

Spare Parts: Navigating Ovarian Cancer as a Transgender Man

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I, Lauren Walker, first met Tristan Bilash, in 2016, before his public gender transition, when Tristan sought me out to be trained with our androgen deprivation therapy (ADT) educational program¹ to better support patients with prostate cancer undergoing ADT. As an oncology social worker, Tristan had been struck by the difficult transition these men experienced when their cancer treatment required obliteration of testosterone. In the years that followed, Tristan and I have continued to have invaluable conversations about his personal gender-related experiences and the intersection of this with both his professional work in oncology and his own cancer experience. Excited by the power of his story, I encouraged Tristan to share it more broadly with oncology professionals and worked with him to prepare this Art of Oncology submission.

This story begins with our acknowledgment that a body is more than the sum of its parts and those parts do not make the person. Today, mainstream conversations about transgender people often center on pronouns, labels, and how body parts may have been modified in one way or another. Although there is validity to the perspective of many transgender advocates that reducing conversations about transgender individuals to specific body parts can dehumanize the person, we believe that in certain contexts, such as healthcare, discussion with transgender patients specifically about their body parts is not only warranted but also essential for providing informed cancer care.

Gender transition is rarely a linear process, and for me (Tristan), this is certainly true. My journey to figure out and affirm my gender identity was not straightforward. This is my story. I am Tristan Bilash. I am a transgender man. My pronouns are he/him. I am a clinical oncology social worker. I am also an ovarian cancer survivor.

It was on the playground, in Grade 1, that I was first confronted with the possibility that I was not a boy. As far as I was concerned, I was a boy, despite looking like and being treated as a girl. I gravitated toward boys' interests, was naturally inclined to stand to pee (although not often successfully), and was not yet cognizant that the anatomy between my legs mattered. Confronted by classmates, I was told "you're not a boy, why are you playing with them?" This was in the late 1970s in a small rural town. Lacking the vocabulary to offer a countering perspective, I began experiencing a disconnect between my authentic self and what others expected of me. In that heart breaking confrontation on the playground, the message was strongly reinforced;

I must be wrong about my gender. With time, my vocabulary grew to include tomboys and lesbians, but neither category quite lined up with my sense of self. Throughout childhood and adolescence, without positive transgender role models and without the understanding that sex, gender, and sexual orientation are distinct constructs, I continued to feel out of place and misunderstood.

Gender dysphoria hit hard with the onset of puberty. Gender dysphoria is distress related to a mismatch between one's sex assigned at birth and their gender identity. I was a late bloomer and had an inconsistent menstruation cycle from the start. Developing breasts and having a period were extremely distressing. I experienced relief each time my period did not appear—relief that outweighed any concern about whether something was wrong. My health care providers seemed exclusively focused on making sure I had a period; "You may want kids someday," but the clear assumption was that because I had these parts, I must also desire to bear children. I did not.

Diagnosed with polycystic ovarian syndrome in my early 20s, I spent much of this decade of my life in pain. Repeatedly told it must be irritable bowel syndrome or that my symptoms were in my head, I felt cast aside by the medical system. Although endocrine treatment enforced a regular menstrual cycle, a criterion that seemed to affirm successful treatment from the medical standpoint, it did not explain why I did not feel at home in my own body. At an endocrinology consult, I recall being told my testosterone levels were above average but not to worry, I would "not turn into a man". I am sure this statement was intended to be reassuring, but I remember feeling a strange disappointment. This is the crux—the medical system was focused on making sure my body parts—parts that not only did not resonate with me but that caused physical and psychological pain—worked properly. In the meantime, I wished to be rid of those very parts, but I did not yet understand that this was possible.

At age 30, when the gynecologist confirmed that I needed a bilateral oophorectomy and total hysterectomy to treat ovarian cancer, my reaction was clearly not typical; it was a combination of relief, elation, and fear: Relief at finally having confirmation that I was correct—something was not right with my body; elation that these body parts, long integrated with pain and dysphoria, would be removed; and fear because this came with a cost: cancer.

What I had been told to expect to be a 3-hour surgery ended up being 7 hours. I recall the surgeon saying that the extent of the stage IIIC serous tumor was only rivaled by patients in their 70s whose tumors had been growing for decades. In a complication during debulking, my

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obturator nerve was severed, which despite immediate repair, left me temporarily disabled, without the use of my right leg.

Although I knew I had years of physiotherapy and an abundance of pain and uncertainty lying ahead, I felt like a ton of bricks had been lifted from my shoulders. Feeling more connected to my body than ever before and having those parts removed was euphoric. Yet simultaneously, and somewhat unexpectedly, my experience included grief and loss. Although those parts did not belong in my body, or resonate with my soul, they were still parts of me—parts that contained lived history and DNA that would never be passed on to the next generation.

At the time of my diagnosis, I still had not figured out what it meant to be transgender and did not have the words to announce that I was a transgender man. However, I was then as I am now—a transgender man who experienced ovarian cancer. I did know that I yearned to connect with other young cancer survivors, so I tried attending an ovarian cancer support group. However, I quickly learned my experience was far from the norm. I described feeling newfound joy in being free from what at that time; I had considered to be spare parts, while sitting among people who were rightfully mourning their lost parts. I did not fit in the world of ovarian cancer survivors—but where did I fit? I searched fervently for years for evidence of anyone else like me. I only found the story of one other—depicted in a documentary film—Robert Eads.^{2,3} After refusal from health care providers to treat a man with ovarian cancer, he ultimately died. To this day, I have not met another transgender advanced ovarian cancer survivor like myself, which is an experience that remains isolating. However, finding Robert's story gave me the context to understand my own gender identity and my emotional response to my cancer experience. The years of dysphoria, disassociation from my body, and the elation of being free of my reproductive organs after my cancer experience, now made sense. I was a transgender man with ovarian cancer.

Recently, a patient who knew me before and since my transition asked me, “Why did you wait so long to transition?” My reply was “It's complicated.” In hindsight, my mental health may have benefitted from transitioning earlier; however, my cancer treatment experience may have suffered. At the time of cancer diagnosis and surgery, I presented as a woman. Thinking back on that time, I do not think I could have done it while presenting as a man. I feel fortunate that at the time of diagnosis my exterior presentation as a woman afforded me timely treatment and avoided the barriers I would have faced had I presented to my doctor as a man. My cancer journey began in the early 2000s, when transgender-knowledgeable cancer care was still a fledgling discourse. Some would rightfully argue it still is to this day. To present as a man, within women-only spaces such as gynecology offices or ovarian cancer support groups, would be difficult even for me, an out and

proud transgender man and health advocate. I may still need to confront this navigation of the health care system if my ovarian cancer ever recurs, however daunting it may be, I will use the opportunity to help providers improve transgender-knowledgeable care.

In the years after my cancer diagnosis, I grappled with concern about what my body had already endured from cancer treatment. Feeling lucky to be alive, I weighed the physical implications of further gender affirming surgery. Depression, anxiety, and hopelessness wore heavy on me, during this period in my life. I received warm and compassionate support from my psychologist and a wonderful transgender-affirming psychiatrist. Both helped provide a safe space in which I could explore what gender meant to me. Propelled by my experience as an oncology social worker, where every day I am reminded just how precious and short life really is; I reached the point at which I could not go one more day without living authentically. If my ovarian cancer recurred, it would at least be in the body of the man I know I truly am.

For years, I had been using estrogen replacement therapy to help manage the menopausal symptoms I was thrust into after my cancer surgery. However, the longer I was on estrogen, the unhappier I became. It was not until my physician agreed to minimize my estrogen dose that I began to feel relief both physically and psychologically. With my new commitment to living my most authentic life, I traded in estrogen therapy for testosterone therapy. With my first testosterone injection I had what can only be described as a coming home experience. For the first time in my life, I felt like I belonged in my body. A further affirming step was my top surgery (ie, double mastectomy), which provided relief from the dysphoria that had tortured me for decades.

Now, a few years into my transition, I pass as a cisgender male, and I am cognizant of the privilege this affords me. However, passing comes with its own set of challenges. Last year, when experiencing several health concerns, my family physician ordered a CA125 test to help rule out ovarian cancer recurrence. While sitting in the waiting area at the local laboratory, it took more than 20 minutes for the technician to approach me. Finally, they said, “I'm so sorry for the wait. We are trying desperately to get ahold of your physician—we can't figure out why a CA125 test was ordered for you. Usually, only women get that test.” The health system continues to require me to constantly declare my transgender status. I do so, even in crowded waiting rooms and behind thin curtain dividers. However, not every transgender person is comfortable disclosing their status. Even to health care providers, many transgender people remain stealth. Sometimes by choice, but often out of necessity: housing and employment may be jeopardized, and risk of violence is real. In fact, many providers reading this article are likely unknowingly treating transgender patients.

Gender dysphoria is a difficult and distressing experience that is often triggered in the context of cancer care. Cancer screening relies on people knowing their bodies to be able to distinguish normal from abnormal. Gender dysphoria can leave patients disconnected from their bodies.⁴ Although not all transgender people suffer from gender dysphoria, medical procedures such as scans, rectal examinations, colonoscopies, and pelvic or breast examinations are all possible triggers for gender dysphoria and can be experienced as traumatic. After my cancer, I have experienced lymphedema from my surgery which requires me to wear compression garments to minimize my lymphatic drainage problems. These garments exacerbate my dysphoria and squish down my silicone penis prosthetic (aka packer). If I do not wear the garments, lymphatic fluid builds up in my abdominal wall, which I experience as feminizing. Being able to look in the mirror and see my anatomy bulging in the right places is extremely important to my psychological well-being. In this way, for me, parts really do matter.

Since my transition, my work with cisgender men receiving ADT has been cathartic. I think about what would happen if I was diagnosed with a cancer that required me to go off testosterone. After finally being able to feel at home in my body, I would be devastated. I see this familiar devastation on the faces of my patients with prostate cancer who are struggling with the side effects of ADT. Here I am, alive and able to be my authentic self by taking the same hormone whose loss has caused them such suffering. The irony is palpable. From a different angle, I understand the psychological process of creating new definitions of manhood and identity. Men on ADT who wish to remain sexually active must redefine the way they experience intimacy and sex.⁵ For me, my penile prosthesis provides relief from gender dysphoria, both in my day-to-day life and during sexual moments. Such resources may be similarly valued by cisgender men receiving ADT or by patients managing penectomy following penile cancer.⁶

My cancer and gender-affirming transition journeys have led me to reconsider the platitude offered to patients undergoing treatment or excision: “The parts do not make the woman or man, do they?” We as providers should not

assume what body parts mean to transgender patients with cancer—as there is just as much diversity within the transgender community as there is in any other community of patients. Every part matters. Every part deserves to be honored, taken care of, and let go of (if needed), with grace and dignity. It is okay to grieve the loss of some parts and celebrate the loss of others or simply have mixed feelings altogether. Human beings are both the sum of our parts and, at the same time, not defined by our parts. Indeed, I have come to realize that there are no spare parts.

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