions for this project.
Methodology

- Looked at institutional websites, Reddit, and X (formerly Twitter)
- Systematic review of each institution’s website
  - Searched “transgender” and looked at all results (or as many results as humanly possible)
- Reddit
  - Searched “transgender” and “[name of institution]”
- Twitter
  - Searched “transgender” and “[name of institution]”
  - Search “trans” and “[name of institution]”
Why Reddit and X (formerly Twitter)?

Anecdotally, that is where trans people tend to talk about these things!

In my life I have seen the most discussion of trans healthcare (people seeking recommendations, reassurance, leaving reviews, sharing results, etc) on these two platforms. It made sense to look where I know people are naturally gravitating for these types of resources, as other platforms do not house the same types or formats of discourse.
Why study medical schools?

Medical schools, especially prestigious ones like NYU, JH, and Perelman, are places where medical knowledge is defined and reproduced. As institutions they set the standards for training, treatment, research, and more, meaning that they have a huge hand in the production of power knowledge (Foucault 1980).

The choice medical schools make necessitate a nuanced discourse analysis because they have tangible impacts on the availability, accessibility, and quality of healthcare for trans people.
Why study medical school websites?

As institutions of power-knowledge, medical schools set an example and have influence on common expectations, both for patients and in the medical world. Increasingly, websites are the most common way to share information, communicate standards, and overall represent the face of the institution.

Institutions should expect to be judged based on their websites, as they are the first place someone will look to learn about what an institution does and what it stands for. Therefore, and especially for the purpose of this project, it makes sense to take these institutional websites at face value and to think critically into how and why the institution chooses to present itself how it does.
Layers of trans healthcare

1. Gender affirming care / medical transition
2. Bedside manner, cultural competence, patient experience
3. General/day to day health, preventative care

Public-facing visibility of each of these layers (in news, media, politics), as well as medical provider competency in general, seem to be highly dependent on their compatibility with the gender binary and outdated ways of understanding gendered bodies.
Nuance in the layers of trans healthcare

- Notably, HRT should not fit neatly into this typology as it requires ongoing care and is often used by trans people to achieve some form of gender transcendence (Elkins and King 1999).
  - However, this transcendence is often invisible. The medical effects of HRT over time are often assumed to be binary and seen as transferring a person from one gender to the other.
  - This imposed understanding (though accurate for some) fits into binary hegemonic understandings of gender affirming care and is part of the flattening of gender affirming care into the visible and invisible.

- Conceptions of trans identity and medical care are also being heavily influenced by recent political attacks on gender affirming care
  - HRT and surgery are the subjects of most political scrutiny, reinforcing them as the most visible formats for gender transition. Political attention likely influences the attention they receive in the medical world.

- Trans people often rely on medical institutions to help produce bodies that the medical institutions and providers themselves cannot entirely comprehend.
  - This complicates patient-provider relationships, patient-institution relationships, and the role of the promise of an authentic self predicated on procedures which is often advertised by medical institutions.
Findings by Institution

- NYU Langone / NYU Grossman School of Medicine (NY)
  - 127 results for “transgender”
- Johns Hopkins / Johns Hopkins University School of Medicine (MD)
  - 120 results for “transgender” (approx.)
- Penn Medicine / Perelman School of Medicine (PA)
  - 38+ results
    - 23 results for “transgender” within “All Faculty Members”
    - 1 result for “transgender patient”
    - 14 results for “transgender health”
These images are intended to provoke positive feelings and trust towards these healthcare providers, which is a way of marketing and branding care at NYU. This goes beyond offering care and into the realm creating desires around it, where one’s body is the product and the desirability of the medical team is related to the fantasy of gender affirming care.
The same is true with discourse around support staff. Trans experiences are used to market further care to other trans people.
What metrics are being used to appraise the quality of this care?

In what ways does the institution benefit (socially, financially, etc) from reporting this on their website? In what ways do trans patients benefit? Are there any risks for either party?
Perceptions and experiences shared on social media

Many reddit posts were by trans people looking for reliable primary care and/or endocrinology.

I found very few reporting trans-friendly PCPs, but this was one account which gives a great review of an NYU doctor. The post describes a strong network between providers which might mean a more cohesive care team.
● Dr. BBL and Dr. Zhao are two of the most highly advertised gender affirming surgeons on NYU’s website
● The care their team provides varies in quality
  ○ “All in all, the consultation was VERY in depth, I had no questions after, and they made me feel so welcome and safe. I’m already thrilled with the care they’ve shown me” (awriwri, reddit, pre-op)
  ○ “I cannot say enough good things about everyone in the hospital. The nursing staff was amazing all my nurses were absolutely fantastic.” (moiraineciritriss, reddit, post op)
  ○ Great experience with these doctors but very bad experience with a dilation coach who is well versed in trans healthcare needs (Dungeons-n-Dysphoria, reddit, post op)
  ○ Two patients had a bad experience of being misgendered, having their pain management needs dismissed, and poor treatment of post-op complications (NYU_PostOp_Throwaway, reddit, post op)
● Seeing this discourse dominate social media may exemplify the influence of Layer 1-centered discourse (centering HRT and surgery) on extra-institutional discourse among trans people
● Dr. Rodriguez
  ○ Many people seeking FFS result images which his office does not provide

● Dr. Dundas in youth endocrinology (NYU Langone trans youth health program)
  ○ “I thought that everyone was kind, Dr. Dundas was very informative, and did a good job communicating with our daughter” (hapachickka, reddit, parent of trans kid)
    ■ The same parent had trouble finding reviews about NYU before the appt
  ○ Someone replied in the thread that as an NYU employee, NYU didn’t take their insurance
● A lot of attention is given to specific renowned gender affirming surgeons, as well as medical transition in general (HRT and surgery)
  ○ Surgeons and surgery support staff further reinforce binary expectations
  ○ Trans healthcare is commodified

● Acknowledges trans people in the medical field
  ○ Robust gender transition guidelines for trans medical students and staff with many protections
  ○ Diversity scholarship application has good gender options but come off as surface-level
  ○ OUT list where LGBT+ medical providers who are “out” list their information to find community

● The need for better LGBT+ competency is named in articles on the website
  ○ Trans USPs, electives, research tracks with LGBT considerations available
  ○ This need is also named by trans people online (outdated categorizations and negative patient experiences)

● Questions and comments by trans people on social media pay more attention to trans-friendly primary care than NYU’s website does
  ○ People are concerned about the quality of care
Johns Hopkins
Looking for a health care provider is never easy, but for lesbian, gay, bisexual, transgender and queer/questioning (LGBTQ) individuals, the search is especially challenging. Faced with inadequate — and sometimes hostile — care, many LGBTQ patients are understandably reluctant to share their sexual orientation and gender identity. Paula M. Neira, Program Director of LGBTQ+ Equity and Education, Johns Hopkins Medicine Office of Diversity, Inclusion and Health Equity, lawyer and former naval officer, explains the importance of coming out and offers advice for finding the right doctor.

**How can I find an LGBTQ-friendly provider?**

**Do transgender people have special health care needs?**

Appropriate medical care can vary widely for people who are actively transitioning. The standard of care has several components — hormone therapy, psychological therapy and surgery — and some combination of that will apply. After transition, transgender patients will have some health needs that are legacies of their gender at birth. For example, even though I had gender-confirming surgery, I may still need to have my PSA (prostate-specific antigen) levels checked as I age.

**What advice do you have for staff members who work with transgender patients?**

If you don’t know what name or pronoun to use, ask. Say: “I’d like to interact with you respectfully. What pronoun would you like me to use? What name would you like me to use?” Then use the ones they give you. Secondly, meet your patient where he or she is. Some transgender people will be questioning their gender identity and will not have begun transitioning. Some will be actively in transition. Then there are people like me, who transitioned 20 years ago. Now it’s a part of my medical history.
Why is it so important to be out?

In short, because your health depends on it.

Although members of the LGBTQ community have many health needs in common with everyone else — LGBTQ people catch colds, get injured and share health risks with others of their gender, race and ethnicity — there are some unique care concerns that are important to discuss with a doctor. If you are not open with your provider, he or she may make presumptions about you and your health care. For LGBTQ patients, that can mean missed screenings for potentially life-threatening conditions, such as ovarian and prostate cancer.

Transgender individuals, in particular, can benefit from coming out to their doctors. Medical support, including hormones, therapy and gender-affirming surgery, are options to help you be your authentic self.

Learn more about LGBTQ-specific health concerns:

- Lesbian and bisexual women
- Gay and bisexual men
- Transgender persons

Better Care

An estimated seven out of 10 LGBTQ patients have experienced negative care. Because of this, they often avoid health care settings, which leads to fewer doctor’s visits and poorer health outcomes. Coming out may help these patients connect with a competent provider who can eliminate some of that concern, allowing them to seek routine care without the fear of violence or harassment.

Greater Visibility

For far too long, lesbian, gay, bisexual and transgender individuals have been invisible in health care. This is especially true for transgender patients, whose medical needs are often ignored or denied. Revealing your true identity to your doctor is liberating. By speaking up, you have the ability to empower yourself and other LGBTQ patients who follow your example.

What’s being done to improve care for LGBTQ patients?

While the industry as a whole has a long way to go, health care systems across the country are finally recognizing their responsibility to provide quality care to all — regardless of sexual orientation or gender identity.

One project, the EQUALITY study, is looking to change how health care providers in emergency rooms gather information about sexual orientation and gender identity. With better data, health care professionals can more easily identify the unmet needs of LGBTQ patients and generate more effective solutions.

Other initiatives are giving medical students the knowledge they need to provide appropriate care. An updated medical curriculum from the Johns Hopkins University School of Medicine enables trainees to connect with — and care for — the diverse patient populations they’ll serve.
Most mentions of trans healthcare were regarding gender affirming services
  ○ Other trans-specific mentions were for fertility preservation and family planning
  ○ Maintains binary approach to trans health overall, primary trans health not mentioned much outside of endocrinology

Trans-specific educational opportunities for doctors were mostly optional and/or short term
  ○ HRT guides available by search, transgender medicine elective available, clinical trials and research studies available, complex gender microsurgery fellowship available JH offers a lot of great resources

The role of the trans doctor
  ○ An expert? A token? Are her words her own?
  ○ Power knowledge, trans voices, and institutional/capitalist influences

Mixed messaging about provider and institutional competency
  ○ Acknowledgement that different trans people will have different needs, experiences, and goals for their transitions
  ○ One article noted that a lot of doctors do not feel competent in trans healthcare
  ○ Language shifts from cis- to trans- centered inconsistently
Transgender Health News Articles at Johns Hopkins

- All Gender Bathroom Map for Johns Hopkins
- (Re) Creation Story (2021)
- The Joy of Being Yourself (2018)
- Helping Transgender Children and Youth (2018)
- A Bright New Start for Transgender Health (2018)
- Showing up for Transgender, Intersex and Non-Binary People (2018)
- Safe, Comprehensive Transgender Health Care (2018)
- Fundamentals for Caring for Transgender Patients (2018)
- To Treat Transgender People, Open Your Hearts and Minds (2016)
- Transgender Patient Care: Meeting the Patient Where They Are (2016)
- Caring for Transgender Patients (2015)
- Embracing the Rainbow (2015)
- Toward Greater Equality for LGBTQ Patients (2015)

From Johns Hopkins Health

- Transgender Health: What You Need to Know
- Tips for Parents of LGBTQ Youth
- Gender Affirmation: Do I Need Surgery?
- Gender Affirmation Surgeries

- Gender Affirmation Nonsurgical Services
- Preparing for Gender Affirmation Surgery: Ask the Experts
- For LGBTQ Patients, the Coronavirus Brings New Challenges
- Facial Feminization Surgery (FFS)

- Metoidioplasty for Gender Affirming Care
- Top Surgery (Chest Feminization or Chest Masculinization)
- Phalloplasty for Gender Affirmation
- Vaginoplasty for Gender Affirmation

- Transgender and Gender-Diverse Voice Care
(CNSNews.com) -- Dr. Paul R. McHugh, the former psychiatrist-in-chief for Johns Hopkins Hospital and its current Distinguished Service Professor of Psychiatry, said that transgenderism is a "mental disorder" that merits treatment, that sex change is "biologically impossible," and that people who promote sexual reassignment surgery are collaborating with and promoting a mental disorder.
The Paul McHugh problem

Dr. Paul McHugh is a well known anti-trans psychiatrist, currently serving as University Distinguished Service Professor of Psychiatry and Professor of Psychiatry and Behavioral Sciences. Almost all posts including “Johns Hopkins” and “transgender” were about this...
One patient had an experience of going to a doctor for vocal therapy, and ended up having an nonconsensual laryngoscopy. She had not communicated any desire for surgical intervention, it was assumed onto her by the provider.

- 3 years later, Dr. Simon Best is still employed at Johns Hopkins
- This can be interpreted as an alarming example of what happens when medical providers assume their patient’s medical desires based on externally-imposed binary gender norms

How/does public institutional paradox impact patient experiences?
- Issues earning patient trust regarding medical hesitancy
- Paul McHugh
- Resource allocation and disproportionate representation of issues (family vs provider resources)

Social media was mostly negative
- How might this impact patient experience, hesitancy, and trust?
Penn
A note about methodology

Perelman’s website has a general search as well as a stratified faculty search for only faculty publications.

Unclear why Perelman has so many more results in the general search than NYU and JH, possibly an algorithmic difference.

Other schools did not separate their results this way which meant I did not see if they had trans-specific faculty research the same way.

I was not able to look at 36,000+ results.
Looking at the results for faculty research specifically showed that some Penn Faculty are researching issues that do address trans biology in a variety of areas related to primary and general healthcare:

- areas like dentistry, cancer research, medical hesitancy, epilepsy management, long-term impacts of HRT, organ donation, telehealth, health of LGBT elders, and more
Perceptions and experiences shared on social media

● Three specific Penn doctors were praised for providing trans competent primary care (PCP, internal medicine, and gender affirming care provider respectively)
  ○ This cannot be extrapolated to all providers but may be a good sign

● Penn was visible in advertising its new trans patient advocacy program, seeking local trans advocates, and other trans-focused initiatives serving different groups (such as trans elders)
  ○ Can help make the resource more widely available to the community it is intended to reach, but can also gain more positive attention than it’s worth
Multiple people recommended Penn Medicine as a trans competent provider

- People seemed excited to share positive feedback which is a good sign
  - A trans health educator talking about being excited to go teach med students about trans health!
  - People had positive experiences with Penn insurance

- I did not see anything bad about Penn in my social media search
● Because I looked at less resources on the website, I didn’t have as clear of an idea of what to expect on social media
  ○ Did not get as clear of a sense of the care provided
  ○ My findings were more about what faculty focus on
● Social media accounts reflect positive patient experiences
  ○ This may indicate a growing understanding of non-binary biology and trans-specific medical care as a possible result of trans-specific research being done by Penn and Perelman faculty
● It’s important to consider what people decide is worth sharing on social media
  ○ People may feel more inclined to share negative experiences for safety purposes while keeping their joy private, or vice versa.
  ○ The positive accounts mean a lot to me as a trans researcher, and it’s lovely trans people sharing joy in their lives
  ○ Trans people may be co-constituting online norms of medical discourse that align with the norms being set by medical institutions
## Three-way comparison

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<thead>
<tr>
<th></th>
<th>NYU</th>
<th>Johns Hopkins</th>
<th>Penn</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NYU</strong></td>
<td>Focus on provider competency training which is primarily short-term or elective</td>
<td>Emphasis on patient responsibility</td>
<td>Some trans-centered research in general health fields</td>
<td>Proclaim that trans healthcare is important to them</td>
</tr>
<tr>
<td></td>
<td>Specific doctors heavily advertised</td>
<td>Resources for trans people focus heavily on surgery</td>
<td>Engaged social media presence</td>
<td>Offer various resources, FAQs, and articles</td>
</tr>
<tr>
<td></td>
<td>More mentions of status, titles, and awards</td>
<td>Resources for non-trans people offer a relatively holistic view (ironic)</td>
<td>Far more mentions of “transgender,” mostly in blog archives and from “Lesbian, Gay, Bisexual and Transgender (LGBT) Health Program”</td>
<td>Emphasize surgery, transition, and cultural competency trainings</td>
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<td>OUT lists</td>
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Discussion & Conclusions

- Gender affirming surgery quality is generally high, though not as high as advertised
  - Important because how the issue is presented on institutional websites is part of how they reproduce knowledge and define experiences for trans people and the general public

- Results showed the division of trans healthcare into the three layers
  - Trans healthcare was largely discussed as HRT and surgery. Surgeons are marketed most
  - General healthcare was discussed the least out of the three layers as expected

- Cultural competency (such as using the correct name and pronouns and understanding medical hesitancy) was addressed by all three schools and had resources available
  - Social and family support resources were more common than expected
  - Most interventions are still optional and one-time-only

- Often it was trans people saying the things I was refreshed to hear, namely discussing non-binary health needs
• Hospitals and medical schools heavily advertise their gender affirming services with a commodified lens
  ○ Based partially in recognition of trans healthcare as essential
• Hegemonic norms seem to be influencing discourse even for trans people, whose lives exist beyond those norms
  ○ Trans people know that their healthcare needs exist beyond just gender affirming care, yet most other needs were still not widely discussed even among trans people online. Why are trans people talking about surgery online but not other health needs?
  ○ Disproportionate attention on just one aspect of trans healthcare influences everyone, norms can become hegemonic for trans people themselves
• Language
  ○ Trans-specific language about “dysphoria” and “affirmation” were present, though none of the schools had any results for “gender euphoria”
  ○ Focus on joy as a product of surgery rather than as a lived experience with multiple origin points
  ○ Language used (or not used) may impact patient experiences and medical hesitancy
Limitations & Future Directions

● Did not find much on Twitter in general
  ○ Refine search

● Look deeper into Reddit and try more searches to get a deeper sense of trans experiences at these institutions
  ○ Learn more about trans people’s interactions with medical school/hospital websites specifically

● Look into NYU and JH faculty publications regarding trans healthcare
  ○ NYU and JH are not making their research visible the way Penn is which is part of how they present themselves. They may be publishing research on trans health similarly and just placing it differently online.

● I only looked at schools/hospitals on the East Coast (NY, MD, PA) which does not account for differences in how trans health might be treated in other parts of the country

● Different factors may lead some people to post negative or positive experiences while others wouldn’t, what I found isn’t necessarily a balanced representation of patient experiences
Bibliography


