Synopsis

Bodies Unbound is a story about the relationship between bodies and gender. Drawing on the experiences of individuals whose bodies and gender identities don't match medical and social expectations, Piper Sledge explores how ideologies of gendered bodies shape medical care when medical professionals use their position of authority to dictate which combinations of bodies and genders are legitimate or not.
Introduction

Cancer in the Public Imagination

The medical profession has a gender problem. This gender problem is especially prominent given that we live in an era of unprecedented access to health-related information about diseases, diagnoses, prevention, and our own genetic makeup. In May 2013, actor and humanitarian activist Angelina Jolie published an op-ed piece in the New York Times in which she explained her decision to get tested for BRCA (BReast CAncer gene), a genetic anomaly that significantly increases a person's lifetime risk of breast, ovarian, prostate, and pancreatic cancers. After testing positive for this condition, Jolie chose to undergo a prophylactic bilateral mastectomy, a surgery to remove both breasts, to minimize her risk of eventually developing breast cancer. She wrote, “I do not feel any less of a woman. I feel empowered that I made a strong choice that in no way diminishes my femininity” (Jolie 2013).

Jolie’s essay launched a flurry of controversy, with medical professionals and other breast cancer survivors critiquing her decision. Concerns in the press and the medical community centered on three main issues: whether such surgery (often deemed “radical” in the press) was medically warranted; the “perils of over awareness” or basing medical decisions on fears about the potential development of breast cancer; and the risk of “psychological harm after having radical surgery” (Davies 2013; Ferro 2013). Jolie’s account of her diagnosis and treatment, along with public criticism of her decisions by physicians, illustrates a conflict between medical authority and patient agency in medical decision-making. The heart of this conflict, as Jolie so clearly addressed, has to do with the idea that by removing breasts people may lose their femininity or their status as women.
Although prophylactic mastectomy has become a standard recommendation for women diagnosed with BRCA, the impact and importance of femininity to this surgery remains contested. At the heart of this conflict is not simply the matter of medical authority, but the relationship between gender identity, embodiment, and the perpetuation of cultural ideologies of gender through the medical regulation of patient bodies. Essentially, this controversy raises the question of who gets to make choices about their bodies, under what circumstances, and for what consequences to the gender order? Ideologies of gender are not only at play in the decisions that patients may make regarding what type of care they receive, but even whether they receive care at all for breast and gynecological cancers. In early August 2011 an array of news media outlets ran the story of twenty-six-year-old Raymond Johnson. A month earlier, Johnson, an insured tile layer, had gone to a South Carolina emergency room (ER) after finding a lump in his chest. His trip to the ER led to a diagnosis of breast cancer. Anticipating lofty medical bills, Mr. Johnson applied for a supplementary program within Medicaid created by the Breast and Cervical Cancer Prevention and Treatment Act of 2000, which provides coverage for low-income cancer patients. His application was denied on the grounds that the act specifically applied only to women. The story of Robert Eads, a transgender man denied care for ovarian and cervical cancer, was even more drastic. When Eads transitioned from female to male in the 1980s, he was no stranger to preventive gynecological care; he had given birth to two children in the 1970s. After his transition, however, he never again sought out such care, and the potential risks of “female cancers” for trans men were understudied and deemed unlikely by doctors of the time. In the mid-1990s, Eads presented at an ER at the urging of two friends because of severe vaginal bleeding, a symptom of what ultimately was diagnosed as ovarian cancer. Two dozen doctors in the region of the South where he lived refused him treatment because he was a man and therefore had the “wrong body” for preventive gynecological care (Davis 2001). These stories are striking because of the ways that health and gender come into tension. Specifically, the study of health “permits the revelation of those elements of western cultures which bear most directly on the construction of gender and its consequences for women, men, and the larger social order” (Lewin and Olesen 1985, 19, quoted in Annandale 2009, 146). This relationship is embedded in the history of the term gender itself. The birth of the term “gender” occurred in the context of treatment of intersex, transgender, and other ambiguously bodied people in the 1950s (see Meyerowitz 2002; Repo 2013, 2016). However, the centrality of gender to health and medical care is not unique to trans* and intersex individuals. Rather, medical care turns on assumptions about gendered bodies that become evident in provider–patient interactions that question these taken-for-granted norms. Although it has been well established that medical practice (and particularly) surgery impose a normative, binary gender order on the multiplicity of sexes possible in human beings (Davis 2015; Davis, Dewey, and Murphy 2016; Fausto-Sterling 1993, 2000; Lucal 2008; Preves 2000, 2002), I use moments of disruption in the cycle of cancer care to dig deeper into the role of medicine in perpetuating cultural ideologies of gender through the regulation of patient bodies, the ways that patients can imagine new possibilities of gendered embodiment, and the role of the medical system in legitimizing (or not) those possibilities. In Bodies Unbound, I investigate the regulation of gendered bodies within the cycle of care for female cancers. I focus on the experiences of fifty-seven individuals whose bodies and gender identities do not match the medical and cultural expectations for gynecological and breast cancer prevention and care. I link together the experiences of transgender men, cisgender men, and cisgender women who all create “gender trouble” for medical professionals when their bodies or their choices concerning those bodies challenge the standards of care for these...
cancers and/or normative expectations for gendered bodies. The cases presented here of individuals who trouble medical protocols and expectations for gendered embodiment highlight the perpetuation of legitimate forms of gendered embodiment as well as factors that may allow us to imagine new possibilities. My central concern in this book is to understand how certain configurations of bodies and gender identities come to be understood as legitimate and intelligible through interactions with medical professionals, family, friends, and strangers. The narrative accounts considered in this project concerning patients with the "wrong body" for gynecological and breast cancers indicate that processes of gender accountability and determination hinge on the alignment of individual identity, physical body, and normative expectations about appropriately gendered bodies. Throughout the book, I draw on empirical data to incorporate ethnomethodological theories of gender with theories of embodiment and medical regulatory power. By focusing on patients who disrupt this alignment in the context of female cancers, I raise the issue of the regulation of gendered embodiment as a critical puzzle that illustrates the ways in which taken-for-granted cultural ideologies of gender both shape and are shaped by medical interactions. It is my intention to question the current framing of medicine as an institution of control with respect to gender and to shift the analytical focus to processes of meaning-making and value creation initiated by patients. This book is not a story about controlling doctors and individual freedom. Rather, this is a story about gender: the meanings we associate with it, and the ways in which we acquiesce, resist, imagine possibilities, and otherwise participate in these processes as patients and practitioners.

Gender, Health, and Biopower

I began this chapter with the premise that medicine—as an institution with authority over human bodies and identities, as a profession, and as space of research on the human condition—has a gender problem. If health is a means by which individuals do gender (Moore 2010) and if accomplishing an intelligible gender is necessary for achieving a livable life (Butler 2004), then this is a problem that begs for resolution. This problem is succinctly summarized across an array of research papers indicating that there are major health inequalities that track on gendered lines. This scholarship asserts that the way to solve this problem is to refute binary, categorical, and normative definitions of gender and find ways to incorporate relational, process-based understandings of gender (see Annandale [2005] 2014; Connell 2012; Hammarström et al. 2014; Springer, Hankivsky, and Bates 2012). In more basic terms, these critiques of the profession call on physicians and clinical researchers to reorient their thinking toward seeing medicine as influenced by, influencing, and deeply embedded within the gender order. Additionally, practitioners and researchers lack a clear and well-understood definition of what they actually mean when they invoke gender, because this term may deployed when researchers mean sex assigned at birth, self-identification, and the degree to which people are perceived/perceive themselves as feminine or masculine (Hart, Saperstein, Magliozzi, and Westbrook 2019). Rather than studying the outcomes of medical care as it tracks on patient behavior, it is necessary to consider the embeddedness of gender within medicine in order to identify the moments when gender is deployed as (and thus re-created) as biopower and the factors that may contribute to resistance. In her genealogy of gender, Jemima Repo argues that “gender emerged specifically as a new apparatus for the regulation of the species” (2013, 240, emphasis in the original). That is, gender is biopower, specifically “a power over human conduct” (Fassin 2009, 45) that was created by and continues to be reinforced within medical care for the purpose of regulating bodies out of (gender) order (see also Meyerowitz 2002).
contend that it is within these interactions that resistance primarily occurs, but that the location of these interactions within medical care is particularly important given the ongoing role of the medical profession in maintaining gender as a taken-for-granted system. With this view, I am aligned with scholars who suggest that health behaviors and healthfulness are intertwined with the gender order and how individuals “do gender” (see Carpenter 2000; Moore 2010).

Especially important to my understanding of participant story is the notion that not only are behaviors implicated in the doing of health and gender, but that through this doing we are actively (re)creating the very meanings of gender (see Moore 2010). The concept of doing gender, the notion that through our daily interaction we create our own gender through accountability to cultural norms, lacks a point of origin for these norms to which we are accountable. Certainly, these norms are historically variable and become enmeshed in institutions and the minutia of daily life, but the centrality of interactions to creating this meaning cannot be overstated. The move to understand gender as biopower not only identifies the historical emergence of the term but also provides an explanation for why the pressure to be accountable to gender norms is so great and difficult to change. The association of gender with biopower also leads to a more effective place to begin understanding the factors that may contribute to change. As Michel Foucault famously argued, where there is power there is resistance (1978), but where might resistance occur given the power of gender over life itself? Much of the scholarship building on the concept of biopower turns on the role of the state while obscuring microlevel interactions. Two threads in the scholarship emerging from the concept of biopower are particularly instructive for unraveling the tension that gender creates in medical care: biocitizenship and biolegitimacy. Biocitizenship refers to the notion that corporeality is essential to personal and interactive practices of identity and that individuals as citizens have a set of biological responsibilities regarding health behaviors and education (Rose and Novas 2005). Given advances in medical and biological knowledge, individuals are now more than ever expected to behave in ways that ensure the overall enhancement of health and the prolongment of the life span. Despite the potential possibilities that attention to biopolitics and biocitizenship create, the biological presuppositions that underpin biocitizenship have “shaped conception of what it means to be a citizen, and underpinned distinctions between actual, potential, troublesome, and impossible citizens” (Rose 2007, 132). Because people are expected to seek out and make decisions based on knowledge about health and related practices, biocitizens are empowered in the ways promoted by the women’s health movement of the 1960s and 1970s. That is, they are expected to have the knowledge to make their own decisions and have those decisions be respected by medical professionals, but this ability is constrained by government structures that need to regulate social order and also by the fact that biocitizenship turns on an implicit distinction between men and women that is taken to be biological fact. In the context of biocitizenship, a person’s accountability to gender ideology cannot be separated from biomedical imaginaries of embodiment. To be a good biocitizen requires adopting certain health behaviors or bodily practices, including submitting to medical exams. This care is predicated on differences between male and female bodies that are naturalized through interactions and legitimized through the institutional practices of the medical profession. Thus, biocitizenship becomes “those citizenship projects that have linked their conceptions of citizens to beliefs about the biological existence of human beings, as individuals, as men and women, as families and lineages, as communities, as populations and races, and as a species” (Rose 2007, 132, emphasis added). Much engagement with biopolitics leaves out the relationship between everyday life and politics. Sociologist Didier Fassin (2009) attempts to fill this gap through the concept of biolegitimacy. Bringing this relationship to the...
fore allows for attention to what lives people may live and the creation of meaning and value in those daily experiences. With this focus, biopower becomes a normalizing factor in the daily lives of people and biolegitimacy as “the power of life” becomes a way to conceptualize “the sort of life people may or may not live” (Fassin 2009, 49). Biolegitimacy then refers to the power of everyday life in creating meaning and value, but it must be held in relation to the forces of biopower if that power is to be resisted or if new meanings can inform the workings of biopower. Through their health behaviors and the interactions that inform and emerge from them, biocitizens buy into or reject normative ideas of healthfulness, but they also have the responsibility to become knowledgeable about their bodies and are empowered to act upon that knowledge in daily life, including interactions with medical professionals. Behaving in ways that fail to align with certain expectations renders one troublesome as a citizen and as a patient. This determination of a person as a troublesome citizen is bound up with the biopower of gender to control and regulate individuals. If gender can be biopower (e.g., power over life), can it also be biolegitimacy (e.g., the power of life and a process of meaning creation in everyday life)? I attest that gendered biolegitimacy brings greater focus to the ways in which embodiment, power, and legitimacy are (re)produced in everyday life within the context of normative structures. Chiefly, I argue that the specific addition of gender to the concept of biolegitimacy suggests that this normative force is not only about how people live, but also about what sorts of bodies they may have and how those bodies become legitimate in our own minds and those of others around us. Further, using the language of biolegitimacy allows for consideration of how the meaning and value of gender may be reproduced or reimagined within daily life while also impacting the locus of gender’s biopower: the medical community. If gender is biopower, then it is upheld not only by medical professionals but also by the imperatives of biocitizenship. Biocitizenship also creates a tension between the institution upholding the system and the subjects who exist within it. The agency and subjectivity afforded to biocitizens empowers patients to imagine new embodiments that may disrupt normative meanings of gender and to request that medical professionals support them in making these possibilities reality. These new possibilities are not automatically afforded biolegitimacy—that is, recognition as viable, visible, and acceptable by the medical community. Biolegitimacy is just not a state matter but a medical matter as well, because medical authorities have access to technologies that these troublesome patients require to construct bodies that make sense to them given the disruptions of illness. Gendered biolegitimacy is about how medical authorities attempt to wrangle troublesome biocitizens back into the order of gender and how biocitizens stretch the limits of gender itself.

I intend my use of gendered biolegitimacy to expand beyond Aihwa Ong’s original use of the term in 2011. Ong used “gendered bio-legitimacy” in reference to the right of female migrants to a “healthy and unthreatened body” (2011, 42). Like much of the scholarship on biopolitics, gendered bio-legitimacy here does not turn to everyday experience but rather equates health with “the good life” and the importance of women as “life-givers and life-nurturers” (Ong 2011, 42). The term describes the right to health that should be afforded to people deemed female based on the physical capacity of bearing and birthing children and the associated expectation that these same people will bear the burden of supporting the life and health of others beyond the womb. This approach takes gender and health as always already defined. I approach gender as a puzzle and consider health to be a changing and conflicted term that also functions as biopower (see Metzl and Kirkland 2010). My use of the term gendered biolegitimacy unites the concepts of biolegitimacy with the notion that gender is biopower, and it links them to the responsibilities conferred to individuals via biocitizenship to consider the ways that biopower confers meaning and value through
ideologies of gender. That is, this is a kind of spiraling process where biocitizens can confront medical professionals (as gatekeepers and upholders of gender as biopower) to advocate for the legitimacy of different configurations of bodies and gender identities, thus effecting changes in gender itself. Fundamentally, the concept of gendered biolegitimacy allows for the theorizing of resistance to normative expectations of gendered bodies and the governing power of medical authorities. If we seek to address gender inequality or to open the possibilities of what livable lives may be, then we need to consider the ways that regularly occurring medical interactions between providers and patients can intervene in the perpetuation of gender as biopower.

The Case of Gynecological and Breast Cancers

Gynecological and breast cancers present an ideal context in which to identify the impact of normative ideologies of gender and to imagine new possibilities for embodiment because they allow for the examination of patient experiences and the embeddedness of gender at every point in the medical cycle of care—the care of these cancers turns on managing the threat to and restoring femininity (see Ericksen 2008; Potts 2000; Sulik 2011). Further, at each point in the cycle of care (i.e., early detection/prevention, diagnosis, treatment, and recovery), biomedical intervention is standard, and the details of diagnosis and treatment of the diseases in question are highly specialized (although well known to many patients). Because of their deeply specialized knowledge, this dynamic places physicians in a position of relative power over the bodies and lives of patients. Still, patients have unprecedented access to knowledge about diagnosis and treatment options. This knowledge and the ever-increasing influence of social media and social networks provide opportunities for resisting the power of physicians as sole decision-makers. "Female" cancers are particularly well situated as a context for exploring how bodies and gender relate and become visible and legitimate in daily life through medical interventions. Bodies assigned female at birth are routinely subjected to medical screenings to catch cancer as early as possible. The Papanicolaou (Pap) test, which involves the extraction of cervical cells via scraping, is the only medical intervention that can identify precancerous cells; early detection thus effectively prevents cervical cancers. Mammograms, administered for early detection of breast cancer, are a part of standard medical care for women although there is some debate over the ideal timing for mammograms. The test for BRCA was the first genetic test to assess cancer risk, although BRCA tests remain a recommendation for some patients rather than a standard for all to follow. "Female" cancers are unique in that the medical community generally agrees that these tests are important components of cancer care for people assigned female at birth, while medical exams for "male" cancers are much less effective. These cancers become enmeshed with hegemonic gender norms because they grow in body parts with a great deal of symbolic importance for the meaning of gender (see Spade 2003). Breasts are especially "celebrated as the principal symbol of womanhood, motherhood, and female sexuality" (Sulik 2011, 14–15). Relying on normative conceptions of femininity based in a binary gender system serves to "recast the uncertainty of illness into something more manageable and valued" (Sulik 2011, 74). In everyday life, breast cancer awareness slogans such as "Save the Ta Tas" and "Save Second Base," and the proliferation of pink paraphernalia in October indicate threats to female embodiment and heterosexuality and communicate that reinforcing femininity is the means by which to recover from this disease. With the "Turn It Teal" and "Teal Heels" campaigns (represented by a teal high-heel shoe with gynecological cancer facts) and slogans that implore women to "check their box" and "help the hoo-hahs," gynecological cancer activism draws on similar narrative tools. Activism for these cancers, primarily diagnosed in cisgender women, draws on tropes of femininity to mobilize research funding and public awareness. Breast and gynecological cancers are unique windows into the everyday medical
interactions that we routinely experience and the role these interactions play in maintaining or resisting structures of gender and sexuality. Gender-specific cancers show how hegemonic gender norms shape public discourse as well as how women and men respond to their diagnosis and treatment options (see, for example, Casper and Carpenter 2008; Hesse-Biber 2014; Klawiter 2008; Oliffe 2009; Sulik 2011). Given the constraints of the gender system, patients often behave in predictable ways; we expect to see people maintain the system. But what might resistance look like and what are potential threats to the system? What other possibilities exist for gendered embodiment? Interpersonal interactions that trouble the system are the foundations for understanding change. If we seek to alter the reality of gender inequality in medical care, we must begin research at these points of gender trouble because they illustrate the often invisible influence of cultural ideologies of gender on medical care. Analyzing the way these ideologies are made real through medical interactions allows us to better understand how these ideologies in turn shape gender inequalities in health. Female cancers allow for the examination of gender ideologies in all phases of the medical cycle of care because medical interventions are standard at every point in the cycle. This cycle is not specific to cancer. Rather, it is the cycle of prevention and treatment that characterizes medical care. In both the cultural imagination and in medical care, the narrative of female cancer assumes a "right body" for care that aligns with a female identified, cisgender woman with normative desires for her body's appearance. When a patient does not meet these assumptions, they create gender trouble for health care providers. Interview data from such troubling patients identifies the importance of normative expectations for gendered bodies to medical care and the ways in which such care reinforces the legitimacy of these expectations.

Project Design and Overview

Within the collective cultural imagination generally and in medical care specifically, the narrative around breast and gynecological cancers turns on stereotypes of femininity and female sexuality: the "right patient" for care is a cisgender, female-identified, heterosexual woman with normative desires for her body's appearance. To understand the ways in which gender shapes medical decision-making, I interviewed individuals whose bodies, desires for their bodies, and/or gender identities do not match the medical and culturally normative expectations for gynecological and breast cancer care: transgender men, cisgender men, cisgender women who choose prophylactic mastectomy, and cisgender women who live flat after mastectomy. These are people whose bodies are out of order with respect to gender and thus make clear the ways that the medical profession attempts to put them back in order—that is, in alignment with normative expectations of gender—thus reinforcing the biopower of these ideologies. I purposely chose to focus on patient experiences rather than on providers because these stories are those that are left out of the public discourse on these cancers. Instead of searching for "true experience," the interviews I conducted provide insight into the processes by which individuals understand themselves and their social worlds; as a result, they also reveal how those social worlds come into being (Connell 2005). Although this process occurs in interactions between patients and providers, I chose to begin with the patients because theirs are the bodies implicated in these interactions and they are the ones who must live with the decisions. I conducted in-depth, narrative interviews to explore the details of participants' experiences and the ways in which they made sense of these experiences. The interviews ranged from 45 minutes to 2.5 hours and were conducted in person, by video conferencing (via Skype or FaceTime), and over the phone, depending on participant's location and preference. The participants ranged in age from 22 to 71 years. I recruited participants through social media groups for transgender men, men with breast cancer, women who are BRCA positive ("previvors"), and women who refuse breast.
reconstruction ("live flat"). I also identified participants through a snowball sample, beginning with both people in my own social networks and from participants recruited through social media. (Appendix A contains further details about participant demographics.) The participants here represent a series of cases that highlight the problem of gender in medical care and the ways in which gender functions as biopower. With the exception of BRCA-positive previvors, medical protocols do not exist to accommodate the bodies, identities, or desires of participants in this study. As the example of Angelina Jolie shows, it is only recently that the medical community has incorporated standards to support BRCA-positive women in choosing mastectomy. Still, living flat after a diagnosis of BRCA or breast cancer remains outside the normative scope of medical care. Taken together, these cases set up a series of contrasts in the ability of patients to determine the relationship between their gender and their bodies in the service of achieving health. These comparisons form the basis of the chapters to follow and illustrate the ongoing role of the medical profession in maintaining the social order through the regulation of gendered bodies. It is important to note early on that participants in my research represent a conservative test of the problems of gender and the body for medical practice and gender theory. This is a privileged sample: white, middle-class, employed, insured, and well-educated.6 These are the individuals who should have the most power to advocate their desires in medical interactions, but my research shows that this is not the case. This book explores how patients experience gender in these moments of uncertainty and how they perceive the response of the medical community. It does not actually matter whether these perceptions are "true," in the sense the providers would corroborate the narratives of the participants. The truth of these accounts lies with the teller: lay people have too long been silenced, dismissed, and ignored by those with certain kinds of expertise and the power that extends from that knowledge. What matters is not actually what the doctors say to patients or how doctors interpret the advice they give. We are conditioned to only believe experts; but experience also provides expertise, and the experiences of one's own body are very real. A patient's perception of an interaction has everything to do with how treatment will progress. Rather than the medical community trying to find ways to convince patients to do what they say and that "doctor knows best" (i.e., patient compliance concerns), the medical community needs to learn to listen to their patients and adapt to what they hear—not to convince, cajole, or guilt patients into doing what providers think is best based on standards of care built on assumptions about gender and acceptable embodiment. Instead, providers need to actually hear what patients are saying and work with patients to live their lives as they wish to live them, not as providers think they should be lived. By focusing on patients who disrupt this alignment in the context of female cancers, I raise the issue of the regulation of gendered embodiment as a critical puzzle that illustrates the ways in which taken-for-granted cultural ideologies of gender both shape and are shaped by medical interactions.

Chapter Overview

This book tells a story about how bodies, gender, and the perceptions of others go together in both expected and unexpected ways. It is also a story of how this relationship becomes intelligible through the experiences of individuals, as well as of how medical professionals use their authority over bodies to legitimize certain combinations of bodies and genders. It is a story of conformity, rebellion, and possibility. It is an illustration of how we become who we are in a neoliberal culture marked by a paradoxical desire to be at once an individual yet to also be a recognizable and accepted member of society. It is a story about creating possibilities for livable lives that account for experiences that are outside the cultural norms that govern gender. The setting for this story is an increasingly medicalized world, in which individuals are interpellated to be biocitizens—that is, to control their bodies, health, and medical fate—but only insofar as those...
behaviors coincide with accepted medical knowledge and culturally prescribed behaviors. The next four chapters of the book are organized by key points in the cycle of cancer care: prevention/diagnosis, treatment, and recovery. The first three chapters emphasize the factors influencing their experiences while the fourth chapter engages with elective surgeries as powerful forces in maintaining and questioning the workings of biopower in cancer care. Within each of these phases of care, different groups of participants explain their experiences of being out of place and troubling the taken-for-granted assumptions upon which care in each phase is predicated. In each chapter, I juxtapose experiences from different groups of patients in order to magnify the influence of normative ideologies of gender on the decision- and meaning-making processes that participants undertake. When I shift to a direct focus on elective surgical decision-making for these cancers, I draw on the arguments of the previous chapters to point directly to medical processes that prioritize gender over empirically based medicine and patient-centered care.

In chapter 1, “Entering Enemy Territory?,” I compare the narratives of transgender and cisgender men as they navigate women-centered spaces of cancer care in order to prevent and diagnose gynecological and breast cancer. Drawing on the experiences of transgender men seeking gynecological care and cisgender men seeking breast cancer care, I develop the argument that assumptions about gendered bodies are at the heart of medical practice yet are problematic for patients. The way these men make sense of the health care they receive reflects the ambiguous relationship of body parts to gender identity and the ways in which normative masculinity is deployed differentially by providers, depending on whether a patient is transgender or cisgender, to manage male bodies in the distinctly feminized spaces of breast cancer care.

Participant stories of prophylactic mastectomy are the focus of chapter 2, “Choosing Mastectomy.” Here, patient perceptions of health risks, interpersonal relationships, and personal identity are revealed in the ways in which cisgender women make sense of their decisions to undergo prophylactic mastectomy as a preventative option after being diagnosed with BRCA or breast cancer. Women with BRCA and women with breast cancer described different responses from health care providers when seeking prophylactic mastectomies. Although women in these groups have similar concerns for their health and the treatment they think they need, some women experienced tension with their medical providers. In this chapter, women explain the ways that gender ideologies seep into their decisions about treatments as well as the recommendations they received from their providers.

In chapter 3, “Returning to Normal,” the experiences of both women and cisgender men in recovering from breast cancer intersect with ideas about normalcy and bodily integrity. Here, I discuss the various external forces that influence women’s reconstruction decisions. I examine how participants make sense of their bodies after cancer and how they come to understand their bodies as authentic, normal, and beautiful, regardless of their treatment experiences. Although reconstruction options are rarely presented to cisgender men, both they and cisgender women struggle with similar factors as they heal from breast cancer treatments.

Decision-making for elective surgeries related to breast and gynecological cancer is the focus of chapter 4, “Ideologies of Gender in Surgical Cancer Care.” These surgeries illustrate the ways in which patients and providers rely on frames of gender to determine whether a given surgery is an appropriate option for cancer prevention or care. These cases explain how medical interactions are shaped by and thus reproduce ideologies of gender through the bodies of patients. The medical interactions leading to these surgeries can be particularly fraught and may bring to the fore the ways in which medical care is implicated in reproducing gendered biolegitimacy. A condensed version of this chapter was first published in Social Science & Medicine (Sledge 2019). Together, these cases comprise a unique perspective into processes by which identity,
bodies, and medical care are relationally constituted, and they demonstrate why certain bodies create such “trouble” for the institution of medicine. The ways in which trans men, cis men, and cis women navigate medical care for body parts imbued with gendered meanings underscores that medical care in practice, policy, and theory needs new tools for making sense of gender in order to improve patient access to and experiences of medical care. Throughout, I argue that medical care is largely shaped by commonly held beliefs about what it means to be a woman or a man and how those meanings map onto and shape the physical body. These beliefs, on the part of providers, shape gender. Gender is not a variable determining access to care and health outcomes, nor is it an individual attribute. Rather, medical practices are embedded within the gender system; as such, they are influenced by cultural ideologies of gender. Medical care is shaped by ideas about gender while also reproducing those beliefs through the bodies of patients. Medical care is instrumental in determining which combinations of bodies and identities are legitimate or socially intelligible. By using medical language to justify normative expectations of gendered bodies, not only do medical interactions regulate patient bodies, but they also mark certain bodies as legitimate and others as illegitimate or wrong. The narrative accounts considered here of patients with the wrong body for gynecological and breast cancers indicate that processes of gender accountability and determination hinge on the alignment of individual identity, physical body, and normative expectations about appropriately gendered bodies. By focusing on patients who disrupt this alignment, I raise the issue of the regulation of gendered embodiment as a catalyst for critical inquiry and a response to critiques of medicine put forth by gender theorists. I argue that we must better understand gender as an embodied process in order to rethink the ways in which the gender system is re-created, resisted, and reimagined as well as to more clearly theorize the linkages between levels of analysis in the gender system.

Chapter 1
Entering Enemy Territory?
The stories in this chapter recount varying relationships between men’s bodies, identities, masculinity, and femininity. Although normative expectations of gendered embodiment link breasts, uteri, and ovaries with women and femininity, and penises and testicles with men and masculinity, the reality is that these relationships are much more ambiguous than many would like to believe. When designing this research, I naively assumed that men would explain experiences of breast and gynecological care as threatening to their identities. Instead, their stories reveal that men experience this care differently based on gradations in their position of “wrong” embodiment. That is, cisgender men described a lack of alignment between their bodies and medical protocols, and transgender men described a lack of alignment between their identities and normative expectations about men’s bodies. For both groups of men, this lack of alignment created a degree of trouble in the health care interaction that required resolution through the management of men’s bodies, identities, and the perceptions of others in the clinic. By understanding this dynamic, the stories shared by these men expose processes of gendered biolegitimacy.

In this chapter, I focus on the experiences of transgender and cisgender men seeking diagnoses and early detection care for breast and gynecological cancers. The chapter begins with the experience of seeking care and follows men as they enter clinical spaces designated for women, describe their perceptions of obtaining care, and their thoughts about being men in women’s spaces.

Suspicions, Seeking Care, and Diagnosis
When I asked Frank about being diagnosed with breast cancer, he said, “I’m a man who was just told you have [breast] cancer. And I am floored.… It was just like someone hit me with a two-by-four … I’m sitting there going, ‘Holy shit. I’m a man’ [laughs], and I have breast cancer.” This was a common sentiment among cis men after receiving a breast cancer diagnosis. Even those who suspected that they had cancer expressed degrees of surprise at their diagnosis. Trans men,
like some of the cis men, had somewhat vague concerns about cervical, ovarian, and uterine cancer risk, but many reported a degree of unconcern and let the relative invisibility of these parts justify not seeking preventive health care. As Zach explained, “I usually just ignore that part of my body.” For most men, breast cancer is unthinkable, and gynecological cancers are not concerning, unless a person experiences alarming symptoms. This is not entirely surprising. Male breast cancer makes up only 1 percent of diagnoses, even though the incidence has been increasing in the United States since 1978 (Speirs et al. 2010; Speirs and Shaaban 2009). Public awareness that men can get breast cancer has been limited, and clinical research on breast cancer in men remains sparse, thus contributing to the unthinkable nature of male breast cancer. There is also a relative lack of data about the risk of gynecological cancers for trans men although data does suggest that part of this risk is due to trans people being less likely than cis people to receive preventive screenings (James et al. 2016; Rollston 2019). For both breast and cervical cancers, screening technologies (i.e. mammograms and Pap tests) and standards of care exist that are highly effective at diagnosing physical symptoms early in disease onset or even before they become cancerous. However, these technologies are not standard care for men. Research on men and health suggests that cultural ideologies of masculinity may render men less likely to seek care (see Bish et al. 2005; Courtenay 2000; Doucleff 2013; Oliffe 2009; Pinkhasov et al. 2010; Rosenfeld and Faircloth 2006; Stibbe 2004; Vaidya, Partha, and Karmakar 2012; Watson 2000). Cis men in this study largely supported this research. Ezra stated that he rarely went to the doctor because “I have no complaints.… If I don’t have a physical complaint, I just don’t go to the doctor.” Similarly, Henry stated that he visited a doctor only “to treat a broken collarbone or other [sports] related injury” and emphasized his overall sense of robust health: “I was always super healthy. I didn’t realize that I was particularly vulnerable to anything.” Tim expressed a clear link between avoiding medical care and masculinity. “I think it’s just us being men. We think that you know, oh, nothing is going to bring me down. You know, I’m healthy as an ox, and unless we feel like we’re on our deathbed, we don’t go to the doctor.” James was one of the few cis men who advocated regular medical care. He expressed a deep disdain for men relatives who “talk with a kind of bravado, ‘Oh, I never go to the doctor.’ ” “Bravado” here serves as a code for masculinity. When imitating this relative, James’s voice dropped an octave, and he added a sort of swagger to his voice. Still, James reiterated the sentiment that medical visits were important primarily if something was wrong. “I mean, if something ain’t right, get it checked out. That’s my philosophy.” The habit of avoiding medical care and the lack of widespread recognition that breast cancer is more than just a women’s disease can impact the care men receive. Some of the trans men in this study were very clear about their concerns going into medical exams that are designed with an expectation of women patients. Isaac explained that after multiple experiences where health care providers struggled to look past his identity as trans and to provide appropriate medical care, he constantly worried about the consequences of failing to align with provider expectations of embodiment. What I’m afraid of is when people are surprised by the fact that my body is not what they expect, that it literally, like, shuts down their ability to process information in their brain [laughs]. Like, it becomes something that’s totally all-consuming. I don’t know if this is actually what’s happening. I’m just postulating. But, like, their ability to then ask relevant medical questions, to provide me with information that’s necessary, to communicate with other medical staff at a level where they were previously before finding out that I was trans, it just goes down. So I think that because it’s such a surprise to people it hinders their ability to function as medical professionals. And so my fear is, I’m going to go in, they’re going to get freaked out, and then they just won’t be able
to do their jobs in the way that I absolutely need them to do their jobs. So that’s what my fear is. For some trans men, this kind of fear shaped gynecological care into what Erik described as a “violent act” because of the forced disruption between body and identity that can result from microaggressions and outright discrimination. For Gabe, fear and past experiences where providers exhibited an inability to reconcile his identity and his embody led to a vehement rejection of gynecological care.

All things being equal, you can have nine women come in, and there’s some kind of understanding and appreciation that you’re helping me to stay healthy. From a transgender patient perspective, you’re not. There’s an anxiety and a pain level and a discomfort level walking in. There’s a tension to the body, and it’s resistant to the care that’s being offered, I would suggest to you, and so that’s gonna present in the exam. It will be more difficult to do what you do and know that we’re fighting you, [laughs] at least I am. I’m fighting whatever you do, and here’s the thing about that—that’s why we don’t go to the doctor. I’m gonna speak because I’ve heard these voices, all right, and most of us would rather die than to be treated for that kind of care, like gynecological or mammograms. We won’t go for those exams. We’d rather die.

Despite the pressures of masculinity and fear of discrimination or poor treatment, the men in this study did seek preventative and diagnostic care, even if they delayed it for a time. In doing so, they directly confronted the ways in which ideologies of gender shape the spaces, medical technologies, and clinical exams for breast and gynecological care. Two factors emerged as the primary motivations for seeking medical attention: unusual physical symptoms and the urging of women friends and family.

**Unusual Physical Symptoms**

Both trans and cis men described physical symptoms as key catalysts for seeking medical attention. These symptoms included pain, discharge, and lumps. Before their breast cancer diagnosis, most cis men in this study noticed some kind of physical abnormality on their chests. Henry felt an unusual pain when putting on a messenger bag; Ezra felt a lump behind his nipple; Tim experienced “yellow-orange-ish discharge out of [his] nipple”; and Frank, a long-distance runner, noticed irregularities in the normal chafing he experienced on runs. Frank said, “I was a runner, and every now and again a man, when he runs, tends to bleed from his nipples, and that’s what happened to me particularly on my half-marathon runs. And I noticed that my right nipple started looking funky … like it may have a blister on it, or it was changing shape or something.”
What people say about this book

Jared Banks, “Gender and Medical Care. A very well researched and written exploration on how gender effects medical care. The first hand accounts from people the author interviewed added extra depth, insight, and relatability. While the book focuses on specific cancers, the lessons and insights pertain to everyone engaging with the healthcare system.”

Elizabeth Daniel, “Every adult needs to have this phenomenal book in their library. What a remarkable and important book this has been for me. I am grateful for the insight, information, knowledge and power this work has brought to me. Thank you Piper Sledge!”

The book by Patricia Greene has a rating of 5 out of 5.0. 2 people have provided feedback.