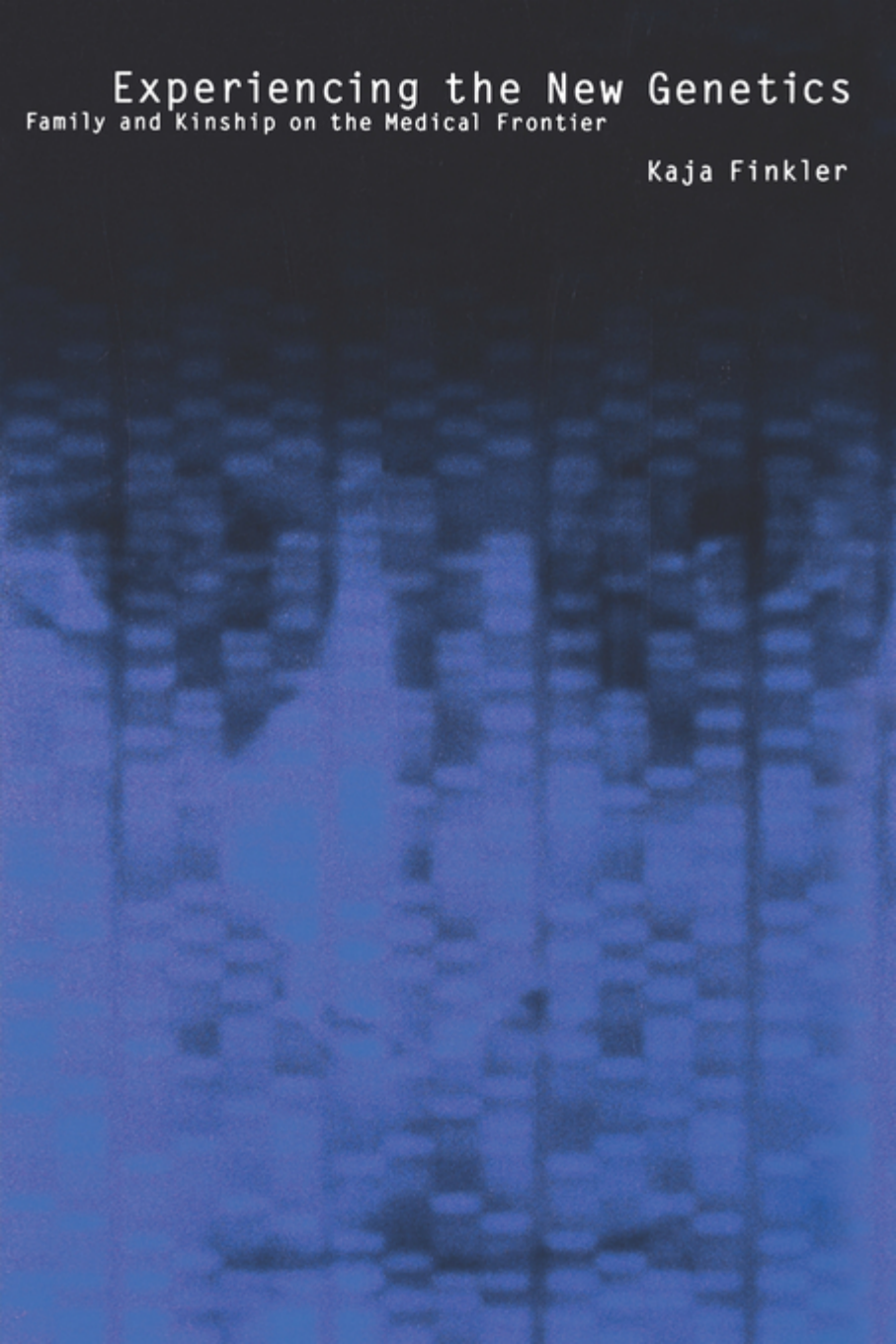
Experiencing the New Genetics

Family and Kinship on the Medical Frontier

Kaja Finkler



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In memory of all my loved ones
and the multitude of others who perished on pyres
fueled by an ideology of biological determinism

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Preface

During a span of twenty-five years as a medical anthropologist, my concern has been with various issues in economically developing nations, especially problems in medical anthropology. Whereas initially my research had focused on peasant economics and politics in Mexico, where I did fieldwork for eight years, as well as other parts of Latin America,[1] for the past twenty-three years I have examined interrelated questions in medical anthropology, including the efficacy of Spiritualist healing, the cultural transformations of biomedical practice, and questions bearing on women's health.[2] In my work on Mexican Spiritualism and biomedicine, my chief interest was with how therapeutic practices, treatment outcomes, and sickness and its alleviation reveal the cultural nature of medical systems and the experience of sickness. During the course of my investigation of biomedical practice and patient response, I found that, among the poor people that I studied, the notion of genetic inheritance was one of several cultural beliefs people held about sickness etiologies.[3] Hereditarian beliefs diffused to Mexico from Europe through biomedical practice and became one of many Mexican folk etiological explanations.[4] After I returned to the United States, I became especially intrigued by the concept of heredity and its origins and I wondered how these ideas impacted on people's interaction with their families, who, after all, presumably transmit diseases to their offspring.

In my training as an anthropologist, I was required to take a comparative perspective on any phenomena I observed in another culture. Having been raised in a European culture and grown up in the United States, I was particularly sensitive to cultural differences, and in my field stays I usually compared American practices with those of other cultures. My interest was therefore piqued by my Mexican findings concerning hereditary beliefs. Inasmuch as conceptualizations of familial inheritance of disease form part of contemporary biomedicine, I turned my anthropo-

logical gaze on the source of these developments in American society, particularly on the impact of the ideology of genetic inheritance on people's experience and especially within the context of family and kinship relationships.

As a graduate student in anthropology during the late 1960s and early 1970s, I was expected to do fieldwork in a foreign land and to become immersed in a culture other than my own, an expectation that also represents a common view of the anthropological enterprise, or what anthropologists do. Reading a book by an anthropologist, an American reader socialized into the dominant culture may thus anticipate learning about some exotic society rather than about his or her own beliefs and practices, but currently anthropologists have rightly moved to analyzing their own society, cultural beliefs, and practices as well. This book thus grew out of a confluence of my past research and my present interests. But in addition to academic concerns this project also emerged out of various personal experiences. On my first visit to a physician for a minor condition, he asked me for a family medical history. I indicated that one of my aunts had died of cancer. Although she was an aunt by marriage, I did not specify and the doctor did not inquire as to the precise genealogical tie between this aunt and myself. On hearing that someone in my family had cancer, the doctor immediately insisted that I needed a complex and costly examination because I was "predisposed" to cancer, and because my condition might eventually develop into the same disease from which my aunt had died. The exchange stirred up memories of a beloved I had only thought about intermittently since her death fifteen years earlier. I realized that the physician had reawakened memories of my kinship connections to my mother's brother's wife, even though she was not even genetically related to me. Another telling and also poignant scene stood out in my mind, when I spoke with a young student about her future plans. She reported that her future might be in jeopardy because she greatly feared becoming an alcoholic. When I inquired into the basis of this fear, she responded that alcoholism was part of her genetic heritage: both her parents were alcoholics, and she was convinced that it was inevitable for her to suffer the same fate. But perhaps on a deeper level, I began to focus on the implications of beliefs in genetic inheritance and the ideology of biological determinism in which they are embedded because, taken to an extreme, it had led to the extermination of my family during World War II.

Whereas I present a *multidimensional* perspective on the repercussions of biological determinism, I nevertheless consider it a moral right to express my concern with the current proliferation of beliefs in genetic inheritance.[5] In my studies in Mexico I noted that various local beliefs and practices might have an adverse impact, but I hesitated to critique

them, even when informants did so, because I was a foreigner. I felt anger and outrage when I witnessed the power men wielded over women,[6] resulting from gender ideologies and economic circumstance, or the abominable treatment to which poor men and women in general were subjected by the authorities. But since I am a part of mainstream American society and since biomedical ideologies, including beliefs in genetic inheritance, comprise, in part, my heritage, I do not feel the same constraints as I did in Mexico. Nevertheless, I have attempted to examine our beliefs in genetic inheritance from various standpoints. Ultimately, however, as in my previous work, the concepts I advance flow not solely from theoretical considerations or moral indignation but also from my association with the people I interviewed for this study. Their insights into the role that genetic inheritance plays in their lives were incisive and enriching and have led me to a multilevel analysis of the contemporary ideology of genetic inheritance.

Originally, I designed this research as a comparative study of the ways people in Mexico and the United States interpret genetic inheritance, which I would conduct by drawing on samples of people in both societies. I interviewed women residing in the southern part of the United States who either had suffered from breast cancer or originated from families with histories of cancer, and adoptees who had searched for or already located their birth parents. Unfortunately, I was unable to locate comparable populations to the ones I had studied in the United States during a field trip to Mexico in 1998. Instead, I interviewed the section heads of genetic counseling units in two of the largest hospitals in Mexico City[7] as well as the head of the breast cancer unit of the oncology hospital.[8] At all three sites I was informed that breast cancer was not usually regarded by physicians as a genetically inherited disease and that none of the physicians ever referred patients with breast cancer to genetic counselors, irrespective of whether any member of a patient's family had experienced the disease.[9] I interviewed sixteen women with breast cancer there, referred to me by a psychiatrist who heads a support group for women afflicted with this disease; *all* believed that their breast cancer was caused by a physical blow, a *golpe*, and none associated it with a family inheritance.

To compare the adoptees here with those in Mexico, I interviewed there the heads of the Association of Adoptive Parents. According to them, adoption in Mexico is an informal procedure, and most children are aware that they have been adopted; most even know their birth parents. There is no movement among adoptees to search for their birth parents, nor had the persons I interviewed ever met an adoptee who had attempted to do so. During my many years in Mexico, I had observed that children from very poor families were given as "gifts" to more fortunate members of their own families or to godparents, but the children were

always aware of their birth parents. Hence, while I make reference to Mexico in the present work, given the lack of comparable populations in Mexico and the United States, my research focus has necessarily remained on U.S. society, where the contemporary ideology of genetic inheritance has largely developed.

Anthropological fieldwork in my own society felt very different from fieldwork in a foreign setting. When I carried out research in Mexico, I was totally immersed in and enveloped by the society and culture. For example, when I studied Spiritualist healing, I was required to become a participant, not only an observer, in ritual and religious healing and training to become a healer, as well as to act as an assistant to the healers. In the study of biomedical practice, I was continually involved in the activities of the outpatient clinic where I carried out the investigation of its patients and physicians.

In this study I used a multisited ethnographic approach. I was not confined by any one specific research site or encompassed by it, as I was accustomed to. The people I interviewed originated from different parts of the United States, although most resided within the university town or its environs and, for the most part, represented varying levels of the American middle class. I usually conducted the interviews in people's homes, where I was received with great warmth and hospitality, but I did not feel the same immersion here as I did in Mexico, other than being a member of the same society.

Whereas my adult cultural understandings paralleled those of the people in this study, my childhood cultural background was built on different assumptions rooted in a religious ideology. Taking into account the role genetic inheritance plays in our lives, I was led to conjure up my personal cultural background and especially to meditate on the way I was named. For instance, with few exceptions all the people in this study—profoundly religious or not—to a varying degree accept concepts of genetic inheritance concerning the length of their life span. In my cultural experience, however, it was believed that the ancestor whose name he or she bore rather than his or her genes chiefly influenced a person's life span. I was initially named after a grandmother who had died at a very young age, and therefore my father insisted that the name of a grandmother who had lived to be 95 years old be added in order that I bear the name of at least one long-lived family forerunner. Longevity thus rested with a name rather than with a gene, or with a lifestyle for that matter.

As an academician and an anthropologist, as well as an informed citizen, I learned to question my own cultural childhood beliefs, in the same way I question the dominant cultural beliefs and practices that have emerged out of the Enlightenment and out of scientific conceptualizations. The impermanent nature of scientific knowledge, including bio-

medical information, invites such questioning because such knowledge is transient, as ideally scientific practice ought to be, but it is also contingent on its social and cultural milieu.[10] As we will see, this knowledge exerts extraordinary influence on people's experience, not only because it is authoritative and explains suffering, but also because it plays on people's fears and vulnerabilities.

This book builds, of course, on the work of many scholars. It also moves among several disciplines. The study was guided by several hypotheses, but I employ an interpretative anthropological microscope in analyzing my findings. The data are based on illness histories and personal narratives. The phenomenological perspective I take does not lend itself to quantification or objective tabulations, and for this reason I cannot say to what degree my findings are generalizable to all Americans. However, I can say that no individual life is ever generalizable, but that one life sheds light on the universals of human existence; to wit, each human life speaks for itself and also for all humanity. I do anticipate that this work will generate hypotheses for other scholars to test on large population samples.

While all the interviews were open-ended, I began each with an explanation of the purpose of the study and with what I characterize elsewhere as a trigger question that allowed each person to respond in her own way.[11] All the interviews were tape-recorded with permission and transcribed. I extracted the major themes of each narrative from these transcriptions, and these themes are reflected in my analysis. As I discuss elsewhere, tensions usually exist in human life between individual agents and the constraints imposed on them by the societal ideologies to which they adhere.[12] In the same vein, this dialectical tension is reflected in my analysis of the interviews I conducted. For, while my culturally construed understanding regards people as agents of their existence impelled by their subjectivity, I recognize that they are nevertheless also governed by regnant ideologies, which structure their beliefs and actions and which in turn contribute to shaping their cultural ideologies and practices in an ongoing structuration process.[13] Because human beings are not passive receptacles for the cultural ideologies they learn, I take a phenomenological perspective. My point of departure is subjectively perceived and interpreted experience in tandem with the actualities and the cultural and ideological templates in which daily existence is played out. Although the subject's perspective elucidates her own life, it is necessary to interject at least one caveat: human beings themselves do not always recognize the consequences of their own ideological beliefs. Our subjectivity restrains us from seeing our existence in its totality. There are, thus, limits to which we can understand our subjectivity. Hence, when people discussed their beliefs about genetic inheritance but could not elaborate on how their subjectivity connected with their actions or on the ways in

which it affected their lives and their familial relations, I brought out the anthropological microscope to assist in further interpretation.

For some people, our interaction may have led them to consider the role of genetic ideologies in ways they had not done before, perhaps because on a very elemental level we take for granted our underlying cultural comprehension and rarely examine it in the course of our daily lives. On another level, people would spontaneously refer to their family and kin relations and their basic notions about heredity when they discussed the fact that their sickness was familial; when they recounted their search for their birth parents because they desired to learn their medical history; or when they noted that they had inherited all their physical and behavioral characteristics from birth parents whom they had never met. To gain an understanding of adoptees' motives for searching for their biological parents, in addition to the interviews I participated in their monthly support group meetings during a period of six months, and I also consulted the World Wide Web, where various sites exist describing adoptees' strategies for searches.

This book is both a practical and a theoretical endeavor. It is intended to instruct about some historical and contemporary aspects of kinship and genetics, to raise questions and to analyze a prevailing biomedical ideology in American society within the context of people's experience, and to contribute to a theoretical understanding of one important facet of present day life. It will be of interest first and foremost to students and to social scientists, especially those concerned with kinship and family, medical anthropologists, scholars in social medicine, and other health professionals attentive to biomedical ideologies and their impact on human experience, as well as to cultural analysts. It is my hope, too, that the book will help the informed general reader make sense of one facet of contemporary life, especially since he or she is unceasingly bombarded by the mass media presentations that a person's health and existence are determined by genetic inheritance and family medical history.

One last point needs to be made. Some readers may find this presentation unbalanced. If so, I can say in my defense that readers may take for granted their views relating to the ideology of genetic inheritance, comprising part of our commonsense knowledge, because they form part of our dominant culture and are constantly presented in professional knowledge as well as popular accounts.[14] But the more critical view is not heard as frequently. According to some, in the 1920s and 1930s few people stood up publicly to oppose genetic and eugenic claims. At present, various serious scholars have addressed some questions raised here,[15] but ongoing critical appraisals are necessary in order for people to gain a multiperspectival perception of the subject to which I hope to contribute with this book.

Chapter 1
Introduction

In the past several decades there has been an explosion of research in genetics and genetic inheritance both in the scientific literature and in the mass media.[1] Not a day passes without some mention of genetics, genetic engineering, or genetic inheritance in the popular press, on radio and television, and in health newsletters. Indeed, the executive editor of the *New England Journal of Medicine,* Marcia Angell, could have been speaking about notions of genetics when she noted the great impact scientific research has on the public: "No sooner do we publish a study on diet or life style than news of its conclusions, though virtually none of its qualifying details, hits the airwaves. Within 24 hours, millions of people consider eating fewer egg yolks or more oat bran to fend off disease."[2] Moreover, as Turner observes, the "mass media foster attitudes of technological and scientific determinism by implying that scientific 'progress' cannot be halted"[3] and that it is a miraculous achievement. In fact, one of the most discussed scientific endeavors has been the Human Genome Project (HGP), which aims at mapping the entire human genome for the benefit of mankind. This new genetics forms part of contemporary biomedicine and forecasts great advances in alleviating disease and prolonging human life.[4]

Clearly, research in the genetic inheritance of disease and behavioral characteristics constitutes the cutting edge of modern science and biomedicine, but the scientific literature is out of reach of the layperson. The mass media present discoveries in genetics, and especially the HGP, as a dazzling new frontier, comparable to the discovery of the New World,[5] the wonders of the automobile, the mastery of electricity at the beginning of the twentieth century, and the space program of the mid-twentieth century. These reports describe the new trend toward the geneticization of existence as a fantastic advance in scientific achievement.[6] Arguably, one of the most thoughtful articles on the subject of genetically inherited diseases was written by Charles Siebert in the *New York Times Sunday*

Magazine. He writes: "Genes are suddenly thought to be responsible for everything from poverty to privilege, from misdemeanors to murder. I seem to recall watching television one night and seeing a man up on homicide charges offer as a defense the presence of a 'criminal gene,' which he claimed ran in his family." Siebert notes examples of headlines in the popular press, like the cover story in one news magazine: "Infidelity: It May Be in Your Genes."[7]

Siebert's article is one of an ongoing array of publications and broadcasts regarding the ways genetic inheritance purportedly determines all aspects of our existence and especially our afflictions. It is now thought that mental illness, stress, risktaking, shyness, social effectiveness, homosexuality, job success, exhibitionism, arson, traditionalism, and even a zest for life,[8] as well as learning problems, vulnerability to smoking, and gender differences,[9] derive from our genetic makeup, forming part of people's commonsense consciousness. While some reports do note that the "biological century will bring myriad moral and legal conundrums,"[10] most accounts fail to question the social consequences or critically examine the trend of the new genetics.[11] More common is the indiscriminate acceptance of notions about genetic determinism and the embrace of the HGP as the panacea for all ills.[12] The recent reports about cloned sheep have, undoubtedly, contributed to the propagation of "genetic essentialism," indicating that humans, too, are a product of their genes.[13]

Ideas about the genetic inheritance of disease place the family and kin group in the spotlight, requiring the scrutiny of all its members. In the August 15, 1996, *Wall Street Journal,* for example, one headline read, "One Family's Search for a Faulty Gene."[14] On the same page another headline announced, "Doctors Recommend Every Family Make Its Own Medical Tree."[15] A September 1996 *Consumer Reports* headline read, "Family History: What You Don't Know Can Kill You." The article informs the reader that deadly diseases "can be influenced or even determined by hereditary factors."[16] Family magazines recommend that individuals work out genograms and family health pedigrees as a way of predicting the future of their children. A Mother's Day card reminds the mother, "It's all in our genes."[17] Or in an article concerning colon cancer, Matthews reports that doctors tell patients that "you may think you have no risk factors, *but unless you know exactly what your great-grandmother and assorted other relatives died of, you could be carrying an abnormal regulatory gene* . . . that has been performing OK for generations until—kerplooie!" (emphasis added).[18]

As long as people are healthy and fertile, they may be aware that genes determine their health and their beings, but they may not give the matter much thought until they are touched personally, when they fall seriously ill and are asked by their physician for a family medical history. At such time the family and kin group enters the person's consciousness in a new