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Gender and the Social Construction of Illness

Second Edition

Judith Lorber and Lisa Jean Moore



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THE GENDER LENS SERIES

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The Gender Lens Series has been conceptualized as a way of encouraging the development of a sociological understanding of gender. A "gender lens" means working to make gender visible in social phenomena; asking if, how, and why social processes, standards, and opportunities differ systematically for women and men. It also means recognizing that gender inequality is inextricably braided with other systems of inequality. The Gender Lens series is committed to social change directed toward eradicating these inequalities. Originally published by Sage Publications and Pine Forge Press, all Gender Lens books are now available from AltaMira Press.

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For Lorrie and Phyllis,
who have gone through life with Judith

For Grace and Georgia,
who begin life with Lisa

Gender and the Social Construction of Illness: Overview

It has been assumed that anything and everything worth understanding can be explained or interpreted within the assumptions of modern science. Yet there is another world hidden from the consciousness of science—the world of emotions, feelings, political values; of the individual and collective unconscious; of social and historical particularity. . . . Part of the project of feminism is to reveal the relationship between these two worlds—how each shapes and forms the other. (Harding 1986, 245)

Illness is not just a physical state; it is a social phenomenon. Different cultures consider some physical states “illness” that others consider “normal.” Westerners usually consider physical health as a state in which people can do what they have to do and want to do, and illness as something that disturbs the physiological equilibrium of the body. But what we actually experience as illness is a disturbance of our social lives so that we cannot go about our usual pursuits, a situation which may or may not be the result of actual bodily dysfunctioning. The perception that something is wrong and the guesses as to the cause are always experienced in a social context. Thus, a homemaker in a poor community, when asked to define illness, said:

I wish I really knew what you meant about being sick. Sometimes I felt so bad I could curl up and die, but had to go on because the kids had to be taken care of, and besides, we didn't have the money to spend for the

doctor—how could I be sick? . . . How do you know when you're sick, anyway? Some people can go to bed almost any time with anything, but most of us can't be sick—even when we need to be. (Koos 1954, 30)

In every society, the symptoms, pains, and weaknesses considered “being sick” are shaped by cultural and moral values, experienced through interaction with members of one's immediate social circle and visits to health care professionals and influenced by beliefs about health and illness. The result is a transformation of physiological symptoms into illnesses with labels (diagnoses) and the people who have them into “patients.” This transformation is heavily influenced by power differences and moral judgments. Not all patients are equal—gender, racial ethnic category, social class, physical ability, sexual orientation, and type of illness produce differences in social worth. Not all health care workers are equal, either—their place in the professional hierarchy determines their power to set research priorities, determine treatment modes, and produce what is considered legitimate medical knowledge.

In Western societies, the culture and language of illness and medical knowledge comes from science—“medical science” is the way we talk about what health care providers know and do. The *biomedical model* of illness assumes that disease is a deviation from normal physiological functioning, that diseases have specific causes that can be located in the ill person's body, that illnesses have the same symptoms and outcome in any social situation, and that medicine is a socially neutral application of scientific research to individual cases (Mishler 1981). Critics of this model have shown that what is normal depends on who is being compared to whom, that many diseases have social and environmental causes, that illness rates and severity vary from place to place, and that the values underlying medical research, practice, theories, and knowledge are deeply biased by the practice situations and the social characteristics of the dominant group of medical professionals—physicians.¹

Critical medical sociologists provided ample evidence of racial and class biases in Western medicine, and feminists added gender to the list.² They argued that medical norms were based on White, middle-class men's bodies, and that physicians did not take women's daily lives into account when considering the causes of diseases or prescribing treatment. Most crucial, they challenged scientific claims to universality. How could medical science be trusted, they asked, when so few women were scientists, when the diseases that killed men were the first priority in research, when women were not included in clinical trials, and when women's bodies and

experiences were ignored as data? The impact of the feminist critique of biomedical research and practice has been wide-ranging. Many more women doctors and men nurses are practicing today than in the past, and their ways of relating to patients reflect the feminist encouragement of attention to the “whole patient.” Women are now routinely included in trials of new drugs and surgical treatments. The gender context of illnesses and disabilities is an intrinsic part of research designs. Women's health is part of medical school curriculums. There has been a proliferation of medical journals devoted to gender-based medicine, women's health and illnesses, and men's health and illnesses.

Our intent in this book is to show how gender, in conjunction with racial and ethnic identification, social class, and sexual orientation, creates different risks and protections for physical illnesses, produces different behavior when ill, elicits different responses in health care personnel, affects the social worth of patients, and influences priorities of treatment, research, and financing. We will concentrate on problems that are located in the body, such as infections, AIDS, or nonfunctioning limbs or senses; and physical processes, such as menstruation and menopause, that in Western society have been transformed into illnesses. These bodily manifestations are often influenced by feelings of stress, anxiety, and depression, but the symptoms or causes are primarily physical. The *context*, however, is *social*, and social contexts are usually gendered—they have different effects on women and men.

Sex Differences and Gender Statuses

Sex and *gender* are often used interchangeably by laypeople and by professionals in science and medicine. In 2001, the U.S. Institute of Medicine issued a book-length report on sex-based differences in human disease (Wizemann and Pardue 2001). In it, reflecting feminist perspectives, the sixteen-member panel of varied professionals struggled to differentiate and define *sex* and *gender*. Their recommendations on terminology were that *sex* should refer “to the reproductive organs and functions that derive from the chromosomal complement,” and that *gender* “should be used to refer to a person's self-representation . . . , or how that person is responded to by social institutions on the basis of the individual's gender presentation” (p. 139). The Institute of Medicine's definition of gender implies that people are treated according to how they perceive or present themselves. However, feminist sociologists have demonstrated that people's gender

identifications and gender displays are a response to social pressures, which, in turn, are embedded in a gendered social order.

From the social construction perspective, gender is a society's division of people into differentiated categories of "women" and "men." Gender operates at one and the same time as an individual social status, a relational factor, an organizational process, and a system-level social institution. Each level supports and maintains the others, but—and this is the crucial aspect of gender—the effects of gender work top down. When gender is a building block of social orders, it gets built into organizations, floods interactions and relationships, and is a major social identity for individuals.

In the social construction perspective, gender is an intrinsic part of many societies' social orders. Gender divisions are built into the major social organizations of those societies, such as the economy, the family, religion, the arts, and politics. In those societies, gender is a major social status for individuals, with established patterns of expectations and life opportunities. The social construction perspective sees gendering as an ongoing process—with people constantly "doing gender" (West and Zimmerman 1987). Through interaction with caretakers, socialization in childhood, peer pressure in adolescence, and gendered work and family roles, people are divided into two groups and made to be different in behavior, attitudes, and emotions. The content of the differences depends on the society's culture, values, economic and family structure, and past history. The gendered social order produces and maintains these differences. There is a continuous loop-back effect between the gendered social order and the social construction of gender at the organizational, relational, and individual levels. In societies with institutional racism and discrimination by ethnic group and social class, gender is intricately intertwined with these other statuses, forming what Patricia Hill Collins (1990) calls a "matrix of domination." *Gender is therefore multiple: Women and men are not homogenous groupings.*

Bodies and biological differences have also been viewed from a social construction perspective. In this view, gender is not an overlay on biology; rather, biology itself is socially constructed *as* gendered. Sex differences do matter, but the way they matter is a social phenomenon. Menstruation, menopause, pregnancy, and childbirth are biological phenomena that are mediated and experienced socially. Female and male bodies are gendered for femininity and masculinity through sports, exercise, and physical labor. Gendered eating patterns have physiological consequences: Men's rates of coronary heart disease rose precipitously after World War II in West-

ern industrialized countries because they had the privilege of eating more scarce red meat (Lawlor et al. 2001). When a woman moves to a different country, her risk of dying of breast cancer gradually changes, for better or worse, to match the risk in her new place of residence (Kliewer and Smith 1995; Ziegler 1993). As Anne Fausto-Sterling says, "Reading nature is a sociocultural act" (2000, 75).

Sex is also not a simple binary. Sex multiplies into physiological characteristics of children and adults at different stages of the life cycle and by physical abilities. Women's biological states change, depending on whether they are pregnant or not pregnant, between periods or menstruating, pre- or postmenopausal. Men's biological states change with fluctuations in testosterone levels and other hormonal cycles. These within-sex differences must be considered when designing experiments for vaccines, medications, and surgery.

Sex differences occur in a social matrix of gender statuses—gendered patterns of social interaction, gendered expectations for how people should behave in families and workplaces, and gendered social institutions that legally and in informal social practices treat women and men of various racial, ethnic, and social class groups very differently. Medical and biological research has to be both sex-based and gender-based; research designs have to recognize that sex and gender are multiple, not binary, and intertwined in complex ways.

The framework for the gender lens on illness and health is the *transformation of the body through gendered social practices*.³ These practices start before birth—what a pregnant woman eats, what prenatal technology and care is available to her, what her family and educational and economic status are, what social worth a child of a woman of her racial ethnic group, economic status, and family background is likely to have—all affect the fetus, infant, and growing child as profoundly as genetic inheritance. Social practices produce social bodies all through life and death—and beyond (consider how corpses are handled). Because gender is embedded in the major social institutions of society, such as the economy, the family, politics, and the medical and legal systems, it has a major impact on how the women and men of different social groups are treated in all sectors of life, including health and illness, getting born and dying. Gender is thus one of the most significant factors in the transformation of physical bodies into social bodies. The *gendered body in its social context* is the framework for the analysis of the social construction of illness.

The Social Construction of Illness

Although it is located in the body, illness as a social experience goes far beyond physiology. The process of what comes to be termed a legitimate illness is entrenched in hierarchies of power and economic resources (Brown 1995). Sociologists use the term *medicalization* to explain how life events, including all aspects of the aging process, and social problems such as alcoholism and obesity, come to be defined and managed by health care professionals. Medicalization makes many physiological differences “illnesses” to be treated with examinations, tests, and prescriptions for frequently very expensive drugs. The health care provider is the expert; what the patient knows about his or her own body and his or her own life is not part of prevention, maintenance, or cure.

Medicalization is deeply embedded in financing structures of health care. Making so many physical states into illnesses enhances the capitalist profit motive in countries like the United States. Conversely, it comes into conflict with the cost-cutting practices in countries that have nationalized services. The combination of medicalization and financing structure affects health care professionals' behavior toward patients. If the goal is to increase the patient load, they will be encouraged to call every symptom a treatable illness. If the bottom line is to cut costs, they may neglect rare, time-consuming, or complex medical problems. In all Westernized medical systems, health care providers use the biomedical data produced by research institutions and federal health agencies, whose priorities are shaped by sources of funding. These sources may be pharmaceutical companies, governmental agencies, or private philanthropies. They all have agendas that shape research questions, and they target populations the research is designed to benefit, exploit, or control. Medicalization can thus do too much to make every common symptom an illness treatable by a pill or injection, and too little to prevent illnesses caused by pollution, occupational hazards, poverty, or substance abuse.

For patients, symptoms occur in the context of their lives. These symptoms become an illness through the process of seeking professional help, but the social experience of being a patient also involves kin, colleagues, friends, and one's place in the world. A broken leg may be a simple fracture, but it is experienced entirely differently by a professional athlete, for whom it is a career-stopper, and an office worker, for whom it is an annoying temporary encumbrance. Two illnesses may be easily treated by antibiotics and quite curable, but the social effects of pneumonia are far different from the social consequences of gonorrhea. If you have had gon-

orrhea, you may want to keep it a secret when you apply for a job. If you have had pneumonia, you may use that as the reason you have to stay home from work with a bad cold.

Because illness is socially constructed, health care providers and patients may see the same set of symptoms (or lack of them) entirely differently. Physicians tend to look first for visible physical symptoms or clear test results. For them, the ideal illness situation is one that produces an unambiguous diagnosis with effective treatment that will cure the disease by removing the symptoms or that will restore the patient to more or less normal functioning. For patients, modified ability to conduct their lives with chronic but treatable conditions is a considerably different situation than a complete cure. A cure restores you to your previous status; a chronic condition forces you to establish new patterns of behavior. Similarly, what the physician may see as unavoidable side effects from necessary treatment, the patient may experience as unwarranted increased pain or discomfort, stress, and financial cost. Patients who feel their doctor has ignored signs of complications or prescribed unnecessary surgery may sue for malpractice. If an HMO defines an illness in a way that deprives a patient of care, the patient may sue for damages. The definition of what constitutes an illness is often an embattled terrain.

The Social Context

The social context is an integral part of any illness. From recognition and attention to symptoms through actions while sick, to coping with recovery or a chronic condition or dying, all of a patient's social characteristics have an effect. This effect is shaped by social networks, work and financial status, family obligations, health care systems, and cultural values. As health care systems change, so does the behavior of patients, caretakers, and health care professionals.

For the greater part of the twentieth century, American medicine was practiced by physicians working alone in their offices, visiting their patients in hospitals, and collecting a fee for their services (Starr 1982). Patients and physicians negotiated with each other directly, but the physician had all the power and prestige. Patients tended to see physicians of their own race and religion, but not their own gender, since women studying medicine were kept to a quota of about 5 to 6 percent in medical schools that admitted them and in hospitals where they did their clinical training (Walsh 1977). One medical school for women survived the professionalization of

medicine in the early 1900s—the Women’s Medical College of Pennsylvania—but no all-women’s hospitals did. Because of religious quotas, Catholic and Jewish men physicians trained in and put their patients into hospitals supported by Catholic and Jewish charities (Solomon 1961). African-American and Hispanic physicians went to federally funded medical schools and used mostly publicly funded hospitals or community-based clinics (Hine 1985; Moldow 1987). Nurses were strictly under physicians’ orders (Reverby 1987). Native American and other indigenous healers, although they had many clients in their communities, were not considered legitimate health care workers.

Today, women physicians of all racial ethnic groups make up half or more of most medical school classes in the United States, but medical specialties are not evenly gender-integrated. More nurses and nursing administrators are men. Nurse-practitioners and nurse-midwives are responsible for their own patients. Native and homeopathic health providers, such as acupuncturists and nutritional specialists, are paid for by some health insurance plans.

The major change in the structure of medical care in the United States is the expansion of health maintenance plans (HMOs), where the provider is paid by a third party (insurance agency or the government), the patient’s choice of physicians and hospitals is often restricted, and the physician’s choice of treatments and medications is confined to what the payer allows. Since the goal of most private health plans is profit, insurers have been extremely influential in creating cost-effective decision models for health care providers. Physicians have lost prestige and authority, but patients have not gained any power in the medical encounter (Freidson 1989). The third party in the negotiation is the payer, a large, for-profit or government bureaucracy that tries to develop one-size-fits-all rules. These include limited hospital stays and ambulatory surgery, where the patient is sent home still needing physical care. Even with visiting health care providers, a family member or friend must be available to be the “nurse” (Glazer 1991). Other important players in Westernized medicine are pharmaceutical companies, which fund many seemingly unbiased clinical trials. Hefty profit margins and expandable markets determine research and development priorities; thus, Viagra for erectile dysfunction gets produced, as well as antidepressants and allergy medications. In such a system, the essence of illness—its diversified social context—is suppressed.

In sum, although all human beings experience the universal physical phenomena of birth, growth, illness, aging, and death, and each individual’s

experiences of these phenomena are particular, between these universals and these particulars are the similarities that come out of membership in social groups—women and men of various racial categories, ethnicities, and economic classes, living at different times and in different places. Social location produces patterns of health and illness behavior, but equally important in shaping experiences as patients are the actions of professionals encountered in seeking help and the organizational and financial structures of health care systems.

Overview of the Book

This book’s focus is a *gender analysis* of the transformation of physiological symptoms into the social reality we call illness. A gender analysis shows how gender is built into almost every aspect of illness in modern society—risks of and protections from different diseases, the perception and response of the patient to symptoms, the organization and delivery of health care, the politics of diagnosis, funding priorities, the problems explored by clinical and scientific researchers, the knowledge and meaning of diseases and their treatment. Each chapter examines a major issue in health and illness through a gender lens perspective. These issues are: *social epidemiology and risks of disease; professional hierarchies and patient-provider interaction; social aspects of physical disability; the politics of diagnosis in premenstrual syndrome and menopause; genital surgeries; and AIDS as a modern plague*. The concluding chapter discusses ways in which the recommendations of *feminist health care* can be applied to all patients.

Chapter 2, “Women Get Sicker, but Men Die Quicker,” explains epidemiological rates of death and illness in terms of women’s and men’s *sociocultural risk factors*. These factors are a combination of gender norms, racial ethnic group membership, economic resources, and social relationships. The social environment and social practices in which risk factors are embedded make different groups of people vulnerable to or protected from the causes of illness. Social epidemiological statistics are influenced by methodological issues, such as what questions are asked and how the answers are categorized, as well as by the reliability of techniques of information-gathering and measurement. Unless women and men of different racial groups and social classes are included in a sample, researchers have no way of making socially useful comparisons of health status, health practices, and risk-taking behavior. These statistics are usually not value-free; priorities are set by those who have the power and resources to get

answers to the questions of importance to them. You might say that what counts gets counted.

Chapter 3, "Hierarchies in Health Care," analyzes *gendered and professional power differences* and the interactive behavior of health care providers and patients. Whether the physician is a woman or a man influences how much attention is paid to women's and men's presenting complaints, especially what kind of tests are ordered and what kind of treatment is recommended. Nurse-practitioners are trained to look for the interaction of psychosocial factors with physiological symptoms and treat them simultaneously. Similarities and differences in culture and lifestyle also influence the interpretation of symptoms.

Chapter 4, "Gender and Disability," examines the *gendered contradictions and status dilemmas* of people with disabilities. It defines disability as a permanent social status that is only partly shaped by medical encounters. More influential is the availability of technological and environmental supports that allow people with disabilities to hold jobs and create families. Both women and men have benefited from the successes of the disability rights movement, but the special needs of women with disabilities for jobs, sexual relationships, and a family life have not been so squarely faced. The gendered expectations of women and men create constraints for both, but women with disabilities have fewer opportunities for long-term relationships. They need unbiased professional services, especially around sexuality and procreation. Another gender difference that impacts on those with disabilities is the expectation that caregivers will be women. Thus, if people with disabilities have special needs to enable them to live mainstream lives, then women with disabilities have even more specialized needs.

Chapter 5, "If a Situation Is Defined as Real . . .," examines the ways in which *premenstrual tension and menopausal mood swings* are socially and medically constructed. Symptoms individually experienced at different points in women's procreative life cycle are medicalized into physiological and psychological syndromes. Some women may pay little attention to premenstrual tension, menstrual cramps, and menopausal hot flashes, while others may need treatment for them. But if these occurrences are routinely labeled illnesses, then all women will be considered "sick" or not able to function normally. The part that medicine as a social institution plays in legitimizing appropriate behavior in women can be seen as a form of social control.

Chapter 6, "Genital Surgeries," looks at the *gender and cultural conflicts* in ritual and medical genital surgery. Although the social contexts of female and male ritual genital surgery, surgery on intersex children, and routine medical circumcisions are very different, the issues are similar—adults make decisions about genital surgery on infants and children in the name of cultural conformity. In ritual genital surgery, adults surgically modify a child's body to make the child appropriately feminine or masculine. The same goal governs genital surgery on children born with ambiguous-looking external genitalia. The body undergoes a profound social as well as physical transformation, a transformation that is, above all, gendered.

The debates over genital surgeries are confounded by opposing cultural, religious, and medical perspectives. Cultural traditions clash with human rights issues; religious beliefs clash with parental reluctance to do bodily harm to their children. Medical researchers argue over the risks and benefits of what seems like minor surgery. Gender weaves into all of these debates because they all involve beliefs about male and female sexuality, how female and male bodies should look, and how to prevent sexually transmitted diseases from spreading.

Chapter 7, "A Modern Plague," takes illness into the moral realm of social identities contaminated by *stigmatized diseases*. AIDS (acquired immunodeficiency syndrome) is an epidemic imbued with gender, sexuality, class, and racial ethnic discrimination. AIDS is very much affected by gender in its transmission and treatment. Its physical ravages and social costs today fall most heavily on poor women and men who live in developing countries. The discourse and dynamics around AIDS is a prime example of how sickness is reflective of cultural views of women and men, homosexuals and heterosexuals, poor and rich, people of color and Whites, "foreigners" and "natives."

How HIV-positive status and the symptoms of AIDS are reacted to and treated reflects heterosexual, bisexual, and homosexual relationships; the constellation of patient, practitioners, and lay caretakers; community attitudes; cultural values; and the politics of medical bureaucracies and government agencies. Those who are known to be HIV-positive or to show the signs of full-blown AIDS have been stigmatized for their sexual practices or drug use and out of fear of contagion from their semen, blood, or breast milk. From negotiations over condom use between sexual partners to allocation of funds for research and treatment by national and

international agencies, AIDS literally and figuratively embodies the material, experiential, and symbolic gendered construction of illness.

Chapter 8, "Healing Social Bodies in Social Worlds," looks at the conflict between the ways in which professionals and laypeople define medical reality and proposes an alternative—*feminist health care*. Such care sees the patient and the health care professional as equals in the medical encounter. The professional knows more about illnesses and their treatment in general, but the patient knows more about her or his particular case. Feminist health care advocates recommend that before professionals apply general medical science, they should understand the patient's social and environmental contexts and the patient's history with the particular disease. When professionals prescribe a course of treatment, they should tell the patient not only what the risks and side effects are, but also advise as to the advantages and disadvantages of other courses of treatment and nontreatment. Then the patient should decide what he or she wants to do, and expect the continued support and help of the professional, even if the professional's first choice for treatment was rejected.

Feminist health care is for all people—men as well as women, children as well as adults. Feminist health care encompasses major transformations of the existing structures of funding, training, and providing biomedical health care. Feminist perspectives on health and illness have been incorporated into medical and nursing schools' curricula, but they need to be reinforced in clinical training and built into day-to-day practices by organizational policies that encourage enough time for listening to patients and pay for diverse types of treatment. These are idealistic goals, but when shared by both providers and consumers of care, they empower many who might otherwise find it difficult to confront the limitations of current biomedical health care systems.

Notes

1. See Freidson 1970a, 1970b; Mishler 1981, 1984; Waitzkin 1983, 1991.
2. For overall feminist critiques, see Fisher 1986; Martin 1992; Todd 1989; Ruzek 1978.
3. For theories of the social body, see Featherstone et al. 1991; Shilling 1993; Turner 1984, 1992.

Women Get Sicker, but Men Die Quicker: Social Epidemiology

In any gender-dichotomized society, the fact that we are born biologically female or male means that our environments will be different: we will live different lives. Because our biology and how we live are dialectically related and build on one another, we cannot vary gender and hold the environment constant. (Hubbard 1990: 128)

There is a saying in epidemiology—"women get sicker, but men die quicker." It is a succinct way of summing up the illness and death rates of women and men in modern industrialized societies. These rates are the cumulative effects of social, environmental, and physical processes and of individual, community, and society-wide behaviors. To a very great extent, they reflect the gender system and the effects of differential life experiences of racial ethnic groups.

Social epidemiology studies disease and death rates from a perspective that emphasizes "the social distribution and social determinants of states of health" (Berkman and Kawachi 2000). The social epidemiologist's task is to explain variances in *morbidity* (rates of illness) and *mortality* (rates of death) and to tease out the causes of persistent group differences. The most familiar rates are those for life expectancy, which are a kind of summary of the physical, environmental, and social conditions that affect how long a newborn can expect to live.

In industrialized countries, in the early years of the twentieth century, women started to outlive men by several years. In the new century, in the