

The Gene and the Genie

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The Gene and the Genie

Tradition, Medicalization and
Genetic Counseling in a Bedouin
Community in Israel

Aviad E. Raz

BEN-GURION UNIVERSITY OF THE NEGEV

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Medical Anthropology Series Editors' Preface

Pamela J. Stewart and Andrew Strathern

In Aviad Raz's book we see an issue of global concern, i.e., genetic counseling, being analyzed in relation to religion, ethics, morality, and medical practice. The practices of genetic counseling, in terms of biomedicine, are themselves continuously changing as new developments in human genetics (e.g., new technologies and further research in mapping the human genome) occur. Numbers of different genetic screening tests are available to patients, including prenatal tests that screen for disorders in the fetus, carrier testing to check for the possibility of an individual carrying a particular genetic marker, and susceptibility tests to determine if a person is at higher risk of developing a particular disease. The philosophy of genetic counseling is impacted by a myriad of complex ethical, social, legal, religious, and educational issues. The specific location of the project presented in this book is a Bedouin Community in Israel but the implications and considerations are ones that apply to many other areas, e.g., the USA, Canada, Europe, the Pacific, etc.

Genetic counseling is a growing field in which health care professionals, working in conjunction with a team of health care workers, offer information and provide support to families who have members with birth defects or genetic disorders, or to individuals who are affected with a genetic condition, or to families in high risk categories for genetically transmitted health conditions. The type of advice offered to patients varies but may include: ways to comprehend medical diagnosis; information on the mechanisms by which heredity contributes to a disorder and the risk of a recurrence in particular relatives; explanations of alternatives available to patients for dealing with risk of recurrence; suggestions of particular courses of action which take into consideration the moral and religious feelings of the patients and their family; and means by which the affected person(s) can make life adjustments to the disorder or the possible risk of recurrence of a disorder.

One of the dilemmas involved in genetic testing and counseling is the question of how genetic information alters an individual's sense of "self" in terms of their relationship to others and their religious beliefs about wellness and morality. Other concerns are how genetic information may be used to a patient's disadvantage through genetic discrimination in regard to health insurance or employment, eligibility to marry and procreate, or loss of medical history privacy in general.

Aviad Raz's ethnographic explorations of the considerations and concerns over genetic testing and counseling in his research community are deftly presented. This work will be of interest to the general reader, those interested in health care practices, and also as a text to supplement courses on bioethics, applied medical anthropology, critical medical anthropology, and genetic ethics.

Of particular interest in this study is Raz's discussion of the role played by Bedouin marriage practices, specifically the norm of patrilineal cousin marriage, along with a religiously based ban on abortion. He portrays the processes whereby both counselors and marriage partners negotiate and exercise agency over their problems in relation to these roles. Similar problems are faced by parents in places such as Saudi Arabia where spinal muscular atrophy can result from consanguineous marriage patterns. "Consanguinity" in Raz's usage, usually refers to these patterns.

We are very pleased to include Aviad Raz's book in the Ethnographic Studies in Medical Anthropology Series. The other titles in this Series include:

"Curing and Healing: Medical Anthropology in Global Perspective", 1999
(by Andrew Strathern and Pamela J. Stewart).

"Healing the Modern in a Central Javanese City", 2001 (by Steve Ferzacca)

"Physicians at Work, Patients in Pain, 2nd edition", 2001 (by Kaja Finkler).

"Endangered Species: Health, Illness and Death among Madagascar's People of the Forest", 2002 (by Janice Harper).

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(by Douglass Drozdow-St. Christian).

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