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VOLUME 34

The titles published in this series are listed at the end of this volume.

A Life (Un)Worthy of Living
Reproductive Genetics in Israel
and Germany

by

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 Springer

A C.I.P. Catalogue record for this book is available from the Library of Congress.

ISBN 978-1-4020-5217-0 (HB)
ISBN 978-1-4020-5218-7 (e-book)

Published by Springer,
P.O. Box 17, 3300 AA Dordrecht, The Netherlands.

www.springer.com

Printed on acid-free paper

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This work is dedicated to the late Prof. Wertz, a symbol of academic cooperation and generosity, as well as to my beloved spouse Ido Dolev and our two boys, Ori and Yoav, who are my pride and joy.

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ACKNOWLEDGEMENTS

It is a great pleasure to acknowledge all the people in Israel and Germany who contributed to this research throughout its different stages and helped me to accomplish the work. First among them I wish to thank Yehouda Shenhav and Haim Hazan, who supervised my Ph.D. dissertation, for their tremendous intellectual inspiration ever since I joined the department for Sociology and Anthropology at T.A. University. To Yehouda Shenhav I am grateful for an enormous contribution to this work, in all its theoretical and practical ups and downs, for his excellent critical reading and above all, for being a caring friend and mentor. Haim Hazan has always been there to support and guide me with his brilliant observations, which helped me to frame my thoughts and with his outstanding humor, wisdom and encouragement for which I wish to thank him. I am deeply thankful to Rivka Carmi, who encouraged me to study her field of medical genetics, for her continual support and open mindedness to a sociological way of thinking. Hanna Herzog has always assisted me with caring advice and trust in the importance of my work, for which I am very grateful.

I would like to thank many people in Germany, who have made this research possible, as well as making the time my family and I spent in Cologne pleasurable. First of all I would like to thank Ute Deichmann, who helped me intellectually, practically and morally and became my good friend as a wonderful by-product of this project.

Similarly, I wish to thank Benno Mueller-Hill for his support, for our interesting talks and for his courageous writing, which inspired this study. Marcus Paus, who was my assistant in Germany, made my encounter with a foreign society easy and fruitful. He was someone to consult on every possible matter and his advice was always of the best kind. Marcus Paus, Ulla Gelbert and Kornelia and Rudolph Knuebel have been like a family to me while I was staying in Germany, for which I am grateful.

Furthermore, I would like to express my deep gratitude to a network of colleague-friends who guided my work. I am thankful to Barbara Prainsack for her brilliant reading and for a very precious friendship and to Sigal Goldin, Hagai Boaz, Noga Weiner, Nurit Kirsh, Nick John, Shiri Shkedi, Carmel Shalev, Michal Frenkel, Shoham Melamed and Shay Lavi, for providing me with an intellectual support group and companionship. I am also grateful to Eva Illouz for helping me to put things together in the early stages of this work and to Larissa Remennick and Ursula Naue for their valuable comments on different parts of this work.

I wish to thank Nadav Gabai, Svetlana Bolotin, Yasmin Alkalai and Amit Kaplan for their support with the statistical calculations and Orna Donath for helping me

to put some order into the bibliography. I am thankful also to Seffi Stieglitz for her endless care and support throughout my years at TA University.

Additionally, I wish to thank all the German and Israeli genetic counselors who invited me into their offices and homes and gave me so much of their time and consideration. Likewise, I wish to express my gratitude to all the counselors who took the time and effort to fill out a long questionnaire they received by mail from a complete stranger. Without them, this work would not have been possible. Zully Kohan, who headed the Israeli organization of medical geneticists, has offered me much help, for which I wish to express my appreciation.

Outside the academic world, I owe an enormous debt of gratitude to Ido Dolev, my deeply beloved spouse, for sharing my life, for following me to Germany and for supporting me throughout those years. Moreover, I wish to thank my dear parents Gad and Ilana Hashiloni, for their endless love, trust and support. Last but not least, I am grateful to the one and only Angie Silva, my children's nanny.

For funding this project, I am thankful to the Shapira Scholarship Trust awarded by the University of TA, to the Chutik scholarship, awarded by the Women's Studies Forum with the NCJW, to the DAAD (German Academic Exchange Service) short-term scholarship and to the David Horovitz Research Institute on Society and Economy Scholarship.

Yael Hashiloni-Dolev

FOREWORD

A few years ago, at the same time that I was searching for a topic for my Ph.D., I was also planning to become pregnant for the first time. As an educated upper-middle class Israeli, apart from following medical advice and taking folic acid before getting pregnant, everybody around me also went for genetic testing, either prior to pregnancy or in the first stages of pregnancy. The idea of a genetic test reminded me that 29 years ago, before having me, my parents went to a genetic counselor for advice. The reason for their worries was that a year before deciding to have another child (which turned out to be me) my eldest sister, then aged 10, was diagnosed with diabetes. Thus, my parents wanted to know the chances of their future children getting the same disease. Being told that the chances were low, they decided to have me.

And here I was 28 years later. What would I do if a genetic test existed which would tell me whether my fetus is prone to develop diabetes? Would I consider abortion? Could I theoretically abort my beloved sister, who is so many other things besides a diabetic? And what would become of me if my sister did not exist? Would I be the same person at all?

Luckily for me, no genetic test for diabetes exists and I did not have to take difficult decisions. Yet, being intimately familiar with a chronic disease made it emotionally and morally difficult for me to take genetic tests for conditions with which I was basically unfamiliar at that time. Yet, I realized my difficulties were not widely shared by others in my community, who largely accepted reproductive genetics as a scientific blessing, which might (for a while) raise the anxiety level of a pregnant woman but on the whole promises a brighter future for individual parents and families, as well as for society as a whole. Going to the library of social sciences and looking for materials about genetic counseling and Israel, I was shocked to find out how correct my intuition was and how exceptional the Israeli public and professional attitude to reproductive genetics was. The most comprehensive comparative study looking into this issue was the study of Wertz and Fletcher (Wertz and Fletcher, 1993–95) which compared the opinions of geneticists in 37 nations around the world, concerning ethics and genetics. Since at that time Dorothy Wertz had only published a few articles based on the international survey, I had written her asking to learn some more about it.

The following data (Table 1) is extracted from the materials she sent me:

These data simply shocked and amazed me, as it demonstrated not only that Israeli geneticists were shown to be extremely enthusiastic about the personal and social uses of reproductive genetics, but also that German geneticists were found to be extremely cautious concerning the same medical technology, its uses and desirable social outcomes. In fact, Wertz and Fletcher's findings revealed that

TABLE 1. The Percentage of Geneticists Agreeing with Various Statements about the Desirable Use of Reproductive Genetics in Israel, Germany and the US

The Statement	Israel	Germany	USA
An important goal of genetic counseling is to reduce the number of deleterious genes in the population.	14%	0.2%	0.5%
Before marriage, responsible people should know whether they or their prospective partner carries a genetic disorder that could be transmitted to their children.	73%	23%	44%
People at high risk for serious disorders should not have children unless they use prenatal diagnosis and selective abortion.	38%	13%	10%
A woman should have prenatal diagnosis if medically indicated by her age and family history.	68%	34%	38%
It is not fair to a child to bring it into the world with a serious genetic disorder.	68%	18%	40%
It is not fair to a family's other children knowingly to have a child with a disability.	59%	10%	22%
It is socially irresponsible knowingly to bring an infant with a serious genetic disorder into the world in an era of prenatal diagnosis.	68%	8%	26%
The existence of people with severe disabilities makes society more rich and varied.	10%	38%	24%
N	23	255	1084

Israeli and German geneticists were placed on two extremes, one enthusiastic, the other halfhearted, concerning the uses and outcomes of reproductive genetics, while geneticists from all other “advanced liberal societies” (and hence the comparative inclusion of the US in Table 1) were placed somewhere between those two poles.

These findings made me curious to learn more about Israel and Germany. The first being my home land, the second, being the place of origin of three of my four grandparents and a country in which I had spend two influential years of my adolescence. And so, the dramatic differences between the two societies, combined with my personal background and familiarity with both of them, made me decide to make this initial curiosity the topic of my Ph.D. research. I thus became eager to answer questions such as: What is it about Israeli society that makes it endorse reproductive genetics with such enthusiasm and without criticism? What makes Israeli women say yes to prenatal genetic diagnosis and what makes the attitudes of Israeli geneticists different from their counterparts in other “advanced liberal societies”? Likewise, I wanted to understand what makes German geneticists a worldwide exception in their cautious endorsement of updated reproductive genetics,

and a completely opposite picture of Israeli geneticists? What is the role of German history with its murderous racial politics (whose major victims were of course the Jews, who now make up the majority of the Israeli population), in explaining these findings and are there other factors besides the most obvious one of history, which can improve our understanding of this phenomenon?

In a second e-mail to Prof. Wertz I had asked her to learn more about the specific findings from Israel and Germany. To my great surprise and joy, she sent me all the raw data collected in these countries and encouraged me to further analyze it in my own research. I was now left with the question of where was I going to look for explanations for the reported differences and what is going to be the focus of my own work?

Seminal studies concerned with PND (prenatal diagnosis) like those of Rapp (1999) and Katz-Rothman (1986), focused on the experience of women with prenatal genetic diagnosis. As Rapp writes, these women turn into moral pioneers. Situated on a research frontier of the expanding capacity for prenatal genetic diagnosis, they are forced to judge the quality of their own fetuses and to make concrete and embodied decisions about the standards for entry into the human community (Rapp, 1999). However, for the purpose of my own study, German and Israeli women seemed to be too internally diversified as groups for me to compare. Moreover, what I really wanted to understand was not the way women justify their actions and describe their experiences, issues so brightly described by Rapp and Rothman. Rather, I wanted to primarily learn about the institutional and cultural premises and constraints that are shaping women's experience, most of the time without their awareness, and with what I consider to be a false claim about their supposed autonomy, since in fact, women's options are always constrained both by the value-laden technology itself and by their society's prevalent ways of using this technology.

Thus, I decided to put genetic counselors, who are the first contact most people have with what may be the most personal of all the advances of the genetic revolution, under the spotlight of my work. Belonging to the same international professional culture and holding the same knowledge, Israeli and German counselors have very much in common and yet, their opinions differ so sharply. Thus, the focus of my work became studying how scientific knowledge is being played out against a background of national differences and describing how local culture is shaping genetic counselors' practice and knowledge, and *vice versa*. What I found out is that cultural ideas about fetuses, normality, health risks, fertility, science and progress, suffering, family responsibilities and the lessons to be learned from history, create very different worlds of reproductive genetics in both countries under study, which adhere to a dramatically different understanding of the cultural concept of "life" or of "a life (un)worthy of living".

Thus, in line with contemporary thought in the sociology of science and technology, this research is an instance of how science, as a field of knowledge and practice, is culturally embedded and is not above, outside or prior to culture and

for how the powerful universal explanatory claims and technological intervention of science are continually constructed and undercut by local cultures and bodies.

Moving towards the end of this foreword, I now wish to remark about the uses of language in this work.

In the tradition of the sociology of health and medicine and of the body, this work problematizes terms like “birth defects”, “genetic illness”, “late-term abortions”, “selective abortion” (these abortions are also commonly referred to as “therapeutic”, “medical” or “eugenic” abortions, as they all apply to wanted pregnancies, which are terminated due to the fetus’ medical condition) and even “life” itself. Putting such terms in inverted commas serves to point out the difficulty of drawing an objective or “scientific” line between what is a unique trait or a special condition and between diseases or between “early birth” and “late abortion”, which in other words, is the line between a fetus that is entitled to protection and a fetus that is not, since its future life is considered unworthy of living.

In doing this, I do not wish to totally abandon the biological reality of disease or of the different stages of pregnancy, but rather to focus attention on the fact that biological “realities” and permissible acts upon human bodies, are always socially constructed. Furthermore, by questioning such terms, I wish to respect the language and politics of the “abnormal” and the “disabled” themselves.

Another word that I do not often use in this work is eugenics. This is because this term is contaminated by its history (which is itself diversified) and hence, it nowadays often operates as a “buzz word”, which serves to block a contemporary, open, moral debate about the current uses of reproductive genetics (Koch, 2004; Paul, 1992; Pritchard, 2005; Novas and Rose, 2000). As I believe that contemporary reproductive genetics has both its blessings and its burdens (Hadley, 1998) as it is both liberating and discriminating and constraining at the same time, I prefer using the term reproductive genetics and not more critical and biased terms like “voluntary eugenics”(Wertz, 1998) or “free-market eugenics”. This of course does not mean those terms do not portray large parts of the picture of contemporary reproductive genetics, only that they overlook other important parts of the picture, which I do not wish to ignore. Yet, while writing about the past, the term “eugenics” is obviously more appropriate.

The discussion about the uses of language is obviously a discussion about moral attitudes and hence, it leads me to the concluding remarks of this foreword, which have to do with my personal moral judgments. Obviously, what initially made me research this topic was my uneasiness with the practices of Israeli society, with its intolerance towards the genetically deviant and its lack of critical thinking about the moral conflicts embodied in reproductive genetics. Yet, as the research advanced (and I became the mother of two boys) and after getting to know the German field of reproductive genetics, things ceased to be so simple. Whereas Israeli women are generally actively recruited (one may even say: seduced) to take genetic examinations and even to abort fetuses which are, (or are suspected to be) “genetically abnormal”, their German counterparts usually simply do not know or know very little about the options opened up by this new technology. Hence,

German women today give birth to abnormal children who could have been quite easily detected in uterus but their mothers (and fathers) were never exposed to an offer to take the relevant tests. Both situations are troubling to me. Therefore, after thoroughly studying this issue, I cannot take sides with either the strong supporters of reproductive genetics or with its opponents, which all seem to me to be blind to some aspects of human suffering. Thus, I will not take a normative position on the act of prenatal genetic diagnosis itself. However, this does not mean I intend to ignore the moral realm altogether. On the contrary, I intend to engage myself with moral questions by contributing to the public debate about genetic medical technology and by pointing to the different options that post industrialized societies offer to their members, regarding the uses of reproductive genetics. This is especially important because science usually runs ahead of our social ability to make moral judgments about how far technology should be allowed to reconstruct our bodies and society (Beck, 1992), and since science and technology force us to rethink our concept of “life”, a concept which is both natural and cultural. Hence, the modest purpose of this study is not to support any side or to offer guidelines for policy makers, but rather to shed light on the very difficult moral dilemmas embodied in reproductive genetics and on how two different post industrialized societies handle them.

This volume deals with the subject matter as follows

Chapter 1 investigates how “life” is managed in our modern technological era. To begin with, it looks into the relationship between technological change and social change, as it studies the institutional and cultural forces with which a medical innovation is confronted in the process of its implementation within different societies. Subsequently, the chapter discusses the interplay between global professional knowledge and culture (that of reproductive genetics and of genetic counselors) and local cultural-medical definitions. Consequently, it discusses “life” itself as a socio-cultural concept. The chapter next reviews the work of Michel Foucault, which laid the foundation for a critical discussion of the management and disciplining of “life” through modern bodily techniques. However, Foucault’s thesis is somewhat problematic when applied to the study of how the concept of “life” is actually constructed in a specific social context and a distinct late-modern cultural environment. This deficiency requires the application of additional theoretical frameworks to understand the different forms that the “politics of the beginning of life” take in Israel and Germany. A Sociological discussion of the normal and the pathological, as well as of Mary Douglas’ notions of the relationship between “the private body” and “the body politic”, together with Rose’s ideas on present-day “politics of life itself” and Giorgio Agamben’s emphasis on the exclusion of life in modern societies, fill this gap and help the reader to follow the theoretical outline of the book. In its conclusion the chapter turns to explaining this book’s cultural perspective and its choice of analytic tools to study the delicate and problematic concept of “life” within the two studied societies.

Chapter 2 lays out the methodological foundations of this study’s comparative empirical research. These are three-fold:

- A. Quantitative analysis of 295 questionnaires dealing with reproductive genetics that were responded to by genetic counselors in Germany and Israel in two time periods. The first data pool is based on materials collected by Wertz and Fletcher in 1993–95 as part of their cross-national study of ethics and genetics, which I extracted and recoded. The second database is a partial replication of the original study I conducted in 2000–01.
- B. Qualitative analysis comprised 32 in-depth interviews with Israeli and German genetic counselors.
- C. Textual analyses of legal, professional and newspaper materials.

Chapter 3 is dedicated to getting to know the field of reproductive genetics in both nations. It starts with an historical analysis of the evolution of Israel and Germany's reproductive genetic fields. The legislative, institutional, cultural, economic, religious and social aspects of these two societies are explored as the main argument links the political logic of reproductive genetics to the idiosyncratic history of each nation. More specifically, it discusses how actors involved in the field of reproductive genetics in Israel and Germany shape a different perspective to the disturbing question of what is a life (un)worthy of living?

Chapter 4 portrays the major findings of the genetic counselors survey in Israel and Germany. Its findings show Israeli counselors to be far more supportive of selective abortions than their German counterparts. Looking for the social factors behind these differences, the paper examines the effects of the counselors' cultural-national, institutional and personal backgrounds on their attitudes to different issues commonly understood as relevant for genetic counselors' moral practices, such as abortion, eugenics, disability, patient autonomy and the rational-scientific planning of life. It concludes by arguing that: A. Despite the nondirective ethos of genetic counseling around the world, professional practices strongly resonate with their cultural context; B. Cultural-national and religious factors affect counselors' practices over and above structural and professional differences, such as place of training and professional sub-categorizations and personal characteristics, such as gender, age and years of professional experience; C. In contrast to theories that understand science and technology to be powerful social tools, which open up options that almost deterministically become obligations later on, the findings of this survey suggest that the passing of time has not relaxed counselors' moral norms but rather made them somewhat more critical of their practice and its promises.

Chapter 5 discusses the only "remedy" for abnormalities found in fetuses that reproductive genetics can offer today; namely selective abortions. It investigates the different practices of selective and "late" selective abortions in both societies. Its major finding is that "late" selective abortions are far more common in Israel than in Germany. However, it is argued that this difference cannot be attributed solely to the legal system, since both the Israeli and the German abortion laws, despite the cultural differences that are registered in their rhetoric, open quite a wide door for "late" selective abortions. Thus, the chapter argues that "late" selective abortions are far more common in Israel than in Germany due to the professional's mediation

of this process, which is conditioned by local understandings of “viability” and of maternal and fetal relationship and rights.

Chapter 6 discusses a specific group of genetic anomalies, namely sex chromosome anomalies (SCAs), whose major manifestation is future infertility. Its major finding is that the issue of whether SCAs are perceived as a highly risky medical pathology or as a normative variance is related in both cultural spaces to assumptions about the importance of fertility in human life. Whereas in Israel parenthood and the reproduction of the ‘national womb’ is understood to be what human life is all about, German adults do not share this assumption. Accordingly, German counselors do not support abortions on the grounds of SCAs, in contrast to their Israeli counterparts, who understand infertility to endanger the worthiness of life and thus **also** to entail a higher medical risk.

Chapter 7 examines the legal responses to the notion of “wrongful life” in Israel and Germany and shows that whereas the Israeli legal system has declared some forms of life to be “wrongful”, the German legal system has not. Furthermore, it shows that this diverse understanding of the bio-cultural concept of “life” characterizes not just the German and Israeli legal systems but also the positions of genetic counselors and disability organizations in both countries. Thus, the professionals in each state seem to accept the typical logics of justification found in their respective societies concerning the moral dilemmas associated with the concept of a life (un)worthy of living, as far more Israeli than German counselors believe some forms of life to be unworthy of living. Likewise, German disability organizations reject the idea of “wrongful life” and its derivatives, namely genetic tests and selective abortions, as they tend to glorify life with disability and to fear selective abortions devalue their own lives. Alternatively, Israeli disability organizations pose no opposition to the practice of reproductive genetics, and its consequences.

Chapter 8 looks at how the concept of a life (un)worthy of living is incorporated into discussions about the “good society”, family responsibilities, the relationship between generations and a moral humanistic ethos. Its findings demonstrate that whereas most Israeli counselors believe the good society should be composed of a “healthy” population, many of their German counterparts believe the opposite to be true. Thus, the conflict between individuals and society concerning this matter is formulated in a contradictory fashion. German counselors imagine a conflict between individuals’ wish to avoid having abnormal children, and society’s need for genetic diversity and tolerance, as opposed to Israeli counselors who imagine a conflict to result from certain parents’ insistence on carrying problematic pregnancies to term, at the expense of burdening society. This difference is further complicated by the two society’s understandings of the potential conflict between the future child and her family, embodied in reproductive genetics. The repeating themes in the German discourse concerning parents’ choice to accept children with genetic “defects” are that those parents are moral and psychological heroes. By contrast, in Israel, parents’ choice to carry problematic pregnancies to term is mainly understood by genetic counselors not only as a social wrong, but also as unfair to the future child and its siblings.

Epilogue draws upon Agamben's discussion of the ancient Greek terms that served to describe what we now call "life"; *zōē*, which expressed the simple fact of living common to all living beings (animals, men or gods) and *bios*, which indicated the form or way of living proper to an individual or a group. Accordingly, the epilogue rereads the German and Israeli politics of life by asking how these different "advanced liberal" societies incorporate *zōē* and *bios* within their bio-politics and thus how their balancing of *zōē* and *bios* affect their differential practices of reproductive genetics. Consequently, the Israeli hegemonic moral order concerning "life worthy of living" is described as "*bios* bio-politics", in which qualified life begins after birth and even then must be characterized by more than the simple fact of biological existence. On the other hand, the current German hegemonic moral order is described as "*zōē* bio-politics", in which life begins upon fertilization and in which all types of life are considered to be politically qualified. The new concepts of "*zōē* bio-politics" and "*bios* bio-politics" are suggested to serve for a less culturally-bound future study of situations in which contemporary societies have to decide about the borders between life and death and about future technological manipulations of life and their effect on what it means to be a human being who is entitled to social protection.