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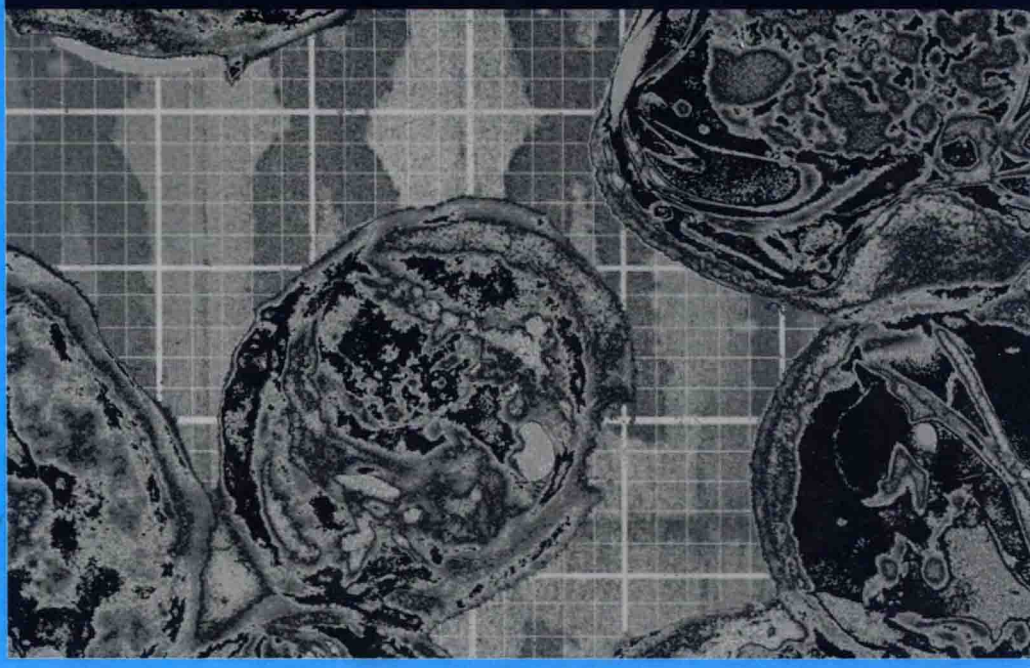
Accounts of autonomy, responsibility and blame

Michael Arribas-Ayllon, Srikant Sarangi and Angus Clarke



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Genetic Testing

Advances in molecular genetics have led to the increasing availability of genetic testing for a variety of inherited disorders. While this new knowledge presents many obvious health benefits to prospective individuals and their families, it also raises complex ethical and moral dilemmas for families as well as genetic professionals.

This book explores the ways in which genetic testing generates not only probabilities of potential futures, but also enjoins new forms of social, individual and professional responsibility. Concerns about confidentiality and informed consent involving children, the assessment of competence and maturity, and the ability to engage in shared decision-making through acts of disclosure and choice are just some of the issues that are examined in detail.

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This book draws on previous work by the authors. In particular, Chapter 5 is a revised and condensed version of two papers: 'Managing self-responsibility through other-oriented blame: Family accounts of genetic testing', which appeared in *Social Science and Medicine* 66(7): 1521–32, and 'Micropolitics of responsibility vis-à-vis autonomy: Parental accounts of childhood genetic testing and (non)disclosure', which appeared in *Sociology of Health and Illness*, 30(2): 255–71. Some material in Chapter 8 also appears in an earlier paper, 'Professional Ambivalence: Accounts of Ethical Practice in Childhood Genetic Testing', *Journal of Genetic Counseling*, 18(2): 173–84.

More than acknowledgement, we would like dedicate this book to our better halves – Kristrun, Usha and Jane – and our families for their unspoken patience and understanding 'writ large' when we returned home late on evenings after our ritual book meetings.

List of abbreviations

CAD	coronary artery disease
CF	cystic fibrosis
CFTR	cystic fibrosis transmembrane conductance regulator
CH	congenital hypothyroidism
CNV	copy number variant(s)
DMD	Duchenne muscular dystrophy
DNA	deoxyribonucleic acid
GWAS	genome-wide association study
HD	Huntington's Disease
HGP	Human Genome Project
HUGO	Human Genome Organisation
IRT	immuno-reactive trypsin
MDT	multidisciplinary team meeting
MODY	maturity-onset diabetes of the young
msAFP	maternal serum α-fetoprotein
MRI	magnetic resonance imaging
PCR	polymerase chain reaction
PKD	polycystic kidney disease
PKU	phenylketonuria
SCA	sex chromosome aneuploidy
SNP	single nucleotide polymorphism
T1D	type 1 (juvenile-onset, insulin-dependent) diabetes mellitus
T2D	type 2 (maturity-onset, non-insulin-dependent) diabetes mellitus
TMS	tandem mass spectroscopy

Contents

1 Introduction

> Remember also, that if you go into the world you will have free will; that you will be obliged to have it; that there is no escaping it; that you will be fettered to it during your whole life, and must on every occasion do that which on the whole seems best to you at any given time, no matter whether you are right or wrong in choosing it (Samuel Butler 1872/1985: 171).

A new ethical landscape

In 1974 an edited collection of papers appeared, bearing the curious title *Genetic Responsibility: On Choosing Our Children's Genes* (Lipkin and Rowley 1974). It was the publication of a symposium on 'Genetics, Man and Society' held two years earlier at the American Association for the Advancement of Science in Washington DC. Attended by medical, legal, ethical, psychiatric and genetic professionals, the symposium explored the implications of what were, at the time, major advances in genetic knowledge. The recent availability of prenatal testing and preimplantation genetic diagnosis raised fresh concerns for both clients and professionals about whether to abort affected foetuses and whether to inform relatives about actual or potential risks. It was not that new genetic technologies 'created' these new and difficult choices, but that choice was necessitated by risks. Within the clinical setting, the complexity of decision making and the greater need for informed consent afforded new opportunities to establish the accepted principles of genetic counselling and to outline its 'non-directive' approach to information-giving (Hsia 1974). The notion of free will that the Butler quote above assumes as axiomatic, is inherently entangled with notions of risk and responsibility when decisions have to be made about self and others, especially in the wake of new technologies and their impact on social lives.

The term 'genetic responsibility', as it was used in 1974, seems to imply not a narrowing of responsibilities but the opening up of a new field of ethical conduct. This applies more generally to social and moral responsibility in other spheres of family life. However, the peculiar qualities of genetic knowledge formed new relations of identification with the bearer of genetic risks; it formed new relations with the unborn child who embodied such risks, but it also formed new relations with relatives who might also have to face similar complex decisions. That

identity, reproduction and health could be framed in terms of 'genetics' and that 'responsibility' now assumed a genetic character meant that one's biological future was now entangled in the calculation and management of one's freedom. As the Butler quote above illustrates, free will is more than simply a liberal 'right', or an ontological 'fact'; it also confers an obligation to manage oneself in terms of freedom. Rose and Novas (2005) have described this phenomenon of managing the present in light of biomedical knowledge of one's future as 'genetic prudence': the activity of responsibly engaging in ethical calculation of future hazards through acts of choice, in this case, genetic choice. The appearance of genetic responsibility in the early 1970s marked an event in which new biological knowledge for the detection and calculation of 'genetic risk' were shaping the values, norms and expectations of individual identity as well as contemporary citizenship.

This book is about 'genetic testing' from the point of view of this new landscape of ethical conduct bounded by choices and responsibilities. It examines the ways in which the testing of inherited risk enjoins new forms of social, individual and professional responsibility, and by extension, provides new resources for blame. Families and professionals, entrepreneurs and consumers, and 'the public' more generally, are being drawn into discussions and decisions, which are changing the ways in which we think about ourselves and our relations with others, about future risks and how these can be minimised, if not avoided altogether. Concerns about confidentiality and informed consent involving children, the assessment of competence and maturity, the ability to engage in shared decision-making through acts of disclosure and choice, the difficulties of communicating risk to close and distant relatives, are just some of the issues faced by 'at risk' families in the clinic. More widely, the commercialisation of genetic information for the general public – for acting on inheritable genetic disorders and lifestyle risks – signals how genetic testing is broadening its circumference. The recent emergence of the personal genomics industry, the realities of direct-to-consumer marketing, and the testing for common complex disorders are raising new concerns about access to, and communication of, genetic knowledge.

In the book we address these issues by considering first the 'technological trajectory' of genetic testing and its implications for genetic counselling (Chapter 2). We then take a wider historical focus, contrasting classical-liberal and neo-liberal perspectives on heredity and genetics (Chapter 3). In Chapter 4, we outline our analytical framework, what we refer to as Rhetorical Discourse Analysis, which can be utilised for dealing with different kinds of data settings covered in the book. Building on the work that has examined representations and metaphors of genetics in the media, we explore the spectacle of genetic testing for common complex disorders on television and the internet (Chapter 5). The extent to which families engage in 'genetic responsibility' and use genetic knowledge as resources for displaying self-responsibility as well as allocating blame to others is also considered in detail (Chapter 6). In the final two chapters, we examine the dynamics of negotiating and communicating genetic knowledge in the clinic (Chapter 7) and the formulation of professional dilemmas arising specifically in the prenatal genetics clinic (Chapter 8). The concluding chapter brings together the various threads

and speculates future directions in terms of social research in genetic testing and its relevance for clinical practice. This book explores a range of data sites – representations of genetic testing on television and on the internet, research interviews with families and professionals, transcripts of clinical consultations and professional forums – to examine how new genetic technologies are discussed and negotiated in these domains.

Genetic technologies and society

Genetic testing is a social practice as well as a technical, laboratory procedure. In fact, how we view the relationship between 'technology' and 'society' in general has important implications for how we think about genetic testing as a phenomenon. There is already a growing field of research that has examined the impact of genetic technology on biomedicine and society. Since the mid-1980s, rapid advances in genetic technology and the events preceding the Human Genome Project (roughly 1990–2002) have attracted the attention of sociologists, bioethicists, anthropologists, etc., many of whom were concerned with the construction of genetic knowledge, the promises of cure and prevention, and the public's understanding of such knowledge. One area that received immediate scrutiny was the communication of risk in the context of genetic counselling (Lippman 1991, 1992b, Bosk 1992, Armstrong *et al.* 1998, Rapp 1999). Other commentators were concerned with what appeared to be the liberalisation of eugenics (Yoxen 1986, Duster 1990, King 1995, Kevles 1995, Kerr *et al.* 1997, Kerr 1998, Taussig *et al.* 2003), while others were interested in how the gene metaphor was shaping the imaginations of both science and the public (Nelkin and Lindee 1995, Rothman 1998, van Dijck 1998, Keller 2000).

A branch of sociology is dedicated to exploring the ways in which technologies are embedded in social networks. This is an important departure from the idea that technology is deterministic and acts 'outside' of society (MacKenzie and Wajcman 1985). Technological determinism or the technological imperative, in its extreme form, allows proponents to argue that advances in society are mainly attributed to advances in technology. Popular accounts of genetics, for instance, exemplify a deterministic view of new genetic technologies improving humanity by 'revolutionising' the diagnosis, treatment and prevention of disease (Petersen 2001). Such accounts tend to oversimplify the social effects of technology and treat the achievements of science as primary and global events. Rethinking the effects of technology requires a more dynamic and heterogeneous conception of society. The relationship between technology and society is neither unilateral nor unambiguously causal; they interact within a complex field of entities, within political and economic conditions, and through technological systems, networks, problems, etc. (Hughes 1983, Bijker *et al.* 1987).

Genetic testing and social change

While it is generally acknowledged within the social sciences that the relationship between technology and society is complex, there are competing understandings

about the extent to which science and technology is changing society. Our explicit empirical focus in this book seeks to make a contribution to such debates. One of our central arguments is that genetic testing not only produces knowledge that we are 'fettered to', as Butler puts it, but that new genetic knowledge is continuously negotiated and contested. The laboratory procedure of a 'genetic test' is only one dimension that has changed our knowledge of health and disease or our expectations of prevention and treatment. We argue that responsibility for the calculation and management of genetic risk is a situated activity accomplished by local actors. This has important implications for considering how, and to what extent, advances in new genetic technologies are transforming patterns of individuality, sociality and their interface.

Such concerns about the 'impact' of genetic testing have encouraged scholars working within the field of Science and Technology Studies (STS) to examine the contextual, mundane and negotiated aspects of 'sociotechnical networks' (Martin 1999, Hedgecoe 2004). In their review of the field, Hedgecoe and Martin (2008) identify two 'broad styles of thinking': what they call 'transformational' and 'contextual' accounts (2008: 819). Transformational accounts are typically 'big stories' that describe revolutionary changes in the structure of self and society. Contextual accounts are often 'small stories' grounded in empirical evidence that highlight local continuities and discontinuities in social practice. These two styles of thinking are not intended to be rigid dichotomies but flexible descriptions of the way in which the effects of genomic technologies are framed as revolutionary and global, on the one hand, and interactional and local, on the other. A position that exemplifies this transformational perspective is found in Novas and Rose (2000) who have persuasively argued that genetic technologies are creating new spaces of identification and ethical orientation, which they view more positively than the repressive implications of the 'geneticisation thesis' (Lippman 1991, 1992a). Kerr and colleagues (Kerr and Cunningham-Burley 2000, Kerr 2003) exemplify the kind of work that might be called contextual, highlighting historical continuities and local tensions which seem to call into question the revolutionary nature of genomics. Far from disappearing, reductionism and determinism continue to underpin modern techniques of genetic screening (see our discussion of genetic testing vs. genetic screening in Chapter 2), while ambivalence towards genetic risk seems to undermine the wholesale move towards the birth of 'somatic individuality' and 'genetic responsibility' (cf. Novas and Rose 2000).

Such tensions illustrate the need to maintain flexibility between contrasting perspectives on social and technological change – they remind us that social change is rarely homogenous and complete, but often uneven and partial. The approach we adopt in this book seeks a balance between transformational and contextual accounts of new genetic technologies. Our focus on discourse and rhetoric seeks to unravel and critically examine the complex interactions between technological and social systems, the continuous negotiation of problems and controversies, and the significance of contextual resources and constraints, all of which give technologies their particular form. Our approach offers a critique of technological determinism through immersion in the local, perspectival and

contingent aspects in which artefacts, like genetic tests, are embedded within complex networks of interaction. From this perspective, we can see that work on the clinical application of genetic testing reveals a more restrained picture of radical, biomedically driven social change.

Accounts of autonomy, responsibility and blame

Why discuss genetic testing in terms of autonomy, responsibility and blame? At the start of our introduction we wanted to draw attention to how notions of responsibility and genetics have become conflated in ways that seem to suggest that the impact of new genetic technologies warrants new kinds of social deliberation and individual reflection. Terms such as 'responsibility' and 'autonomy' are the kinds of vocabularies experts use to identify ethical dilemmas, to anticipate future scenarios and to prescribe codes that might otherwise avert the uncomfortable consequences of screening populations, or testing at-risk individuals. In Chapter 3, we suggest that autonomy/responsibility can be treated as a relational pair that describes two sides of the same phenomenon: the double bind of freedom. Samuel Butler expressed this point with compelling familiarity over a century ago when he described a fictitious society in which the healthy were morally superior to the unhealthy and that 'free will' was both a right and an unavoidable obligation. Freedom is the condition of making choices for which we are *accountable*. And one of the claims that we want to explore in this book is that genetic technologies provide relatively new conditions within which these old concerns are recast.

Our interest in 'accounts' arises from the belief that the social order is always a moral order. For instance, Kant argued that moral action arises out of duty and respect for social norms embedded in the law:

> It is of the greatest importance to attend with the utmost exactness in all moral judgements to the subjective principle of all maxims, that all morality of actions may be placed in the necessity of acting from duty and from respect for the law, not from love and inclination. (Kant 2008/1788: 57)

From a more contingent and contextual perspective, other scholars such as Garfinkel (1967) and Goffman (1971) have also treated the social order as a moral order. The morality of action is not simply the condition of being-in-the-world but also of being accountable to the world. 'Accountability', in this sense, refers to ordinary actions that constitute the social order by making its moral codes visible, explicable and sensible to others. Thus, when discussing accounts of autonomy and responsibility, we are more concerned with the relational and discursive dimensions of normativity. We want to understand the conditions under which it becomes necessary to provide accounts that defend, assert or problematise freedom and choice of action. And these issues are particularly relevant in the case of new genetic technologies and their application for calculating 'genetic risk' via screening and testing. The individual and relational nature of 'genetic risk' is such

that people are simultaneously accountable to their own embodied concerns as well as the embodied concerns of others – close or distant relatives, actual or potential offspring, members of groups to whom they express some affiliation or social bond. The chain of accountability also extends to professionals, who are themselves accountable to clients, the institutions within which they work and their professional organisations. In the context of genetic testing, individuals are more or less impelled to decide whether or not to screen an unborn child, whether to terminate if the risks are evident, whether and when they intend to inform their relatives of familial risks. The moral, technical and cascading implications of genetic risk have become embedded within political and institutional rationalities, characterised by vocabularies and practices of accountability.

Concerns about the management of accountability are evident in the way that professional communities have responded to the ethical and legal challenges emerging from new genetic technologies. Accountability has become enshrined within the principles and codes of genetic professionals. For instance, the professionalisation of genetic counselling in the 1970s embraced notions of 'genetic responsibility' in order to distance genetic counsellors from the old eugenic ideologies by foregrounding an ethos of non-directiveness to uphold patient autonomy. The management of genetic risk would become a shared affair, the process and product of good communication between professionals and clients (Kenen 1984). This awareness has created new spaces of moral negotiation: 'good' counselling relied on the construction of persuasive accounts, the ability to deflect unreasonable requests, the tactics of eliciting ethical decision-making through strategic and rhetorical interaction (Arribas-Ayllon *et al.* 2009).

If managing genetic risk is both a moral and a situated activity, then it follows that risk management is also linked to systems of blame. Extending on her earlier work on danger and taboo, Douglas (1992) argues that our modern preoccupation with risk is symptomatic of a moral-political system that explains misfortune by assigning responsibility to others through blame:

> The theme, well known to anthropologists, is that in all places at all times the universe is moralized and politicized. Disasters that befoul the air and soil and poison the water are generally turned to political account: someone already unpopular is going to be blamed for it. (Douglas 1992: 5)

Blaming systems are symptoms of the way a society is organised; they are moral explanations of events that fulfil political purposes. In neo-liberal societies, characterised by decentralised and devolved government, systems of blame are reorganised in ways that now distribute responsibility to all 'active' citizens. Galvin (2002) vividly describes this phenomenon in which personal responsibility for health is inexorably linked to blame:

> The healthy person is, in effect, symbolic of the ideal neoliberal citizen, autonomous, active and responsible and the person who deviates from this ideal state is, at best, lacking in value and, at worst, morally culpable. (Galvin 2002: 117)

But in the context of new genetic technologies, even the healthy person can be assigned a 'presymptomatic' risk status, which confers a responsibility to manage one's health and affairs wisely.

New genetic technologies are also linked to blame in much more subtle and normative ways, especially when genetic screening services become routinised in reproductive medicine or in wider public health programmes. For instance, Duster (1990) observes that the availability of genetic screening services is enough to create their own demand. The subtle pressure to use these services is linked to systems of blame because once the technology is available and a woman chooses not to have screening then the birth of a child with a disability is no longer an act of fate but of personal irresponsibility.

Issues of blame and responsibility also arise from the consequences of what one does with genetic risk information. Within the family, disclosure of genetic information is often linked to blame, which can flow in different generational directions (Featherstone *et al.* 2006). Siblings, cousins and parents are blamed when the responsibility to disclose risk information does not result in reciprocated understandings or when disclosure has no impact on reproductive responsibilities (Arribas-Ayllon *et al.* 2008a). As we will see, the genetic basis of risk provides individuals and families as well as experts with new resources for assigning responsibility and blame. In the accounts that we explore in this book, we treat autonomy, responsibility and blame as formulations that seek to either problematise or restore a socio-moral order that has become fully enmeshed with concerns over the management of risk (Beck 1992, 2009).

Our approach

We adopt a discursive approach which, in the broadest sense, means that genetic knowledge, such as 'risk genes' or 'genetic testing', emerges as historically variable devices for conceptualising actual and potential pathologies. This version of discourse lends itself to understanding how technical innovations in biomedicine engender corresponding transformations within systems of thought and action. However, as mentioned earlier, to give balance to such transformational views of genetic knowledge, it is necessary to consider the contextual and interactional aspects in which these technologies are locally embedded.

For the purposes of this book, we employ a less abstract and more situated definition of discourse, one that seeks to understand how categories of 'risk' and 'genetic testing' are actually problematised and negotiated in different domains. The rhetorical discourse analytic approach (elaborated in Chapter 4) draws on several traditions from sociology, social psychology and sociolinguistics. It combines the action and epistemological orientation of discourse in order to highlight that language does things, brings about effects, and constructs knowledge via modes of representation and interaction. We believe that the rhetorical aspects of discourse are essential to understanding language use and other modes of communication, which is not simply propositional or informational, but argumentative and persuasive.

Furthermore, the rhetorical nature of accounts is central to understanding how genetic knowledge is embedded in the problem of social order. This is an 'ethical' problem insofar as genetic technologies enjoin new relations of self-identification and self-management (i.e. the relation of the self to the self), but it is also a 'moral' problem insofar as genetic knowledge enjoins new relations of obligation and commitment (i.e. the relation of the self to others). By focusing on the rhetorical organisation of social action, we highlight the kind of tensions that arise in concrete situations. These are practical dilemmas faced by professionals and individuals in the making of choices and decisions over health and wellbeing, over life and death; these are practical difficulties in the communication of risk when the 'transmission' of genetic responsibility is suffused by stigma, ambivalence and dread; these are practical concerns over the competence of minors and the understandings of adults for whom these risks apply. In contrast to normative and principle-based ethics, we offer a method of investigating these issues that goes beyond mere justifications of codes and principles as far as professional practice is concerned. Drawing from empirical examples (see Chapter 8), we propose a kind of 'situated communication ethics' that shows that ethical and moral dilemmas reside not so much in knowing what code to implement when but in how to accomplish the management of genetic risk through interaction.

The data corpus

Clearly, genetic testing is a phenomenon that has ethical, moral, legal, medical, economic and personal dimensions, the nature of which is broadly conceived as 'social'. To capture this multidimensionality, we collected data from different domains – public, private and institutional – to provide a rich and well-rounded discussion. The data used in this book consist of five types: research interviews, clinical encounters, professional discussion groups, web-based text, and televised (reality-based) documentary. As a body of data, the corpus has been selected to reflect the relevant domains, the people working or acting within these domains, as representative of the practice of genetic testing. We have also selected forms of mediated text in which new genetic technologies are represented to the wider public as forms of knowledge and promise. And finally, the corpus has been designed with the purpose of capturing the tensions and contradictions arising from different actors as requests for, and interpretations of, genetic knowledge are negotiated in different domains.

The data corpus is the aggregation of several projects conducted between 1998 and 2007. Each project was subject to the approval of Local and Medical Research Ethics Committees. Prior to their taking part in these projects, informed consent was obtained from professionals, clients, patients and family members. All identifying information has been removed or altered to preserve anonymity. In some cases, information about genetic disorders has been suppressed or described generically to avoid identification of particular families.

With the exception of media representations, the data presented in Chapters 6, 7 and 8 represent talk between an interviewer and family members (Chapter 6),