

The Gene and the Genie

Carolina Academic Press
Medical Anthropology Series

Pamela J. Stewart *and* Andrew Strathern
Series Editors



Curing and Healing
Medical Anthropology in Global Perspective
Andrew Strathern *and* Pamela Stewart

Physicians at Work, Patients in Pain, 2nd Edition
Biomedical Practice and Patient Response in Mexico
Kaja Finkler

Healing the Modern in a Central Javanese City
Steve Ferzacca

Elusive Fragments
Making Power, Propriety and Health in Samoa
Douglass D. Drozdow-St. Christian

Endangered Species
Health, Illness, and Death Among Madagascar's People of the Forest
Janice Harper

The Practice of Concern
Ritual, Well-Being, and Aging in Rural Japan
John W. Traphagan

The Gene and the Genie
Tradition, Medicalization and Genetic Counseling
in a Bedouin Community in Israel
Aviad E. Raz

Social Discord and Bodily Disorders
Healing Among the Yupno of Papua New Guinea
Verena Keck



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

CAROLINA ACADEMIC PRESS
Durham, North Carolina

Copyright © 2005
Aviad E. Raz
All Rights Reserved

Library of Congress Cataloging-in-Publication Data

Raz, Aviad E., 1968-

The gene and the genie : tradition, medicalization, and genetic counseling in
a Bedouin community in Israel / by Aviad E. Raz.

p. cm.

Includes bibliographical references.

ISBN 0-89089-448-5

1. Genetic counseling -- Israel. 2. Bedouins -- Medical care -- Israel. I. Title.

RB155.7.R39 2004

362.196'042'095694--dc22

2003027142

CAROLINA ACADEMIC PRESS

700 Kent Street

Durham, North Carolina 27701

Telephone (919) 489-7486

Fax (919) 493-5668

www.cap-press.com

Printed in the United States of America

Contents

| | |
|---|-----------|
| List of Tables and Figures | ix |
| Medical Anthropology Series Editors' Preface | xi |
| Acknowledgments | xiii |
| Introduction | xv |
| The Book's Composition | xx |
| Chapter 1 The Rationale, Role and Dilemmas of Genetic Counseling | 3 |
| Perspectives on Nondirectiveness versus Eugenics | 4 |
| Genetic Counseling and Medicalization | 7 |
| Geneticization and Public Policy | 8 |
| Genetic Counseling in the Community | 10 |
| Models of Community-Based Programs for Genetic Counseling | 10 |
| Genetic Counseling for Inherited Hearing Loss and Thalassemia: Two Concepts of "Genetic Community" | 12 |
| Consanguinity and Genetic Counseling | 14 |
| Genetic Counseling as an Arena for Symbolic Interaction | 18 |
| Genetic Counseling in the Socio-Cultural Context of Bedouin-Israeli Relations | 20 |
| Chapter 2 The Setting | 27 |
| The Bedouin As a Target Community for Genetic Counseling | 28 |
| The Background of the Genetics Program | 31 |
| The Social Construction of Congenital Hearing Loss among the Bedouin | 34 |

| | |
|---|-----|
| The Design of the Program for Carrier Matching | 37 |
| Methodological Considerations | 38 |
| Researching and Intervening: Ethnographic Reflection | 42 |
| Chapter 3 Biomedical Culture and Ethical Dilemmas: The Professionals' Point-of-View | 51 |
| The Dilemma of Disclosure | 51 |
| The Dilemma of Nondirectiveness and Autonomy | 53 |
| The Dilemma of the Disease's Mildness | 55 |
| Bioethical Criteria for Genetic Screening | 59 |
| The Point-of-View of Bedouin Health Professionals | 62 |
| Chapter 4 Utilization and Attitudes: The Bedouin Point-of-View | 75 |
| Basic Information Regarding Consanguinity Levels, Education, Religiosity and Prevalence of Genetic Testing | 76 |
| The Instruction Session | 79 |
| The Counseling Session | 86 |
| The Bedouin Agenda | 88 |
| Attitudes of Bedouin Women | 91 |
| Etiology and Heredity | 92 |
| Carrier Matching | 94 |
| Abortion | 96 |
| Chapter 5 Cross-Cultural Genetics Education: Between Acculturation and Ambivalence | 99 |
| Knowledge of Basic Genetic Information | 100 |
| Attitudes towards Genetic Counseling | 101 |
| Correlation between Knowledge and Attitudes | 103 |
| Susceptibility, Knowledge and Attitudes | 103 |
| Chapter 6 Questions of Reception | 107 |
| "Āysha": Staging the Drama of Carrier Matching | 107 |
| The Script and Its Versions | 109 |
| Audience Reception | 114 |

| | |
|---|-----|
| Teachers' and Pupils' Views on the Authenticity and Efficiency of the Film | 114 |
| Perceptions of Consanguinity | 116 |
| Genetic Tests | 117 |
| Abortion | 118 |
| To Match or Not To Match? | 119 |
| Nondirectiveness and Its Lay Interpretations | 121 |
| Questionnaire Development | 122 |
| The Use of Optimistic vs. Pessimistic Questionnaire Versions | 122 |
| Study Recruitment and Questionnaire Administration | 123 |
| Results | 124 |
| The Bedouin As an Interpretive Community | 128 |
| Conclusion: Beyond a Western Bioethics? | |
| The Future of Community Genetics | 135 |
| Cousin Marriage and Carrier Matching | 136 |
| The Jewish-Bedouin Situation | 138 |
| Speaking of Agendas | 140 |
| Communitarian and Liberal Perspectives on Community Genetics | 141 |
| Appendix: Questionnaire Assessing the Interpretation of Counseling | 145 |
| Glossary | 147 |
| References Cited | 151 |
| Index | 167 |

List of Tables and Figures

Tables

| | |
|---|-----|
| Table 1. Educational Levels in the Targeted Population | 77 |
| Table 2. Prevalence and Degree of Consanguinity in the Study Group | 78 |
| Table 3. Distribution of Age in Tested Individuals | 78 |
| Table 4. Frequency of Correct Results for Teachers and Pupils | 101 |
| Table 5. Hypothetical Decisions of Teachers and Schoolchildren about Personal Use of Premarital Genetic Testing | 102 |
| Table 6. General Attitudes towards Genetic Testing | 102 |
| Table 7. Socio-Demographic Characteristics of the Study Sample | 124 |
| Table 8. Selections of Jewish and Bedouin Students in the “Pessimistic” Version | 127 |
| Table 9. Selections of Jewish and Bedouin Students in the “Optimistic” Version | 129 |
| Table 10. Selections of Jewish and Bedouin Students Regarding the Goal of Counseling | 130 |

Figures

| | |
|--|-----|
| Figure 1. Diagram of Mendelian Heredity of Recessive Traits | 81 |
| Figure 2. Diagram of a “Typical Bedouin Pedigree,” Illustrating the Linkage between Consanguinity and Recessive Diseases | 82 |
| Figure 3. Diagram of First-Cousin Consanguinity with an Affected Child | 83 |
| Figure 4. Depiction of Mutation in Flip-Chart for Instruction | 84 |
| Figure 5. Interpretation of Nondirectiveness Measured by Percent of Selections in Each Group, Version 1 (“Pessimistic”) | 125 |
| Figure 6. Interpretation of Nondirectiveness Measured by Percent of Selections in Each Group, Version 2 (“Optimistic”) | 125 |

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).

"Elusive Fragments: Making Power, Propriety, and Health in Samoa", 2002
(by Douglass Drozdow-St. Christian).

May 2003
Department of Anthropology
University of Pittsburgh
Pittsburgh, PA 15260
USA

Acknowledgments

The two worlds studied in this book comprise people whose help and cooperation have kept this research going. I am grateful to the many members of the Bedouin community studied here, who devoted precious time to my inquiries and were kind enough to let me into their homes and their lives. This study would not have been possible without their help and hospitality. I am particularly grateful to ‘Abd al-Muaati al-Sāyyed and Dina Shahāda, whose contribution as community-outreach assistants was invaluable. I am equally indebted to the health professionals who introduced me to the genetics project and shared their thoughts and quandaries with me. I am indebted to Ha’lil al-Ba’dūr, Ā’māl abu-Sā’ad, Hana Beit-Or, and all the genetic counselors at the Genetics Institute. I would like to acknowledge the cooperation of Rivka Carmi and Ilana Shoham-Vardi, who initiated and oversaw the project described here and who were responsible for the tremendous genetic and epidemiological work that preceded this project. This study could not have taken place without their collaboration, and it benefited from their wisdom and experience. Thanks to Joel Zlotogora for explaining his approach to community genetics and the uses of the “Family Tree” software program in data analysis.

I am grateful to Marcela Ātar, Maya Rodnāi, and Muhammad al-Dāda, my graduate students at the Dept. of Behavioral Sciences, Ben-Gurion University, for their help in data collection and analysis. Special thanks go to Marcela, whose research skills and insights helped to shape the ideas and analyses that appear here. This research contains data collected by Marcela as part of her PhD study, a study she is presently pursuing in order to further explore the issue of genetic counseling to the Bedouin.

Among my academic colleagues, I am particularly indebted to Gideon Kressel, who saw the potential in this study and sharpened my perception of the culture of cousin marriage. The International Workshop on Health and Illness in Middle-East Societies, organized in April–May 2002 by Aref Abu-Rabi’a in the Dept. of Middle-East Studies at Ben-Gurion University of the Negev, provided a well-appreciated opportunity for sharing my ideas. I am also grateful to Ruth Chadwick for her useful comments on earlier versions.

My bioethical sensibilities were shaped in discussions held at the Advanced European Bioethics Course “Ethics and Genetics,” November 2000, at the University of Nijmegen, The Netherlands. I am particularly grateful, in this context, to Roberto Del’Orro, Nora Groce and Eric Juengst, who strengthened my conviction that bioethics should be studied in the community. Thanks are due, as always, to Norman Denzin for planting the seed of symbolic interactionism in me and for cultivating it through his continuing support. I am indebted to Pamela Stewart and Andrew Strathern, co-editors of this Medical Anthropology Series, for their close reading of the manuscript and incisive comments. This study was funded by grants from the Israel Foundation Trustees (project PS14/3) and the Israel Science Foundation (grant # 769/00-2) for which, needless to say, I am very grateful.

As always, I am deeply grateful to my wife, Ayala, for her continuing support, and to my sons, Orr, Yoav and Hillel, for the strength and happiness they give me.

Large portions of the following papers are reprinted in this book by permission of the publisher. Raz, Aviad & Marcela Atar, (2004), “Upright Generations of the Future,” *Journal of Contemporary Ethnography* 33(3): 296–323, Sage Publications, Inc.; Raz, Aviad (2003), “Āysha: Genetics Education and Community Engagement in a Consanguineous Arab-Bedouin Population in Israel,” *Health: The Inter-Disciplinary Journal for the Social Study of Health and Illness* 7(4): 32–56, Sage Publications Ltd; Raz, Aviad & Marcela Atar, (2003), “Nondirectiveness and Its Lay Interpretations: The Effect of Counseling Style, Ethnicity and Culture on Attitudes towards Genetic Counseling,” *Journal of Genetic Counseling*, 12(4): 313–31, Kluwer Academic/Plenum Publishers; and Raz, Aviad, Atar, Marcela, Rodnai, Maya, Shoham-Vardi, Ilana & Rivka Carmi, (2003), “Between Acculturation and Ambivalence: Knowledge of and Attitudes towards Genetic Counseling in an Arab-Bedouin Population in Israel,” *Community Genetics* 193, S. Karger AG, Basel.

A.E.R