

Chapter 2

Setting the Methodological Scene: The Value of Explication and Pluralization of Moral Grammars

Bioethics is currently experiencing a tremendous change as it is moving from its previous, formative, “neutral view from above” of principle-based and theory-oriented ethics to a more local, dynamic, and grounded “view from here” (De Vries et al. 2006). The thrust of this shift is derived from contrasting the previously dominant expert discourse with perspectives of non-academics, non-professionals, lay or affected persons. As a possible synthesis of these opposing views we would like to add a third view. It will be substantiated in the ensuing chapters of doing socio-empirical bioethics “through the looking glass.” The act of looking at the image of our familiar culture as it is reflected on by the opposite side has the potential to produce fertile epistemological distancing, a hermeneutic repositioning from which the familiar can be seen in a new light. The metaphor of looking glasses may also be applied to the various microscopic puzzles (as well as ocular regimes of surveillance) faced by people when confronted with medical complications.

The basic methodology underlying our approach can be described as an attempt to come closer to what Habermas (1979) suggested as methodology of “rational reconstruction” of our implicit moral practice. As Habermas pointed out, our social practice of communication is characterized by argumentation—particularly in cases of disagreement. Such arguments can relate to our social world of moral conflicts, (e.g., arguing for the right of privacy), our epistemic world (e.g., arguing for the theory of evolution) or even our inner world (e.g., arguing that we are sad and disappointed). When we start to argue, we enter (according to Habermas) into a discourse. Moral discourses, in particular, force us to question our implicit assumptions or to rationalize hidden presumptions. In other words, we activate our knowledge and interpretation about relevant “cultural scripts.” We borrow the term from sociologist Seale (2000). He used the term “cultural scripts” to address narratives that contain cultural representations of health and illness, for example of a good life and a good death. These cultural representations are disseminated by various means, including official discourse, the media, and so on. Seale (2000), for example, has identified four cultural scripts of dying in Anglophone countries:

modern medicine, revivalism, an anti-revivalist script, and religious scripts. Even though much of dying is defined within the institutional and technical terms of reference of modern medicine, “revivalist” scripts emphasize the psychological aspects and subjective implications of death, arguing that personal acceptance of dying is an important site for the expression of individual autonomy and even personal growth. In contrast, the anti-revivalist script prefers a “closed awareness” of dying (such as not knowing one’s diagnosis and/or prognosis), rejecting the more psychologically-oriented services of hospice nurses, social workers, or other professional supporters. Finally, religions all have their cultural scripts of death reflecting the religious view of (passive/active) euthanasia in the context of the sanctity of life and “not playing God” versus self-determination. Seale stresses that such scripts are not determinative, but rather should be regarded “as raw materials that are strategically (though not always consciously) used in particular situations” (1998, p. 68). People choose between different cultural scripts to deal with their particular circumstances.

2.1 Cultural Scripts Between Generalization and Enacting

While cultural scripts provide broad frames with which to discuss issues of health and illness, they should not be taken as statements of actual behavior, or confused with the ways that people think and act. One of the characteristics of post-modern societies, according to many sociologists, is the lack of master-statuses and master-narratives; the empirical study of ethics should hence examine the various kinds of scripts that are implemented. Even though religion, class or gender still may each have their corresponding “master-narrative,” expressed in social stereotypes, rules, and traditions, their individual expression is often composite and versatile. When lay people express a desire for a meaningful death that is timely, pain-free, and appropriate to the way they have lived, this desire may practically interconnect various elements from different cultural scripts, including modern medicine, revivalism, and religion. Cultural scripts are therefore considered in this study as repertoires of metaphors that lay people may draw upon as they use, modify, combine, or ignore these cultural scripts.

An illustration of this complexity is provided by considering religion as a cultural script. Religious teachings are often regarded as having direct influence on decisions regarding the life course of believers, from reproduction to dying. No doubt religious faith contributes impressively to the cultural variation in attitudes towards reproduction, health, and dying. There are, however, at least three arguments that seriously undermine such generalizations. First, religious denominations such as Christianity or Judaism never imply a singular and monolithic view. For example, whereas higher religiosity in the Christian context often correlates with more skeptical/hostile attitudes towards new genetic technologies (Evans 2012), it was found that British Christians perceived religious arguments in a less constraining manner when confronted with concrete scenarios relating to their own

life-worlds (Prainsack and Spector 2006). Second, religious restrictions represent formal statements which follow general principles, while actual decision-making is performed by lay people in concrete situations. As in the case of other cultural factors which are the source of general scripts, such as class, gender or nationality, religion can certainly provide a more restrictive or permissive backdrop for individual decision-making, but it does not necessarily predict it. Among Muslims in Britain, for example, as many as 67 % said that they would consider abortion following a prenatal diagnosis of thalassaemia, in contrast to the Muslim stance which bans abortion (Atkin et al. 2008).

Third, the articulation of the religious script is made, as in the case of all cultural scripts, by lay people in the context of other cultural, political and historical narratives, which shape their attitudes. In this book, we use the case of the modern-religious—Jews and Christians—to provide an actual setting for these quandaries. Our initial premise is that when shifting from the declarative to the more practical and personal, we might find a more pragmatic outlook amongst participants. It is possible that when making a decision regarding life and death, responsibilities for one's own future, as well as one's family, are seen as more influential than religion per se (Atkin et al. 2008).

Another important cultural script we work with and question at the same time is the script of “medicalization.” With medicalization we refer here to Peter Conrad's term of describing a hegemonic, historical process of redefinition, power, and construction (Conrad 1975). The driving force, or biopower, is modern medicine. It is an area, both rational and pragmatic, which redefines, even in very subtle forms, all kind of issues in life as “medical issues” (Rose 2006). Already around the 1970s, “medicalization” was used by sociologists and anthropologists to denote medical, scientific understandings of human behaviors that define these behaviors as *problems* requiring surveillance and control, through treatment or management (Zola 1972; Illich 1975). Medicalization in this broad sense has occurred across many areas of human life, from “deviant” behaviors such as mental illness to “normal” life processes such as pregnancy, childbirth, and even partner choice. Genetic research and testing, an issue we focus on in this book, can be seen as an extension of the medicalization of human life by means of its clinical applications while, simultaneously, medicine is increasingly geneticized. It has for example been claimed of American breast cancer patients that the “new” genetics is medicalizing kinship by promoting inter-family discussion of genetic risk information (Finkler 2001).

The term “geneticization” was first coined to refer to the prioritizing of genetic over other understandings of human behavior (Lippman 1992, 2003). It is closely related to “genetic essentialism,” a phrase used to denote scientific discourse “with the potential to establish social categories based on an essential truth about the body” (Franklin 1993, p. 34). Scholars have elaborated on the idea of the gene as a “cultural icon,” suggesting that cultural representations of genetics have a life of their own, independent of the scientific research that gives rise to them (Nelkin and Lindee 1995). The thesis of geneticization has since been challenged on grounds that include the fact that empirical evidence to support it is thin: the increasing use

of genetic technologies in medical practice is not in dispute, but this does not necessarily entail a widespread acceptance of a social script of deterministic or essentialist genetics (Hedgecoe 1998).

A key difficulty with medicalization and geneticization is that this terminology generally implies that lay people passively accept and use biomedical knowledge and its associated technologies, and that medical and genetic models increasingly dominate our understandings of human behavior. For us, this is something to examine rather than a premise to be taken for granted. This study asks whether acceptance and dominance of biomedical models and technologies is uniformly and unidirectionally occurring in relation to genetic risk and life plans. We expect to encounter forms of resistance and counteractions not only in the context of genetic testing but also in our second context of inquiry, end-of-life care. For example, the striving for advance directives, the discussion about respecting the patient's will to withdraw and withhold medical care, must also be seen as a form of resistance towards the modern project of medicalization.

2.2 Methodological Engagements: From Cultural Scripts to Narrative Investigation (and Back Again)

The analysis of the deliberations in the focus groups generally demonstrated that common narratives reflecting cultural scripts are created and maintained through inter-personal discourse. They are not fixed or persistent but rather dynamically and discursively (and sometimes ephemerally) negotiated as particular lay people respond to particular constraints of postindustrial technology, institutions, demographics, and notions of self. In our experience, group discussions are a very useful setting for this purpose and can be understood as an experimental form of a "mini" public discourse. Methodologically, we are not excluding other qualitative methods such as interviews or even observation. However, in these latter sources of eliciting attitudes, the researcher might have more influence on what is being said. Focus groups provide a dynamic, "natural" discourse resulting from the participants' different characters and inter-personal exchange. When interested in the hermeneutic reconstruction of arguments, hence, this qualitative methodology is particular fruitful.

According to Glaser and Strauss' (1967) classic approach to grounded theory, constant iterations of comparative analysis lead to inductive themes representing patterns of similarity and difference. Theory, or the meaning-building process of hermeneutic understanding, should not, however, be restricted to the text and its elements. The puzzle is much bigger. Meanings are deeply embedded in cultural scripts, or to use the terminology of Haraway (1988): all knowledge is situated. Along with the classic, positivistic assumption of text as covering some formal, fixed, authoritative message (to be exposed through grounded theory), we also work through these texts to expose them as knowledge situated within other, multifaceted cultural scripts. The texts produced by our focus groups are therefore treated as both

“readerly” and “writerly” (Barthes 1975). As readerly texts, they should be analyzed to convey the message of the narrator. As writerly texts, they call out for multiple interpretations by us, demanding that we make an active effort in completing the text which is always a fragment of knowledge that is never morally absolute or per se valid, connecting it with broader cultural scripts.

In terms of ethical analysis, our methodology draws on the concept that the empirical social study of attitudes provides descriptive “facts” that can be understood as normative statements (Rehmann-Sutter et al. 2012; Haimes 2002). The convergence of social science and ethics intended by this approach is both of epistemological and methodological nature (Haimes 2002; Haimes and Williams 2007). This allows integrating those perspectives which are often neglected or marginalized in the dominant expert discourse (Schicktanz 2012).

First, we add to the expert discourse of abstract ethical principles and formal policies the moral arguments of lay people, which are often ambivalent, informal and “unprincipled”—a morality without theoretical foundation which is nevertheless the morality we “live by.” Second, we add a methodological focus on social context—in our case lay, affected, religious, and national groups. In addition to providing empirical data for ethical analysis, the sociological analysis of these focus groups enables new questions to be asked, such as “why are these issues defined as ethical concerns by these people in these times and these places?” (Haimes 2002). Such questions can then be further discussed as indicators of broader concerns and comparative trends within Germany and Israel. The juxtaposition of the two countries is expected to highlight the context of national variation and pluralism, as well as to offer a more fine-tuned examination of group diversity and similarities within the contexts of being affected and of religiosity (Raz and Schicktanz 2009a, b). This methodological design is used to examine how cultural (national and religious) contrasts exist alongside shared positions which might reflect a common sense of being affected by disease-based experiences.

Our methodological design is used to examine how cultural (national and religious) contrasts exist *alongside* shared positions which might reflect a common sense of *being affected* by disease-based experiences. Since in both countries medical care is technically highly advanced providing intensive care and life-prolonging measures, similar contexts and decisions about treatment and health care within the medical setting can be assumed. In order to qualitatively explore these questions, we conducted focus groups with modern-religious adults, affected people, and secular (non-affected) people, in Germany and Israel. The biomedical issues discussed in each group focused on end of life and genetic testing. Similar scenarios concerning these topics were used for the semi-structured discussion. In total, 5 focus groups (N = 48) on genetic testing were conducted in a preliminary study between 2005-7.¹ Using the same methodology, 16 focus groups (N = 60) on

¹All groups were recruited, organized and conducted in early 2005, following the guidelines for setting and content of the EU Project “Challenges of Biomedicine,” Contract No. SAS6-CT-2003-510238.

end of life and genetic testing were conducted as part of the GIF-sponsored study between 2009–2012.

Focus group discussions were preferred for this study because they allow for collecting detailed material, in a purposeful and manageable way, over a short period of time (Carter and Henderson 2005; Morgan 1997). Furthermore, the scenario-based discussion which develops in a focus group combines speculative enquiry concerning normative values and assumptions in relation to specific examples in which legitimization occurs within a social context. Our focus group discussions were composed in a manner that reflected our interest in understanding personal experience with a genetic disease and with the medical system. In both countries we recruited respondents who were either patients or close relatives of a patient (i.e., “affected”) or had no experience of a particular disease, test, or treatment (i.e., “non-affected”, or “lay”; see Schicktanz et al. 2008). We also had a focus group discussion composed of modern-religious respondents (Christians in Germany and Jews in Israel) in each country, which provided a source of comparison concerning the bioethical arguments of the other (secular) groups as well as to the expert bioethical discourse, where religious arguments often play a major role.

We conducted eight focus group discussions ($N = 60$, 17 males (28 %), 43 females (72 %) with volunteers recruited in Germany and Israel between 2009–2012. In each country, two focus group discussions comprised people affected by genetic diseases. By affected we mean that the participants had clinical symptoms, or were diagnosed as carriers of a genetic disease, or had a first degree relative who has a genetic disease, and two focus group discussions with non-affected lay people—one group of secular lay people and another group of modern-religious respondents. Similar scenarios and questions were used in all focus group discussions. Focus group discussions in Israel and Germany usually included seven to nine people and lasted about two hours. There were at least two facilitators, always members of our research teams, who guided the discussion and encouraged people to comment on other people’s statements.

In terms of education, groups were mixed with a slight tendency to higher level education, probably reflecting self-selection preferences. The participants’ age range was 22–80 years with a heterogeneous composition in each focus group discussion. Respondents affected by genetic diseases were recruited from self-help groups and support organizations of and for people with genetic diseases. German and Israeli respondents not affected by genetic diseases were recruited by means of disseminated flyers and ads in urban public places (libraries, hospitals, pharmacies, cultural centers), and in modern-religious associations for recruiting the modern-religious participants.

The discussions were audio recorded, anonymized and transcribed, and translated into English. The transcripts from each country were analyzed thematically using the scientific software ATLAS.ti®. The analysis was compared cross-nationally in order to uncover discursive themes and categories of themes recurring within and across groups (Bloor et al. 2001). For the purpose of juxtaposing “lay moralities” and “expert discourse,” emergent topics identified through

inductive coding were further compared with the general categories of bioethical discourse gleaned from public policies and expert interviews. Following the cross-analysis of the transcripts, the preliminary coding was discussed by the whole team and cases of interpretive disagreement were clarified with additional codes and sub-codes added as needed.

Each focus group discussion began with expository case vignette(s) demonstrating basic dilemmas and problems. This method was used to provide a concrete narrative that invites participants to imagine a real case, to consider what other information they would need to know to make a judgment, to consider the reasons and motives of significant others, and so on. Variants of the starting scenario were then offered to move the discussion. Standard questions asked in the focus group included a focus on moral and ethical attitudes, such as: who are the primary actors (family, individuals, professionals, the state and so on); who is seen as responsible for making the decision and why; who is seen as having the authority to decide and what are the sources of such authority (religion, morality, culture, ideology); what are the morally acceptable consequences of the decision made (feeling guilty/shame, being accused, and so on). The detailed information of the scenarios and open question presented will be described in the respective topical chapters.

We should also mention the limitations of using such qualitative methods. Qualitative studies are by nature limited in their generalizability and representativeness, as their value is in hypothesis- and theory-building (Whittemore et al. 2001). Furthermore, only a few scenarios can be discussed in depth in a single study. The selection of our discussion scenarios was inspired by controversial issues in the academic debate, such as the relevance of old age, clear-mindedness, suffering, and untreatable pain for end-of-life decisions.

References

- Atkin K, Ahmed S, Hewison J et al (2008) Decision-making and antenatal screening for sickle cell and thalassaemia disorders: to what extent do faith and religious identity mediate choice? *Curr Sociol* 56(1):77–98
- Barthes R (1975) *The pleasure of the text*. Hill and Wang, New York
- Bloor M, Frankland J, Thomas M et al (2001) *Focus groups in social research*. Sage, London
- Carter S, Henderson L (2005) Approaches to qualitative data collection in social science. In: Bowling A, Ebrahim S (eds) *Handbook of health research methods: investigation, measurement and analysis*. UK Open University Press, Maidenhead, pp 215–229
- Conrad P (1975) The discovery of hyperkinesis: notes on the medicalization of deviant behavior. *Soc Probl* 23:12–21
- De Vries R, Turner L, Orfali K et al (eds) (2006) *The view from here: bioethics and the social sciences*. Blackwell, Oxford
- Evans J (2012) *The history and future of bioethics: a sociological view*. Oxford University Press, Oxford
- Finkler K (2001) The kin in the gene: the medicalization of family and kinship in American society. *Curr Anthropol* 42:235–263
- Franklin S (1993) Essentialism, which essentialism? Some implications of reproductive and genetic technoscience. In: De Cecco JP, Elia JP (eds) *If you seduce a straight person, can you*

- make them gay?. Haworth Press, New York, Issues in biological essentialism versus social constructionism in gay and lesbian identities, pp 27–39
- Glaser B, Strauss A (1967) The discovery of grounded theory. Aldine, Chicago
- Habermas J (1979) Communication and the evolution of society. Beacon Press, Toronto
- Haimes E (2002) What can the social sciences contribute to the study of ethics? Theoretical, empirical and substantive considerations. *Bioethics* 16(2):89–95
- Haimes E, Williams R (2007) Sociology, ethics, and the priority of the particular: learning from a case study of genetic deliberations. *Br J Sociol* 58(3):457–476
- Haraway D (1988) Situated knowledge: the science question in feminism and the privilege of partial perspective. *Feminist Stud* 14(3):575–599
- Hedgecoe A (1998) Geneticization, medicalisation and polemics. *Med Health Care Philos* 1(3):235–243
- Illich I (1975) The medicalization of life. *J Med Ethics* 1(2):73–77
- Lippman A (1992) Led astray by genetic maps: the cartography of the human genome and health care. *Soc Sci Med* 35(12):1469–1476
- Lippman A (2003) Eugenics and public health. *Am J Public Health* 93(1):11
- Morgan DL (1997) Focus groups as qualitative research. Sage, Thousand Oaks
- Nelkin D, Lindee S (1995) The DNA mystique: the gene as a cultural icon. Freeman, New York
- Prainsack B, Spector TD (2006) Twins: a cloning experience. *Soc Sci Med* 63(10):2739–2752
- Raz A, Schicktanz S (2009a) Lay perceptions of genetic testing in Germany and Israel: the interplay of national culture and individual experience. *New Genet Soc* 28(4):401–414
- Raz A, Schicktanz S (2009b) Diversity and uniformity in genetic responsibility: moral attitudes of patients, relatives and lay people in Germany and Israel. *Med Health Care Philos* 12(4):433–442
- Rehmann-Sutter C, Porz R, Leach-Scully J (2012) How to relate the empirical to the normative: toward a phenomenologically informed hermeneutic approach to bioethics. *Camb Q Healthc Ethics* 21(4):436–447
- Rose N (2006) The politics of life itself: biomedicine, power, and subjectivity in the twenty-first century. Princeton University Press, Princeton
- Schicktanz S (2012) Epistemische Gerechtigkeit. *Sozialempirie und Perspektivenpluralismus in der Angewandten Ethik. Dtsch Z Philos* 60(2):1–15
- Schicktanz S, Schweda M, Franzen M (2008) “In a completely different light”? The role of being affected for epistemic perspectives and moral attitudes of patients, relatives and lay people. *Med Health Care Philos* 11(1):57–72
- Seale C (1998) Constructing death: the sociology of dying and bereavement. Cambridge University Press, Cambridge
- Seale C (2000) Changing patterns of death and dying. *Soc Sci Med* 51:917–930
- Whittemore R, Chase SK, Mandle CL (2001) Validity in qualitative research. *Qual Health Res* 11(4):522–537
- Zola I (1972) Medicine as an institution of social control. *Sociol Rev* 20:487–504

Comparative Empirical Bioethics: Dilemmas of Genetic
Testing and Euthanasia in Israel and Germany

Raz, A.E.; Schicktanz, S.

2016, XI, 121 p. 2 illus., Softcover

ISBN: 978-3-319-32731-0