BOOK REVIEWS

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LGBT Experiences With Health Care
BY SEAN CAHILL

The Remedy: Queer and Trans Voices on Health and Health Care
Edited by Zena Sharman
256 pp., $18.95

In recent years the US health care system has devoted increased attention to lesbian, gay, bisexual, and transgender (LGBT) health and health disparities and has endeavored to create care systems that are culturally competent and affirming of LGBT patients. The Joint Commission has encouraged hospitals to adopt sexual orientation and gender identity (SOGI) nondiscrimination policies and collect SOGI data from patients to better understand LGBT disparities and differences in health care access and quality that correlate with SOGI. In the United States SOGI data are being collected for twenty million patients in the community health center system, and twelve national surveys are now collecting data on sexual orientation.

Reducing LGBT disparities, such as higher rates of obesity and lower rates of preventive cancer screenings among lesbians, is a key goal of the Healthy People 2020 program. The American Association of Medical Colleges published a curricular guide to integrating LGBT health into medical school curricula; the National Institutes of Health created a Sexual and Gender Minority Research Office in 2015; and the Department of Health and Human Services funds the National LGBT Health Education Center to train staff at health centers and other institutions to recognize and address the population’s unique challenges.

Progress in Canada has been less robust: Nick Mulé and Miriam Smith reported in 2014 that “LGBTQ health concerns continue to be marginalized in federal health policy.” However, recent elections might result in more progress in Canada, where liberal Prime Minister Justin Trudeau was elected in 2015, and potential rollbacks might occur in the United States, where conservative Republicans now control the White House and both houses of Congress.

One thing lacking in much of the analysis of this increased focus on LGBT health is the human element. The Remedy: Queer and Trans Voices on Health and Health Care is a welcome contribution to the field that fills this gap. This collection of thirty-two essays, two poems, and one graphic cartoon provides a variety of perspectives on the often traumatic experiences that LGBT people have with the health care systems in Canada and the United States. Some of the essays were written by health care providers and researchers in the field, but most are poignant, heart-rending patient stories of anguishing and frustrating experiences that included discrimination and incompetency. At least half of the personal essays are from transgender individuals, with a smaller number of lesbian, gay male, bisexual, and queer perspectives.

That LGBT people experience discrimination in health care is well documented. That this serves as a barrier to accessing care has also been shown. What The Remedy contributes to the research literature is the human toll of such discrimination.

One of the contributors to the collection, Francisco Ibáñez-Carrasco, immigrated to Canada from Chile in 1985 and has lived with HIV since. He describes being repeatedly put on display for medical education—for example, in Vancouver in 1994, when he had Kaposi’s sarcoma and was photographed naked every week for a research study. He celebrates the democratizing force of the Internet for patient self-education and empowerment, and he provides helpful suggestions for patients on how to be an effective self-advocate.

Many essayists in The Remedy describe being “misgendered” by health care staff. “The message is clear: They do not understand my body,” writes Sinclair Sexsmith. “So why would I trust them to help me with my health and wellness?”

In a graphic cartoon, Kara Sievewright provides an account of her transgender male partner Brady’s experience with breast cancer. In addition to the challenges all cancer patients face, right before Brady’s operation, Brady and Kara are told to wait in the hallway, because “only women are allowed in the waiting room.”

Chase Willier provides a compelling case of intersectional identities as a First Nations transgender man who served in the Royal Canadian Mounted Police as a closeted lesbian in the 1980s. “I was an anomaly, much like today, being transgendered.... I considered this to be one of life’s ironies, an Indigenous person feeling alien in their own land.”

Craig Barron describes the arc of life he experienced as an older gay man: police raids on gay bars and widespread social disapproval in the 1970s, the AIDS crisis starting in the 1980s, and achieving marriage equality in 2003. He describes the challenges that gay and HIV-positive people face as they enter senior services systems and elder health care institutions, including discrimination, silencing, and being forced back into the “closet.”

In “Navigating This Life as a Black
Intersex Man,” Sean Saifa Wall tells the compelling story of being born with androgen insensitivity syndrome (when a person has some or all of the physical traits of a female but the genetic makeup of a male) and ambiguous genitalia. Sean’s mother refused persistent efforts by medical providers to surgically alter him as an infant but followed their advice to raise Sean as a girl. At age thirteen, Sean experienced intense pain in the groin and was subjected to genital surgery and put on female hormones. “At no point did anyone ask me what I wanted to do with my body,” Sean writes. As an adult Sean transitioned to male, and he now “advocat[es] for a world where intersex children can enjoy body autonomy and where the uniqueness of their bodies, and our bodies as intersex adults, are upheld in their integrity and beauty. I am advocating for a world where we are meant to exist.”

In another piece, lesbian mother Caitlin Crawshaw describes the heterosexist assumptions of health care providers, who wrongly assume she has a husband and assume that her female partner, five years older than she, is her mother.

Perhaps the most compelling personal essay is by J Wallace Skelton, who describes his travails trying to get perinatal care as a pregnant “trans guy who still has all original parts.” One midwife repeatedly misgeneres the author and uses his legal, not chosen, name. This midwife also steers Skelton toward a c-section, apparently out of discomfort with his transgender body.

One thing that those of us who work in LGBT health struggle with is the constantly changing nature of LGBT identity categories and the increasing problematizing of gender and sexual categories. For example, how do you ask questions about sexual behavior without reifying the gender binary: “Do you have sex with men, women, or both?” or “males, females, or both?” As Kyle Taylor-Shaughnessy notes in the collection, “While the constantly evolving language and concepts of gender and sexual identity in youth populations can be overwhelming at times, if we don’t keep up we lose the ability to connect and therefore to do effective work. ...Being able to effortlessly flow between pronouns, names, and identities in conversation—being able to weave these together in a way that fully honours and respects the person in front of you, however that looks for you, is a necessary skill.”

While The Remedy gives voice to important, compelling perspectives that rarely have a platform, ideology overruns science at some points. For example, obesity and overweight status, which lesbians experience at nearly three times the rate of other women, are not listed in the collection as a disparity affecting lesbians, although “fatphobia” is listed as a form of oppression. Of course, obesity and overweight status are complex conditions, and our understanding of these complexities could be improved. But because these are major causes of cardiovascular disease, it’s odd that the book does not address them.

In an essay about her experiences as a transgender woman in nursing school, Soma Navidson notes that she frequently suffers “transphobic microaggressions” in class. While I agree that health professional schools should incorporate transgender and LGBT health education into the standard curriculum for all students, some of the teachings that Navidson objects to are medically relevant. For example, she objects to the belief that “our bodies are somehow inherently ‘sexed,’ leaving us disenfranchised in the hands of providers who think we’re ‘male-bodied women’ or ‘female-bodied men.’” However, there are some aspects of anatomy that don’t change with gender affirmation surgery. Transgender women retain their prostate glands, and most transgender men have a cervix. Prostate and cervical cancer screenings should be offered to transgender patients, as well as breast cancer screenings. Navidson also says she “exploded” in class when her professor introduced genograms as a way to model families. “‘Family’ is not a useful term in attempting to assess genetic risk for my queer self, as it’s broad and amorphous,” she writes. “Family shifts and changes, with relationships often being based on anything but blood.” Certainly there is a legitimate critique of the thirty-seven-year-old genogram model—which models both genetic hereditary factors and interpersonal family relationships. Important nonparental influences, same-sex parents, and “chosen family” could be integrated. But to the extent to which genograms model genetic influences on health, blood relation—for instance, who gave birth to whom or who fathered whom—does matter. It is not violent or “cissexist” to state this fact, as Navidson claims.

While some of the claims in The Remedy may be challenging, they all offer important perspectives for health care providers to hear. If a patient experiences discriminatory or culturally incompetent care, the patient might not return for follow-up care, including both routine and emergency care. As Sossity Chiricuzio writes in the final essay: “Healing requires love. The providers I work with understand this. They use their hands gently, deeply, probing for ease, not faults. They push themselves to learn about what they will never live in their bodies so as to not compound the errors and terrors already endured. They apologize when they get it wrong. They work to make it right. They listen.”

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NOTES
2 Lambda Legal. When health care isn’t caring: Lambda Legal’s survey of discrimination against LGBT people and people living with HIV. New York (NY): Lambda Legal; 2010