

BODIES AND BARRIERS

QUEER ACTIVISTS
ON HEALTH



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A DISCUSSION GUIDE

THEMES

- Health equity
- Patient-centered care
- Disparities in health for LGBTQ+ people
- Social and political determinants of health

IMPORTANT DEFINITIONS

When teaching or facilitating discussions about *Bodies and Barriers*, it is recommended to reinforce the following definitions, which were provided in the book. Consider asking participants to identify practical examples to unpack these definitions.

- **Health equity**, as defined by Healthy People 2020, is the attainment of the highest quality of health for all people (5)
- **Wellness**, defined by a 14 year old youth program participant at Whitman Walker Health, is about surviving in a world that wasn't made for you (3)
- **Stigma**, defined by HIV activist Sean Strub, is about other people making moral decisions about your worth (2)

CRITICAL ANALYSIS DISCUSSION PROMPTS BY CHAPTER

Foreword by Admiral Rachel L. Levine, MD (she/her)

Admiral Levine begins the book by writing “As a physician, I’ve seen the health consequences of neglecting a patient’s needs; as a policy maker, I’ve seen the cost of creating policies that are uninformed; and as a transgender woman, I’ve felt the burden of other’s ignorance” (xi). Discuss how each perspective--that of physician, policymaker, and healthcare consumer--is necessary to increasing access to care for historically excluded populations. Brainstorm how physicians and policymakers might effectively solicit and utilize constructive insights from LGBTQ+ healthcare consumers.

Note: Since the book’s publication, Admiral Levine has been appointed and confirmed by the U.S. Senate as Assistant Secretary for Health at HHS and has been named a four-star admiral in the U.S. Public Health Service Corps.

Introduction by Adrian Shanker (he/him)

After sharing his own negative past health care experience with a dermatologist, Shanker writes “We are demanding that our health care systems respond to our lived experiences with culturally appropriate care at all stages of our lives” (4). *Bodies and Barriers* is framed as an anthology of healthcare consumer experiences. Shanker’s demand at the start of the book explains that professionalized and clinical medical knowledge is not enough; culturally-appropriate care, informed by healthcare consumers, is needed throughout the lifespan. What can healthcare professionals learn from such storytelling, and how can these lessons lead to structural shifts in how healthcare is delivered to LGBTQ+ communities as well as other historically excluded communities? How can healthcare policy and practice change when it is guided by patient needs?

Chapter 1: “Human Rights and Health for LGBT Youth” by Ryan Thoreson (he/him)

Thoreson draws on UN conventions for human rights to make the case that LGBTQ+ youth experience human rights violations within the U.S. healthcare system. In one example, Thoreson writes, “Susanna K., the mother of a transgender boy in Utah, told me that her son began suffering from bladder infections in junior high, and that she eventually discovered that it was because he did not feel safe in male or female bathrooms at school. When she enrolled him at a charter school that respected his gender identity, the bladder infections stopped. When transgender students are required to use bathrooms and other facilities according to their sex assigned at birth, they are highly vulnerable to harassment and assault. Many transgender students thus avoid using these facilities at all. Students have described how they limit fluid intake or wait until the school day ends to relieve themselves, which can lead to dehydration, bladder infections, urinary tract infections, and other health complications” (14-15). Human rights frameworks are not often incorporated into conversations about health equity in the United States. Discuss how

Thoreson's use of human rights frameworks to address health challenges for LGBTQ+ youth impacts your understanding of the need for policy change in schools.

Chapter 2: "Informed Consent for Intersex Youth" by Katharine B. Dalke (she/her)

Dr. Dalke starts and ends her chapter by referring to a protest in front of a children's hospital in 2018. She writes, "During that protest last summer, I declined the megaphone, preferring instead to listen and learn from people I love and people I didn't yet know. Had I spoken, I would have shouted a message to a younger me and the younger selves of my parents and doctors: 'This body is beautiful, and this person is stronger and smarter than you assume. Teach me about my body, and I'll teach you about myself. We can figure this out together'" (27). Dr. Dalke is making the case that doctors have to unlearn what they *think* they know about intersex children, and allow intersex people to make decisions about their own bodies. Discuss how the informed consent framework (that patients have enough information to make the best medical decision for their body and their life) impacts your understanding of the health needs of intersex youth.

Chapter 3: "Navigating Pediatric Care for Transgender Youth" by Alisa Bowman (she/her)

Bowman writes about the decision to switch pediatricians for her trans son, writing, "During several doctor's visits, I'd even mentioned telling signs — how my child refused to go to the bathroom at school, for example. There had been plenty of openings. Yet our pediatrician never once asked us questions about our son's gender nor suggested that our child might be trans. It was akin to treating a child with high blood sugar and never once saying anything to the child's parents about type 1 diabetes" (29-30). Her son's care improved after switching away from this pediatrician. Identify and discuss the strategies that Bowman shares that the second clinic utilized. How would these practices of holistic, patient-centered care, if made to be ubiquitous, would change the landscape of care for the trans patient population. Also, discuss how she, as an informed advocate for her son, was able to impact his immediate and long term health outcomes.

Chapter 4: "Not Your Average Sex Talk" by Emmett Patterson (he/him)

Patterson writes, "The first time I was asked if I had thought about becoming pregnant in the future was right after my primary care provider placed my first hormone shot into my hands. My providers seemed to not be bothered to think about or, perhaps, couldn't imagine a trans person being sexual, which prevented them from assessing what some of my sexual health concerns might be. So I stayed silent and researched on my own, struggling to find myself in news stories about teen pregnancy and deciphering if HPV vaccine guidelines applied to trans men" (35). What harm comes from failing to provide patients with the appropriate and relevant reproductive and sexual health care information and resources. How can healthcare providers and parents act to ensure that youth receive comprehensive care in this regard? What role should educators and policymakers play in making inclusive sexual education accessible to young people of all sexual orientations and gender identities?

Chapter 5: "Resiliency for Homeless Queer Youth" by Arin Jayes (he/they)

Describing their project in partnership with Casa Ruby, Jayes writes, "The goal was to empower homeless LGBT youth to be leaders in their community and their own self advocates. Through sharing their life experiences, they could build resilience in the face of oppression and ultimately affect local and national public policy" (44). Why is cultivating resilience important for LGBTQ+ youth? Discuss examples of building resilience in the chapter and in your own experience. What outcomes could building resilience yield? Consider what a healthcare system would look like that does not require people to become resilient, but automatically meets their needs and allows for a holistic healthcare experience. Discuss the benefits of resiliency as well as the trauma that causes people to become resilient.

Chapter 6: "Beyond Duct Tape: Binding for Transmasculine Youth" by Preston Heldibridle (he/him)

Heldibridle writes, "When I finally was able to buy a binder, it was wonderful. As I wore it, I noticed an almost jarring absence of anxiety I had not previously realized I was carrying. Wearing my binder did not make my chest flat, but it did make it much less noticeable, as it is supposed to. I felt so much better as I went about my days and was able to be more present and focused in school and at home, without the constant stress of dysphoria" (page 50). Discuss how healthcare professionals can better address misinformation about the health and safety of practices that assist youth in aligning their body with their gender

identity. Discuss how practitioner bias, or lack of education around transgender care, can directly impact the health outcomes for rural transgender and non-binary individuals.

Chapter 7: “Surviving Suicide” by Tyler Titus (they/them)

Titus writes, “When a child perceives and receives their surroundings as untrustworthy, they will strengthen their ability to protect themselves from it. The end result varies from anxiety and depression to anti-social behavior and aggression. For me, the experiences took shape in self-deprecation, depression, and emotional dysregulation that sabotaged several of my relationships with friends, family, and partners later in life” (page 58). What can we do to facilitate the needed or necessary connections to Queer and allied adults? How can those adults proactively work to create spaces where LGBTQ+ youth can truly be themselves? What does the comparison between prevention and intervention tell us about how we should respond to the needs of children who may identify as LGBTQ+?

Chapter 8: “Sex and Safety in the Digital Age” by Jack Harrison-Quintana (he/him)

Harrison-Quintana writes, “Technology does not exist outside of our lived experiences, it supplements it” (70). Discuss the ways that sexual health and safety has changed due to current technology, and how healthcare professionals and public health practitioners can utilize current technology to improve access to care.

Chapter 9: “Living Proudly, Living Longer: Advocating for Queer Spaces to be Tobacco-Free” by Adrian Shanker (he/him) and Annemarie Shankweiler (she/her)

Shanker and Shankweiler write, “We go to gay bars to find community, to feel safe and supported, to be around *our* people. It’s the same reason we go to LGBTQ+ pride celebrations or LGBTQ+ community centers. We want to be in places where we can be free to truly be ourselves. So what does it mean when to be in these spaces we must inhale secondhand smoke for the entire evening?” (73). The effects of secondhand smoke are well-documented. Even for non-smokers in states where smoking is legal in bars and clubs, LGBTQ+ people are more likely to receive over-exposure to secondhand smoke. Discuss the role of advocacy to prioritize smoke-free spaces for LGBTQ+ people. What role can healthcare professionals and public health practitioners play in supporting or leading advocacy efforts to make LGBTQ+-spaces smoke-free.

Chapter 10: “Queer Family Planning: A Remedy for Depression” by Kate Luxion (they/them)

“Whether blended, biological, adopted, chosen, or any variation thereof, a family is made in many ways and should be supported and respected legally, medically, and socially. And when we do so, we will ease the depression plaguing LGBTQ+ young adults.” (84). Luxion lays out many examples of practices that help queer families feel included in family planning like on page 81 they write, “To facilitate inclusion, gendered medical language should be reconsidered.” Discuss ways Luxion suggests for replacing gendered language in family planning and the benefits this could have for queer and trans families. How does talking about family planning to young queer people have an impact on mental health and depression? Discuss the practical and administrative ways we can address a non-traditional, queer inclusive, family structure.

Chapter 11: “Social Service Navigation for the LGBT Community” by Anthony Crisci (he/him)

In the chapter, Crisci explains how a call he received from a community member in crisis ignited his work to create better systems to help LGBTQ+ people navigate social services. Crisci writes, “From my experience providing social service navigation, the hardest thing was letting a client know that there weren’t services available for them. Whether a client was homeless, had no supportive family, or was dealing with substance abuse disorder, I knew their experience accessing social services would be much harder than a non-LGBT person” (89). Discuss what additional struggles LGBTQ+ people might face accessing social and health-related services and how healthcare professionals and public health practitioners can assist LGBTQ+ people find the support they need. Discuss what a centralized resource center could look like, and the larger implications of a fractured service system has on marginalized people.

Chapter 12: “That Ass Tho! Anal Health for the LGBT Community” by Adrian Shanker (he/him)

In this chapter, primary care clinician Dr. Beth Careyva is quoted as saying, “Many primary care clinicians have never provided an anal Pap test and may be unsure how to order it. Clinicians tend to feel more comfortable when there are clear guidelines and standards of care. In general, there’s a significant knowledge gap here in determining who should be screened and at what interval” (page 96). In addition to supporting the development of more robust medical and allied health school curricula and advocating to address inequities in insurance coverage for various procedures, as Shanker suggests, what else can healthcare professionals and public health practitioners do to ensure LGBTQ+ community members are receiving all of the appropriate cancer screenings, even in the absence of clinical guidelines? Discuss how bias and discomfort can sometimes act as a substitute for clinical guidance, perhaps especially when there is no guidance.

Chapter 13: “Addiction and Recovery in the Queer Community” by Atticus Ranck (he/him)

Ranck writes, “I hesitated to be out about being transgender in my own recovery spaces because of the lack of transgender-knowledgeable people. Part of recovery is being able to bring your whole self to the rooms, and I wasn’t doing that. I started to feel that not being out entirely about who I was would jeopardize my sobriety” (page 109). Ranck describes some of the challenges to getting sober that are unique to LGBTQ+ people. Given how LGBTQ+ people experience different reasons for using and different obstacles to recovery, how can service providers tailor treatment supports to LGBTQ+ people? Identify some specific ways that the recovery community, including peer-to-peer groups and professionally-led treatment facilities, improve outreach and care for LGBTQ+ people in active addiction or in need of ongoing recovery support.

Chapter 14: “Without Wincing or Clenching: Bisexual People’s Experiences with Healthcare Professionals” by Robyn Ochs (she/her)

Ochs writes, “The first thing I want [my health care providers] to know is that—even after all these years—the thought of telling a health care professional that I identify as bisexual fills me with anxiety [...] Are my feelings based on actual bad experiences, or are they based on anticipated bad experiences? Yes. Both” (page 113). Discuss the professional and affirming ways a service provider should respond when a patient comes out as bisexual. Then consider that most LGBTQ+ healthcare consumers have *not* shared their LGBTQ+ identity with all of their healthcare providers. How does this compromise the quality of the care they receive? How can healthcare providers proactively address anticipated discrimination among their patients who are bisexual, LGBTQ+ and/or members of other marginalized groups?

Chapter 15: “Gender, Cancer, and Me” by Liz Margolies (she/her)

Margolies discusses the gendered aspects of cancer treatment that often go overlooked, including, for example, breast cancer patients’ attitudes towards breast reconstruction and wigs. She expands on this theme further, saying, “The ‘pinking’ of breast cancer, the unrelenting forced optimism, expressed with pink ribbons and teddy bears, is the most ubiquitous and largely invisible gendering of the breast cancer experience. It was no surprise to me that many people in our national survey expressed disgust at the cuteness and girlyness of the campaign” (129). Discuss how the gendering of health promotion campaigns contributes to health disparities for LGBTQ+ people. How is this especially harmful to transgender patients who may be uncertain of which cancer screenings they should be receiving? When it comes to treatment options, like breast reconstruction surgery, how can healthcare professionals and social workers make space for patients to articulate what they are most comfortable with?

Chapter 16: “Laura is a Transgender, Didn’t the Surgeons Do an Amazing Job?” by Laura Jacobs (they/them)

Jacobs writes, “Every trans-identified person I’ve ever met has experienced it: a medical interaction during which we felt fetishized or inappropriate language, where a professional pried for information not relevant to the clinical issue. Rather than encouraging a bond, these moments only amplified the resistance” (133). Discuss why some of the examples Jacobs provides from their interactions with doctors are inappropriate and the impact these interactions can have on trans people’s quality of care and trust in the healthcare system. How can healthcare professionals make trans patients feel comfortable and safe in healthcare environments after they’ve experienced these harmful interactions?

Chapter 17: “Tobacco Free Queers: Prime Time to Quit” by Scout (he/him)

Scout gives examples of how the tobacco industry has curated the LGBTQ+ community as effective defenders of tobacco industry interests through targeted advertising in LGBTQ+ media, sponsorship of major events including pride festivals, and the contracting of LGBTQ+ community leaders to speak out against anti-tobacco legislation. Scout writes, “Because we have been ignored by so many, because we have suffered such stigma, and in part because other people do not want to upset us, we have unwittingly been pawns for the tobacco industry to deploy in their larger legislative battles” (146). Discuss how public health professionals can utilize these same strategies--targeted media campaigns, event sponsorships, and partnerships with trusted messengers in the LGBTQ+ community--to improve access to care for LGBTQ+ people.

Chapter 18: “Challenging HIV Stigma” by Sean Strub (he/him)

Strub writes, “But to the stigmatized person, the person living with HIV, the stigma is far more nuanced and complex than simple fear of casual contagion. The stigma is about our moral worth being judged when others find out we have the virus. It is about our words being discounted before they leave our mouths, marginalization, ‘othering,’ and very importantly, self-stigmatization and the internalized stigma we absorb from the broader society” (151). Discuss Strub’s assertion that stigma is “worse today than ever before” (151) and the role that healthcare providers and public health practitioners can play to reduce this stigma and fully support people living with HIV. Strub also writes, “The reality is that the consequences of disclosure [of HIV status] are greater today than they were years ago” (155). Discuss some of the consequences Strub enumerates and then consider what we can do to center positive people’s experiences as we continue to destigmatize this issue. Discuss how a provider’s knowledge of history can also be a factor in creating a safe environment.

Chapter 19: “Archiving AIDS: Intergenerational Education About an Epidemic” by Chris Bartlett (he/him)

Bartlett writes, “Grounding our health promotion work in movement history helps us to understand our hard work in organizing as part of an effort that goes back decades and that will continue into the future long after we are gone” (161). Discuss how Bartlett went about archiving the movement history of ACT UP Philadelphia and the Marielitos. How can we work to connect past LGBTQ+ movements to health advocacy in the present? What is the role of intergenerational knowledge and education in public health efforts for LGBTQ+ people, and what can we do to promote those efforts?

Chapter 20: “Organizing Against Social Isolation: Older Lesbians in Rural Communities” by Kat Carrick (she/her) and Ntlotleng Mabena (she/her)

Carrick and Mabena reflect on their experiences developing support systems for older lesbians in two distinct rural communities. They write, “Navigating heteronormative social expectations and cultural intersections can be challenging for many in the LGBT community, but the intersection of older-age, lesbian identity, and rural geography can lead to social isolation. Living isolated in rural communities, challenges may include invisibility or denial of significant relationships” (166). Discuss some of the health impacts of social isolation on older-lesbians in rural communities and some of the techniques the authors explain are being used to create community connectivity.

Chapter 21: “Caregiving Concerns for LGBT Older Adults” by Liz Bradbury (she/her)

Bradbury describes how LGBTQ+ people are more likely to be elder orphans--people who are aging alone with no family caregivers to attend to everyday needs--and more likely to be unpaid, informal caregivers. She also writes, “Even when an institution or individual is not intending to be exclusive, saying ‘we treat everyone equally’ indicates that the older LGBT adult client or patient’s needs will probably not be met” (175). Discuss how the models of care for older adults in the U.S. is, by design, leaving LGBTQ+ older adults without the support needed to age with dignity?

Chapter 22: “Housing and Health for LGBT Older Adults” by Imani Woody (she/her)

Woody writes, “Recent research has shown that LGBT/SGL people are more likely to experience depression, increased isolation, and loneliness because of the stigma, prejudice, and discrimination related to aging in a youth-oriented society [...] Emotional distress and social isolation are two of the largest threats to health for LGBT/SGL elders and are exacerbated by

perceptions of having been treated badly or discriminated against...” (pages 188-189). Mental and emotional health challenges are particularly concerning in a population that is socially isolated and disengaged from healthcare providers due to anticipated discrimination. What obstacles, opportunities, strategies, and promising practices to re-engaging this population in needed health and social services? How can models for communal living, like Mary’s House for Older Adults, facilitate such engagement?

Chapter 23: “Grieving Together: LGBT Bereavement Support Groups” by Justin Sabia-Tanis (he/him)

Sabia-Tanis writes, “I genuinely felt that the group members did not, in fact, see me as particularly different. I was the same as everyone else. Here lies the crux of the problem--my differences and those of queer culture were neither seen nor even acknowledged as existing” (193). In his experience, feeling included was not enough to feel adequately served by the support group. In what ways does inclusivity differ from equity when it comes to providing comprehensive care? What benefits are there to providing programs and services that are designed exclusively for specific marginalized identities?

Conclusion – Adrian Shanker (he/him)

In Shanker’s conclusion, he writes “There is nothing biological about LGBT people to prevent health equity. Our health challenges are grounded in a history of bias, discrimination, stigma, and structural barriers to care” (203). From your own lens as a healthcare professional, public health practitioner, or activist, how do you envision your own role in helping to achieve the unmet dream of health equity? And what are the structures, issues, and social determinants of health you can actively be a part of changing to enact material change?

Afterword – Kate Kendell (she/her)

National LGBTQ movement leader Kate Kendell closes the book by writing “Our movement for equality, for liberation, has been breathtaking in its gains. But we still fight for our humanity, our health, and our happiness. The priority for a new generation must be the health of every one of us and the promise of a long, healthy, fully embraced life” (206). Why is it important to prioritize health equity within the broader framework of LGBTQ liberation? Discuss tangible changes that clinicians and public health practitioners can make to support what Kendell calls the “promise of a long, healthy, fully embraced life.”

FURTHER READING

Fine, Michael. *Healthcare Revolt: How to Organize, Build a Healthcare System, and Resuscitate Democracy - All at the Same Time*. PM Press, 2018.

Lassiter, Jonathan. *Black LGBT Health in the United States: The Intersection of Race, Gender, and Sexual Orientation*. Lexington Books, 2019.

Strub, Sean. *Body Counts: A Memoir of Politics, Sex, AIDS, and Survival*. Scribner, 2014.

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