

## COUSIN MARRIAGES

# Fertility, Reproduction and Sexuality

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### **Cousin Marriages: Between Tradition, Genetic Risk and Cultural Change**

Edited by Alison Shaw and Aviad Raz

COUSIN MARRIAGES  
BETWEEN TRADITION, GENETIC RISK  
AND CULTURAL CHANGE

Edited by Alison Shaw and Aviad Raz



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## PREFACE AND ACKNOWLEDGEMENTS

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Cousin marriages are marriages between people considered to be relatives, and who are usually, but not necessarily, biological kin. Increasingly, in recent years, cousin marriages have come to be regarded as genetically risky. A discourse of genetic risk in marriages between consanguineous kin – defined by geneticists as second cousins or closer – has been promulgated in media and public health debate in many countries where cousin marriage is practiced. There has, however, to date been little systematic comparative analysis of how these understandings of genetic risk are being incorporated within state health policies and how they may be influencing traditional forms of spouse selection. This book attempts such an analysis. It is an interdisciplinary volume presenting the work of anthropologists and geneticists from the Netherlands, Denmark, Germany, France, Israel and the UK. The case studies in this collection represent a range of societies in the Middle East, the Mediterranean and Europe, and minority populations of Middle Eastern and South Asian origin in Europe.

Alison Shaw wishes to thank Hanan Hamamy for encouraging comparative thinking about the social aspects of consanguinity. Aviad Raz wishes to acknowledge his debt to Gideon Kressel, who many years ago introduced him to the value inherent in the anthropological study of cousin marriage. We thank Joel Zlotogora for putting us in contact with one another, and all the contributors to this volume for their enthusiasm, hard work and patience. Special thanks to Philip Kreager, Director of the Fertility and Reproduction Studies group (FRSG) at the Institute of Social and Cultural Anthropology (ISCA) at the University of Oxford. For funds for seminars at Oxford in 2011 on the theme of ‘Cousin Marriages and the Medicalisation of Spouse Selection’ we thank the Galton Institute, FRSG and ISCA. We are grateful to two reviewers for suggestions for revising the manuscript for publication.

Alison Shaw and Aviad Raz  
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## INTRODUCTION

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*Alison Shaw and Aviad Raz*

This book explores what is happening in different parts of the world to traditional practices of cousin marriages in the light of an increasingly global discourse of genetic risk and new and emerging technologies for managing this risk. Cousin marriages can be understood as marriages between people who are closely related, usually as biological kin and often as first cousins, but ‘cousin’ can also denote genealogically more distant kin or even a social category rather than a genealogical position. Cousin marriage is widely described in anthropological literature as the ‘preferred’ type of marriage in many populations, particularly in the Middle East, but, contrary to popular understandings, it is not enjoined by Islam, and can be found in most of the major faith groups (see chapter one, this volume). It has now also come to be widely regarded by the media and in public health discourse as genetically risky because cousin marriages are usually consanguineous to some degree.

Consanguineous literally means ‘related (*con*) by blood (*sang*)’. Geneticists define marriages between people related as second cousins or closer as consanguineous. According to the principles of Mendelian genetics, consanguineous marriage confers an elevated risk that a child will have an autosomal, recessively inherited genetic disease (Modell and Darr 2002; chapter two, this volume). A recessive condition is one that is caused by inheriting two copies – one from each parent – of a gene mutation that in a single copy carries no significant health risk. If two people carry

the same recessive mutation, their risk of having an affected child is 25 per cent. Two biologically unrelated people have a chance of about 2–3 per cent of both being carriers of the same gene mutation, but for first cousins this risk increases to approximately 4–6 per cent because they have a grandparent in common from whom they might inherit the same gene mutation (see chapter two, this volume, for elaboration).

Consanguineous marriages account for 20–55 per cent of marriages in the Middle East, North Africa and Central Asia today (chapter one, this volume). They are also practised by migrants from these parts of the world living in Europe, North America and Australia. In Europe in recent years, as we discuss in more detail later in this Introduction, media attention and public health debates have centred on the genetic risks and the apparently forced nature of cousin marriages among Muslim migrants, raising concerns about the potential stigmatization of consanguineous couples and migrant communities on the basis of their marriage patterns. In the ensuing policy debates, attention has been focused on connecting the social practices of these minorities with their apparent failure to integrate into contemporary European society. An important comparative question for us concerned the degree to which this discourse of genetic risk in cousin marriage is confined to Muslim migrants in Europe. Has it also gained hold in many of Europe's Muslim migrants' countries of origin, where consanguineous marriage is more widely practised, and if so, what forms does it take, and what steps are being taken to manage it?

To date, there has been little comparative analysis of the forms and impacts of this discourse of genetic risk in consanguineous marriage across diverse global settings. This book aims to provide a state-of-the-art overview of this complex new area of enquiry. It juxtaposes contributions from medical geneticists, clinical geneticists and social anthropologists who, from slightly different angles, address the key questions that motivate our project. What trends and common themes can be identified in state and local people's perceptions of cousin marriages in the light of risk discourse? Through what kinds of strategies, and with what effects, is the biomedical identification of genetic risk in consanguineous marriage being accommodated within genetic service provisions in different parts of the world? And what, more broadly, might these strategies reveal about the nature of social change, such as changing processes of spouse selection under 'modernizing' influences that include more education for women and more opportunities for young people to choose partners

without deferring to parents, elders or religious orthodoxy (chapters five, seven and nine, this volume)?

In this book, we use cousin marriage as a lens through which to explore the ways in which genetic risk is being understood and put to work in different global contexts. Our focus on consanguinity enables us to locate the contribution of this volume within the burgeoning literature concerned with exploring the construction of the idea of genetic risk. The recent rapid growth in genetic research made possible by techniques of molecular analysis that date from the mid-1980s, and now also by advanced techniques of ‘next generation’ genomic sequencing, continues to open up new possibilities for preventing the births of children with serious genetic conditions. Alongside these technical developments there has been a parallel expansion in public and academic engagements with genetic research and its social and ethical implications. Critics have raised questions concerning the positive and negative social consequences of measures to identify genetic risk for individuals and communities (Duster 2003). There is potential for coercion in constraining reproductive choice, and for stigmatizing carriers in programmes aimed at preventing the births of babies with haemoglobin disorders in immigrant communities in Europe, even in initiatives without any particular focus on consanguinity (Giordano, Dihal and Hartevelde 2005). The relative novelty of genetic – rather than, for example, infectious – illness as a disease category demanding public health provision invites further questions about how scientific and local understanding of illness causality may differ from one another (Böck and Rao 2000; Meiser et al. 2001; Richards and Ponder 1996). It also raises questions about the novel ways in which ‘genetic’ concepts can be accommodated within local conceptual systems concerning ancestry, the structure of kinship relations, inheritance practices, and personal and family identity (Shaw and Hurst 2008; chapters four and five, this volume).

## **Geneticization and Medicalization**

In theorizing on these processes of societal engagement with genetics, much recent debate has centered on ‘geneticization’ and related terms used by sociologists to describe media and popular accounts of the achievements of genetic science. The term geneticization was first coined to refer to the prioritizing of genetic over other understandings of human behaviour (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: 43). 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 deterministic or essentialist genetics (Hedgecoe 1998).

A similar debate occurred in the 1970s over the use of 'medicalization' to denote medical, scientific understandings of human behaviours that define these behaviours 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' behaviours such as mental illness to 'normal' life processes such as pregnancy, childbirth and even partner choice – as we discuss in this book in relation to genetic risk. Genetic research can be seen as an extension of the medicalization of human life by means of its clinical applications in reproductive medicine and genetic counselling, 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).

A key difficulty with medicalization and geneticization is that this terminology generally implies that laypeople passively accept and use biomedical knowledge and its associated technologies, and that medical and genetic models increasingly dominate our understandings of human behaviour. For all the contributors to this volume, this is something to examine rather than a premise to be taken for granted. This volume asks whether acceptance and dominance of biomedical models and technologies is uniformly and unidirectionally occurring in relation to genetic risk and cousin marriage. Modern genetic counselling, governed by principles of respect for patient autonomy and non-directiveness, itself demands a degree of reflexivity on the part of practitioners about the values and motivations underpinning the provision of genetic risk information and the offer of reproductive options to at-risk couples (see chapter ten, this volume). Alongside the study of traditional practices of cousin

marriage through the medical lens of genetic risk, there are other perspectives that interrogate the discourse of risk and explore the diversity of influences on contemporary patterns of partner choice in migrant communities in European countries (chapter seven, this volume) and within families with a history of a genetic condition (chapter five, this volume).

Within genetic epidemiology and genetic medicine, the interest lies in establishing degrees of genetic (or 'blood') relatedness (i.e. consanguinity) that significantly increase a couple's risk of having a child with a genetic problem in comparison with the risk for more distantly-related or unrelated couples. On the basis of elevated risk, geneticists usually define consanguineous marriages as unions of people related as second cousins or closer. Consanguineous or 'shared blood' marriages are therefore already implicitly medicalized by their distinct biological terminology.

However, 'cousin' marriages and 'consanguineous' marriages are, as noted, analytically distinguishable. The study of 'cousin' marriage is not solely the study of consanguinity but may instead entail an exploration of the socio-economic and political forms and cultural meanings of the practice, even as concerns about consanguinity and genetic risk become increasingly global. Moreover, in the contemporary study of cousin marriage, where we locate this book, there is considerable scope for examining the synthesis of traditional social and cultural perspectives with medical representations, rather than for merely essentializing cousin marriage as consanguinity – even where consanguinity is the focus of discussion. As the chapters in this volume show, this hybridizing process is visibly at work in the strategies of health professionals themselves, where there is a concern to enable 'healthy consanguinity' (see especially Part 3 of this volume). It is also apparent in the strategies of patients and lay populations, as they negotiate the meaning of health messages that portray cousin marriages as genetically risky (see Parts 1 and 2). Our choice of subtitle, 'Between Tradition, Genetic Risk and Cultural Change', is intended to open up these themes, which run throughout this book.

To situate our contribution within the existing literature on cousin marriage and consanguinity, we turn now to distinguishing (i) traditional anthropological perspectives on cousin marriage, (ii) contemporary concerns with consanguinity and genetic risk, and (iii) a third approach, where we locate this book, that of current reflexive and synthetic responses that attempt to engage with the cultural and social meanings of cousin marriage without dismissing

genetic risk. There has been, we argue, a general shift from social and cultural analysis of cousin marriage to analysis and arguments that focus on the medical representation of genetic risk in consanguinity. We describe this shift and then argue in favour of a third, synthetic perspective that looks at cousin marriage from both previous perspectives. This third space of synthesis provides elbow room for hybridity, such as in strategies to enable 'healthy consanguinity', and emphasizes reflexivity and representation, for instance in focusing on lay representations of health professionals' representations of cousin marriage.

### **The Tradition of Cousin Marriage**

The 'tradition' of the book's title refers to anthropological and also, very often, lay descriptions of a marriage practice common in parts of North Africa, the Middle East and the Eastern Mediterranean region as well as among migrants from these parts of the world now living in Europe, North America and Australia. In anthropological analysis, traditions of cousin marriage encompass two main forms. One is the Middle Eastern pattern of preferential patrilineal parallel cousin marriage, whereby a man marries a father's brother's daughter (FBD) or a woman referred to by the genealogical kinship term for a FBD. This is the pattern of cousin marriage most commonly cited in the case studies in this volume. The other is matrilineal cross cousin marriage, as in the South Indian system, whereby a man marries his mother's brother's daughter (MBD) or a woman classified as standing in this genealogical relationship to him.

According to nineteenth-century evolutionary theories in anthropology, prohibitions against close cousin marriage were characteristic of fitter, more intelligent human groups (Lubbock 1870 Morgan 1871, 1877; Westermarck 1891), because 'marrying out' of the close kin group enabled the creation of extra-group alliances that were crucial to socio-political survival (Tylor 1889: 267). Cousin marriage, as the marriage of close kin, confused this theory. Some eminent Victorian anthropologists were married to first cousins (Kuper 2008, 2009). Conveniently, certain types of cousin marriage could be defined as forms of exogamy (marrying out). Exogamy here referred not to genetic distance, but to marriage 'outside the descent group', and a descent group did not necessarily map onto biological consanguinity or genetic relatedness (McLennan 1865;



Morgan 1877). In these analyses, the kinship categories employed referred, moreover, to genealogical classifications, not to genetic relationships, so a 'cousin' might be someone only distantly related, or someone *classified* as a particular kind of cousin (Morgan 1877). The North American Iroquois, for example, forbade marriage with the FBD but prescribed marriages with the MBD and the FZD (father's sister's daughter) because these women belonged to different descent groups (Morgan 1877). In later work, the South Indian or 'Dravidian' kinship system of prescribed MBD marriage became recognized as the exemplar of cross cousin marriage.

From this perspective, the so-called 'Arab' or Middle Eastern pattern of parallel cousin marriage challenges conventional anthropological approaches to kinship and marriage: 'It represents a striking exception to the principle of exogamy and, because it unites people who are already united and between whom there is, in a structural sense, no sociological difference, it plays precisely the opposite role from that played by marriage throughout most of the world' (Holy 1989: 1). In his review of ethnographic accounts of cousin marriage in the Middle Eastern region, Ladislav Holy notes that anthropological attempts to explain the motivations, functions, meanings and structural consequences of 'preferential patrilineal parallel cousin marriage' are beset with problems of theory, definition and representation (Holy 1989: 2–8). For one thing, there is considerable statistical variation across the region in the proportions of different types of marriages actually contracted: the most frequent cousin marriage is not always or necessarily with the FBD or someone considered to be in this genealogical category, and marriages may be with parallel and cross cousins (children of same sex and opposite sex siblings – FBD, MZD, FZD and MBD), more distant kin and even with unrelated women. In societies where cousin marriage is practised, it is unusual for more than 20–50 per cent of marriages to take place with people related as second cousins or closer (see chapter one, this volume). Thus, cousins are not prescribed but are preferred as spouses, with close agnatic and cognatic kin generally preferred over distant agnates and strangers (Holy 1989).

Analytically, the preference for marriage with cousins is distinguishable from what governs actual marriage choices. The motives underlying particular choices of spouse in practice are the result of a balance of quite varied, pragmatic, instrumental and individualistic interests, which seemingly have little direct relationship with cultural preference (Eickelman 1981; Donnan 1985; Bourdieu 1990).

As a result, largely endogamous (intermarrying) patrilineal descent groups ('tribes', in the Middle East, and *birādarīs* in Pakistan) cannot be assumed to be biologically self-contained units (see chapter three, this volume). What, then, is the justification for the preference? Is preferential FBD marriage best viewed as a rhetorical device, a metaphor for preferential endogamy (Bourdieu 1977), or is it merely a construct of the anthropological imagination (Holy 1989)?

Cousin marriage has deep historical origins: it was permitted and practised within ancient Israel, Greece and Palestine, was not prohibited in the early Hebrew or Christian religion and predates the rise of Islam (Tillion 1983). Anthropologist Germain Tillion links it with the rise of settled agriculture, with the strengthening of ties between kin who held land in common, and with the perpetuation of gender norms that promote female seclusion and dependence on men. Throughout the ancient Mediterranean world, she argues, the most desirable marriage came to be defined as 'marriage with a very close relative belonging to your own lineage' (Tillion 1983: 37). Rather than exchanging women, the idea became 'to keep all the girls in the family for the boys in the family' (Tillion 1983: 74), a cultural ideal that has emotional and psychological consequences for gender roles and female dependency on men.

Holy's analysis of the cultural meaning of preferential FBD marriage takes forward Tillion's observations and raises several points that are relevant for the themes in this book. In Holy's view, preferential FBD marriage represents a desire to marry the closest kinswoman outside the category of prohibited spouses, a desire more powerful than concerns with lineage (Holy 1989: 34–35). As Tillion puts it, across the Magreb, the ideal marriage 'takes place with the female relative who, while not a sister, most resembles one' (Tillion 1983). Holy notes that this preference has various pragmatic socio-economic consequences. Such marriages are easier to arrange than those outside the kin group, they help to keep property and other assets in the family – as many other observers have noted (e.g. Westermarck 1891) – and they express the solidarity and honour of kin. Holy concludes by emphasizing that preferential FBD marriage should be understood as supporting the region's gender norms, which require male control of women in a kinship system that emphasizes the solidarity of agnatic kin at the expense of conjugal relationships and affinity. This point has particular salience within contemporary debates of cousin marriage. In Europe, as we discuss below (and in Part 2 of this volume)

cousin marriage has been linked to forced marriage and to conservative, 'outdated' gender norms. It has also been theorized anthropologically as a mechanism for protecting cultural and religious values by ensuring their effective transmission over generations (Otteneheimer 1996).

The observation that it is the closeness of kin ties that matters most also has implications for how people who practise this form of marriage understand descent and the construction of patrilineage identity. Marriages of first cousins or their genealogical equivalents generally secure socio-economic and emotional connections between the households of siblings. These connections are usually more important than the precision of the genealogical relationships through which they are created. One means of creating inter-household solidarity is by sibling-exchange marriages, known in the Middle East by the Arabic term *badal* (exchange) and in Pakistan as *watta satta*, whereby a pair of siblings from one household marries a pair of siblings from another household (see chapter five, this volume). These are usually (but not necessarily) first cousin marriages, and the children of such marriages will be related to each other as double first cousins, through both their fathers and their mothers. Consequently, lines of descent are frequently traceable both through men and through women and are characteristically complex and overlapping, while simultaneously preserving the identity of the patrilineage (*nasab*) across generations (Conte and Walentowitz 2009). In this process, the 'closest' ties are between male kin, following the logic that Holy identifies in demonstrating that marriage with the FBD represents a marriage with the closest kinswoman permitted by incest rules. In a similar vein, Marks (1974) explained cousin marriage among the Bedouin as a factor contributing to the clustering of men into 'co-liable groups'. The first right of a Bedouin man to marry his cousin (*awlād 'amm*) – that is, the expectation that for a man the first proposition to be considered will be a cousin marriage – is functional in sustaining clan (*khamule*) borders and implies respect for one's family. Where first cousin marriage is not feasible, alternate choices (in descending order) consist of more distant paternal kin, agnates and group members in general, and finally strangers (Kressel 1986, 1992). We see the same logic at work in two case studies in this book: in Turkish Alawi and British Pakistani constructions of 'genetic' ties in marriage. Of all first cousin marriages, the marriage of the children of brothers (i.e. of a man to his FBD) is the closest (chapters four and five, this volume).

### *Predictors of Change*

The practice of cousin marriage depends essentially on two things. One is having cousins to marry. The other is having good reasons for arranging such marriages for one's children or desiring such a marriage for oneself. Over the centuries, high birth rates and large families, combined with socio-economic and cultural motivations, have sustained the practice across culturally and religiously diverse populations.

In industrializing Europe, close kin and first cousin marriages served to protect economic interests in land, property, businesses and to safeguard cultural and religious identities, a striking example being the Rothschild banking dynasty (Kuper 2009: 117–125). Sibling exchange marriages, such as that of a sister and brother to a brother and sister, other close kin marriages and first cousin marriages were important in such groups as Highland Scots in the first few generations of their settlement in the New World, where they were not inclined 'to mix with strangers' (Molloy 1986). They were also key to the establishment of English middle-class family businesses (Davidoff 2006; Davidoff and Hall 2002). Indeed, in a wide-ranging new analysis of first cousin and close kin marriages within prominent families during the Victorian era, Adam Kuper argues that the preference for marriages within the family was a crucial factor in the success of the leading bourgeois clans of industrial and imperial Britain. 'In short', he writes, 'the preference of the English bourgeoisie for marriage with relatives is one of the great neglected themes of nineteenth-century history' (2009: 28). And not just in England: historian David Sabeian argues that close kinship networks were a crucial resource in nineteenth-century capital accumulation and business enterprise across most European countries (Sabeian et al. 2007).

What brought this tradition into decline in England and beyond, across other parts of Europe and North America? The popular belief today is that people in Britain gradually came to realize that cousin marriage harms children's health. In the mid-nineteenth century, people such as Charles Darwin (himself married to his cousin) were beginning to worry that cousin marriage might have biologically harmful effects on children (see Afterword, this volume), even though the scientific evidence at the time was inconclusive. The puzzle of why only some but not all cousin marriages have deleterious effects was one that could not be settled then, because Mendel's work on the inheritance of recessive traits was not re-discovered until 1900 and modern population genetics developed even more

recently, in the 1950s. Even so, in North America, legal prohibitions against cousin marriage began to be enforced in many states; rather than being grounded in scientific evidence, these prohibitions emanated from the desire to promote more rapid assimilation of cultural and religious minorities (Otteneheimer 1996). In England, popular opinion towards cousin marriage had changed by the end of the nineteenth century. However, a far more convincing explanation for the decline in cousin marriage lies in the fertility transition that occurred from about 1870 onwards, in the context of wider social change.

A falling birth rate meant smaller families, so people had fewer cousins among whom they might find a spouse. In addition, the social transformations of the late nineteenth century gave women (in Western Europe and North America) greater financial and emotional independence from their fathers and brothers, and more opportunities to meet men outside the close family circle. As a result, processes of spouse selection became more diverse (Anderson 1986). Today, around 0.6 per cent of marriages in Europe, North America and Australia are to consanguineous relatives, except among certain immigrant-origin minority populations.

A demographic transition is now occurring across many parts of the world where cousin marriages are common. Epidemiological and demographic studies from the Middle East indicate that with increasing urbanization and modernization, rates of close kin marriage can be expected to decline alongside an overall decline in total fertility rates, because there will be fewer suitable spouses among a person's diminishing circle of cousins (see chapter one, this volume). Later age at marriage, higher levels of female education and employment, contraceptive use, a larger number of people who never marry, and changes in ideas about desirable family size will all contribute. A similar change is expected among minority groups from this region now living in Europe, North America and Australia as their marriage practices diversify and shift towards those of their new societies of residence (Hamamy et al. 2011).

In practice, though, trends in close kin including cousin marriages are rather variable, especially across the Middle East, where local continuities and increases in rates of cousin marriage are inconsistent with the prediction of a decline (chapter one, this volume; Raz 2005). Fertility rates themselves vary, not just as a result of differences in such factors as the desired number of children but because of variation in people's ability to have children (Kreager 2005). A decline in the rate of cousin marriage may also be slower than

expected even with low fertility, depending on sibling configurations: if half a population, sub-population or minority group has no children, but half has three children, then everyone in the next generation has two siblings. Cousin marriage may also remain important within some minority populations for socio-economic and cultural reasons, under conditions of political instability or economic insecurity (Khlat 1988; Al Gazali et al. 1997; Raz 2005; chapter five, this volume; Selby 2010; Hamamy et al. 2011). Indigenous ideas about which cousins are suitable as spouses may also be changing or widening, with the result that, despite a falling birth rate, rates of consanguineous marriage show no significant decline. In the 'ultra modern' Gulf societies of Qatar, Yemen and the UAE, a traditional preference for FBD marriage seems to be shifting towards a situation in which patrilateral and matrilateral cousins are acceptable spouses (Dresch 2005, 2006), though it should be remembered that preferential FBD has never been exclusively (patri)lineage endogamous.

Among immigrant-origin minorities in Europe, too, trends in cousin marriage have not always declined as expected (Reniers 2001; Selby 2010; chapter five, this volume; chapter seven, this volume). Frequently these are transnational marriages, in which a European citizen of minority background marries in their country of origin and their spouse joins them in Europe once entry clearance from the authorities is obtained (Beck-Gernsheim 2007). Such marriages have a number of practical and expressive aspects. Structurally, they help to maintain transnational connections, which in turn may have the effect of countering pressures that may lead towards the fragmentation of minority communities and families. In minority groups such as British Pakistanis, transnational cousin marriages are often also viewed as less risky, in socio-economic, cultural and emotional terms, than marriages outside the family (Shaw 2009; Charsley 2007).

At the same time, access to higher education and employment, motivated by the desire for socio-economic improvement, creates new opportunities for young people to meet and marry outside the family circle. In Denmark, marriage is being redefined not only by generational change within families but also by the state, through its policy of family reunification across the generations (Rytter 2013; chapter six, this volume). Future trends are difficult to predict because of the complex interplay of internal and international socio-economic and political factors (Reniers 2001). Even so, there are clear signs of heterogeneity and intergenerational change in attitudes towards arranged transnational cousin marriages within South Asian and Middle Eastern Muslim minorities in Europe; for

some, cousin marriage is not the safe haven their families assumed it would be (chapters five and seven, this volume).

## **Consanguinity and Genetic Risk**

A further and, up to now, relatively unexplored influence on the processes of spouse selection discussed above is the medical genetic evidence that parental consanguinity increases the risk of recessive genetic problems in children. A great many medical genetic and epidemiological studies have demonstrated an association between parental consanguinity and adverse birth outcomes, mainly as pregnancy loss (miscarriage and stillbirth), infant death and childhood morbidity (chapter one, this volume; see also Bittles 2012 for elaboration). This association reflects the elevated risk of recessively inherited single-gene disorders (associations between parental consanguinity and dominant, sex-linked or multifactorial conditions are poorly established). There are literally hundreds of recessive conditions, many of which are serious or fatal, and some of which are so rare that only a handful of cases have ever been reported globally. Recessive conditions can and do occur in the general population without there being a family history of the condition and in the absence of parental consanguinity, although these factors make their occurrence more likely.

Examining the actual and potential social impacts of this evidence on traditional processes of cousin marriage is complex because it requires an engagement with diverse arenas of representation. First of all, some understanding of the basic science of genetic risk in consanguinity is necessary, as well as of the kinds of calculation of risk that geneticists can make for individual couples. In their chapter in this volume, Ten Kate et al. describe how these risks are calculated, both at the population level and in the genetic counselling of patients. Risk estimates are usually given as 4–6 per cent (for couples who are cousins) or approximately ‘double’ the baseline risk (2–3 per cent) for an unrelated couple. However, actual risks can vary quite considerably, depending on the prevalence of carriers for particular recessive conditions in given populations, and on whether a couple has a family history of consanguineous marriage over generations, and/or of a genetic condition. In the case of a consanguineous couple with an affected child, one should not jump to the conclusion that the condition is the result of the parental consanguinity, but one must take into account the family history of the parents, ‘the inbreeding

coefficient, the relative frequencies of different pathogenic mutations and the total gene frequency' (chapter two, this volume).

### *Alarmist Statistics and Moral Panics*

Yet in public health circles, the public domain, media representations and lay understandings, the risk for and cause of genetic conditions in children of consanguineous couples are frequently confused. Not surprisingly, the families and communities targeted by risk discourse and medical intervention are sometimes sceptical of the messages they receive, observing, for example, that not every child of consanguineous parents has a genetic condition and that children of non-consanguineous parents may also have health problems (see chapters three and seven, this volume).

In addition, scientific risk estimates are frequently exaggerated in media reporting through alarmist presentations of statistics. A feature of this risk discourse, particularly as it is promulgated in the media, is that the statistics documenting the risk are frequently presented in an alarming manner. Sometimes the emphasis is not on the rarity of many recessive conditions but on the fact that there are *more* recessive conditions diagnosed within consanguineous than in non-consanguineous groups. In such reporting, cousin marriage is, in effect, 'reduced' to a long list of – sometimes hundreds – severe or fatal genetic conditions, some marked by peculiar constellations of dysmorphic physical features, a list that is then compared with the smaller number of conditions diagnosed in non-consanguineous populations.

Recently, British researchers linked data for congenital anomalies and consanguinity in a multi-ethnic population as part of the 'Born in Bradford' (BiB) study (Sheridan et al. 2013). They found that the risk of having affected children was about 2 per cent greater for mothers of Pakistani origin than for those of white British origin. A similar increase in risk was found for mothers of white British origin older than thirty-four years. The researchers conclude that sensitive advice about the risks should be provided to communities at increased risk, and to couples in consanguineous unions, to assist in reproductive decision making.

While the researchers insist on 'sensitive advice', the media and public interpretation of such studies is often alarmist. Radio 4 programmes about the BiB study were quite carefully put together to try to de-sensationalize the findings; they included observations where some of the behaviours of Pakistani mothers were constructed as 'protective' against birth defects compared with white



mothers (alcohol, smoking, etc.). But the headline in the Guardian story covering this study stated that ‘Marriage between first cousins doubles risk of birth defects, say researchers’ (Boseley 2012).

A perceived ‘doubling’ of a risk is much more likely to alarm rather than to inform, unless it is accompanied by the baseline disease prevalence. Doubling a low risk result is a risk that is still not high, but at most moderate. As noted, 2–3 per cent is usually quoted as the baseline risk in unrelated couples, to which another 2–3 per cent can be added for first cousin offspring, resulting in a risk of 4–6 per cent. Some of this extra risk can, moreover, be pinpointed and foretold by looking at the family history. Case-by-case genetic counselling, taking advantage of next generation sequencing, to identify carrier couples who are at 25 per cent risk is the way forward in the care for consanguineous couples, who can then be offered appropriate reproductive choices (see chapter two and all chapters in Part 3 of this volume). However, this type of case-by-case counselling, which has been advocated under the premise of ‘healthy consanguinity’ (see chapter eight, this volume) is frequently contradicted by the message that cousin marriage should be strongly discouraged, or stopped altogether.

In these messages, moreover, consanguineous marriage frequently acts as a vehicle through which social and political agendas concerning apparently ‘non-assimilating’ minority groups are played out. The assumption that marriage between cousins in Muslim communities is causing terrible disabilities in children, and/or is ‘forced’, is often used to stereotype and stigmatize on medical and/or political grounds (chapters five and six, this volume). Data on the linkage between cousin marriage and forced marriage is scarce and full of loopholes. In 2012, the UK Forced Marriage Unit gave advice or support related to a possible forced marriage in 1485 cases. While these cases involved 60 different countries, most were from Pakistan (47.1 per cent), Bangladesh (11 per cent), and India (8 per cent). In all of these communities, cousin marriage is prevalent; however, we do not have data on how many of these cases represent cousin marriages (Forced Marriage Unit 2012). Forced marriage evidently exists and should be determinedly discouraged; our point is that it would be wrong to label each and every cousin marriage as forced unless proven otherwise, just as it is wrong to claim that each and every cousin marriage is genetically risky. The analytically separable issues of forced marriage and of genetic risk have been connected in policy-related debate linking consanguineous marriage to the creation of ‘a high degree of insularity with barriers to integration and lack of

contact with the wider community' (Hasan 2009: 275). Cousin marriage is, moreover, frequently portrayed as the practice of outdated traditionalists, as 'a centuries-old Islamic custom' that is 'unacceptable in the twenty-first century' (see chapter five, this volume), with rarely any attention paid to the fact that Islam permits but does not prescribe cousin marriage, and to the diversity of Islamic opinions about its desirability, including concerning the risk of birth defects (chapter seven, this volume; Shaw 2009: 52, 55–56). Yet an earlier, wide-sweeping claim by a conservative commentator in the United States held that the 'Muslim kinship structure is an unexamined key to the war on terror'; for this commentator, the 'in-group solidarity' that results from cousin marriage produces a 'self-sealing insular world' (Kurtz 2007).

This stigmatization of cousin marriage in Europe on medical/social/political grounds prompts comparison with the situation elsewhere in the world where cousin marriage is still practised by a substantial proportion of the population. In fact, awareness of genetic risk in consanguineous marriage is now global in biomedical circles, as a result of the international training and transnational movement of medical personnel (see chapter three, this volume). As Beck has observed for modern society in general, identifying risk is accompanied by the imperative to 'manage' it (Beck 1992). Concern with managing the risks associated with consanguineous marriage is now also prominent among public health professionals across the Middle East, Central Asia, and parts of the Indian subcontinent, disseminated through government health institutions and by doctors, geneticists and the media (see, for example, chapters three and four, this volume).

In a recent public debate held in Qatar and broadcast by the BBC, the motion 'marriage between close family members should be discouraged' was overwhelmingly supported, by 81 percent (Doha Debates 2012). It is likely that such public condemnation is fuelled by both popular prejudice and powerful media constructions, in which the nature of the genetic risk, at the population level, is not sufficiently understood. The difference between one-off cousin marriage and continuous intra-family cousin marriage over generations, for example, is important and not sufficiently understood in such debates (chapter one, this volume). The concentration of genetic diseases that are the result of descent/consanguinity might well occur in a subgroup of families while other cousin marriages may not have a significantly higher risk compared to the general population. In the wider context of the Doha debate on cousin marriage one can

spot powerful and rapid forces of modernization already at work. Changes in gender norms, education and employment patterns, age at marriage and patterns of spouse selection are all likely to have an impact on attitudes towards cousin marriage, and across the Gulf region there is considerable investment in new, modern medical facilities including genetic screening and counselling (chapter three, this volume).

What we witness in these processes is that cousin marriage globally is not only 'medicalized' but also represented as the unreflexive and irresponsible custom of 'backward' and 'ignorant' traditionalists. We see here an inversion of the original anthropological representations of cousin marriage: the antithesis of 'cultural continuity' (Ottenthaler 1996), security and 'solidarity' (Holy 1989) being re-cast as 'cultural stasis and isolation', 'insularity' and 'the terror wars' (Kurtz 2007). So much so that cousin marriage even features as the focus of a recent study on 'Consanguinity as a Major Predictor of Levels of Democracy' that examines the hypothesis that although the level of democracy in a society is a complex phenomenon involving many antecedents, consanguinity is 'an important though often overlooked predictor' of it. This recent study found that measures of democracy and consanguinity negatively correlate to a large extent in a sample of seventy nations, advancing the explanation that 'restricted gene flow arising from consanguineous marriage facilitates a rigid collectivism that is inimical to individualism and the recognition of individual rights, which are key elements of the democratic ethos' (Woodley and Bell 2013: 263). In addition, the authors argue that 'genetic similarity stemming from consanguinity may encourage resource predation by members of socially elite kinship networks as an inclusive fitness enhancing behavior'. In citing this study, our purpose is to highlight how it illustrates the social construction of 'consanguinity as taboo', i.e. as a source of symbolic and perceived physical danger (Douglas 1966, 1992) in which the rudiments of 'primitive society' are supposed to endure as obstacles to modernity and democracy.

### **Cousin Marriage and Consanguinity: Hybrid Perspectives**

The case studies in this book represent a synthesis of traditional anthropological perspectives on cousin marriage and the contemporary concern with consanguinity and genetic risk. Only after

appreciating the nature of this risk, and examining how it is propagated in public health circles and in the public domain, particularly in the media, can we fully understand the significance of how these risks are understood within the families and communities that are the direct and indirect ‘targets’ of risk discourse and medical intervention.

To establish the perspective that we wish to advocate in this book, the first two chapters provide the epidemiological and medical genetic background for the case studies presented in the book’s three main sections. Bittles offers up-to-date background information on the current global prevalence of and trends in consanguineous marriages, reflecting on consanguinity as both a genetic and a legal concept. As a legal concept, consanguinity is used in laws of inheritance and in codes governing which marital unions are permitted and which are considered incestuous. As a genetic concept, it usually refers to the marriages of people related as second cousins or closer, but endogamy and population structure can also affect a couple’s risk of having a child with a recessive genetic condition, and this is one reason why it is so difficult to establish the precise contribution of parental consanguinity to infant mortality and morbidity. Where the carrier frequency of particular recessive mutations is high, the prevalence of these conditions – for example, thalassemia and Tay Sachs disease – may be high without the parents being first or second cousins (see also chapters three and nine, this volume).

Ten Kate and colleagues take forward the points about genetic risk in consanguineous marriage raised by Bittles. This risk is frequently overestimated, and their chapter explains how realistic estimates can be made using mathematical calculations and observational data. It also shows how risk estimates can be made in the clinical context for individual consanguineous couples, both where there is a family history of disease and where there is none. The chapter introduces some formal genetics and population genetics concepts, in order to explain essential concepts such as gene frequency and carrier frequency. Readers unfamiliar with these concepts can refer back to this chapter as and when they need when reading the individual case studies that follow.

We have organized the rest of the book into three parts, in order to trace the routes that the discourse of risk has taken across three domains: in countries where cousin marriage is, or until very recently has been common; in countries where it is now a minority marriage pattern; and in situations detailing active attempts to manage genetic risk in cousin marriages.

Part 1, 'Continuity and change in traditional consanguineous marriage', presents case studies where the state-level genetic risk discourse focuses on the significant public health challenges caused by  $\beta$ -thalassaemia and sickle cell anaemia (SCA), conditions that occur at a particularly high frequency among people of Mediterranean, Middle Eastern and South Asian ancestry.  $\beta$ -thalassaemia is a major cause of childhood mortality in poorer parts of the world, and its treatment is expensive and entails a lifetime of regular blood transfusions and medications. In the UK, prenatal screening to identify carrier-status women is offered generically in areas of high ethnic minority concentration, and to women of Mediterranean, Middle Eastern or South Asian ancestry in other areas. Couples identified as carriers with 25 per cent risk of having an affected child are then offered prenatal diagnosis with the option of abortion for an affected foetus.

In countries with less developed screening, diagnostic and treatment services for thalassaemia, and where the condition is more prevalent, an alternative strategy is to focus on identifying at-risk couples before they marry – following the well-known example of Cyprus where this strategy has resulted in the almost complete elimination of thalassaemia. What is less well known is that the reduction of thalassaemia births in Cyprus is mostly due to prenatal diagnosis and selective abortion, in a medical environment in which couples' reproductive choices are strongly influenced by health professionals (Angastiniotis et al. 1986; Hoedemaekers and ten Have 1998). Some of the rapidly modernizing Gulf countries have introduced mandatory pre-marital screening; how directive these policies are is an open question, given the uneven implementation of prenatal diagnostic facilities and the variability of laws permitting termination of pregnancy.

In Oman and Turkey, as chapters three and four show, cousin marriage has been identified as an obstacle to be overcome in reducing the incidence of haemoglobin disorders. In Oman, which currently lacks systematic prenatal diagnostic facilities, a public health discourse advocates the carrier screening of couples on the basis of their consanguinity, rates of which are believed to be especially high among people from tribal areas, since tribes are assumed to be biological units. Ironically, Beaudevin suggests, this targeting of already-stigmatized categories of people is unlikely to reduce the incidence of haemoglobin disorders because of the high proportion of unaffected carriers in the Omani population, which is in effect endogamous because Omani marriage regulations – like

those of Saudi and some other Gulf states – restrict marriage with non-Omanis.

In Turkey, a recent public health campaign discourages cousin marriages. Together with premarital screening and diagnosis for consanguineous couples, it represents the government's attempt to reduce the incidence of haemoglobin disorders, which are seen as arising from consanguineous marriages. In keeping with attempts to improve the nation's health that date from the 1920s, consanguinity has been added to the list of mandatory pre-marital health checks for 'social diseases'. Prager describes a striking form of indigenous response to this situation: one of the targeted ethnic groups has adapted the biomedical discourse to their own understandings of genetic risk and reshaped the system of cousin marriage in a way that would cause Mendel 'to turn in his grave'. This neatly illustrates how biomedical risk as a scientific construct derived from a set of statistical assumptions can be re-interpreted rather than readily transferred across different contexts.

Part 2, 'Cousin marriages within migrant populations in Europe', turns to case studies from the United Kingdom (chapter five), Denmark (chapter six) and the Netherlands (chapter seven). We see here an overwhelmingly negative public perception of cousin marriage broadly embedded within debates about integration and immigration, especially with regard to Muslim minorities. Yet there are also some intriguing differences across these contexts in terms of the emphasis placed on genetic risk.

In the UK, Pakistani consanguineous marriage shows no sign of decline, contradicting conventional expectation, and despite evidence of a disproportionately high number of rare genetic conditions in Pakistani children and heated debate in public health and the media about the management of this situation. In the UK, risk of haemoglobinopathies is managed through prenatal screening for all pregnant women in high prevalence areas of the UK and by ethnicity in low prevalence areas, with no formal top-down medical management of risk associated with parental consanguinity. Shaw's discussion in chapter five of the experiences of families with genetic conditions complicates the stereotypical media and public health view that British Pakistanis are in denial about genetic risk and do not engage with clinical genetics services or techniques of risk management. She describes parents' deliberations over their children's marriages in the light of awareness of genetic risk, and details a variety of ways in which couples given an estimate of reproductive recurrence risk engage with genetic risk and its management.

In Denmark, by contrast, as Liversage and Rytter show in chapter six, cousin marriage has not been debated in terms of genetic risk. Rather, bureaucrats have reconfigured cousin marriage as ‘forced’ unless proven otherwise, and put this concept to work in the loaded political context of immigration policies. In Denmark, the ‘family reunification’ of foreign ethnic collectivities – of Turks and Pakistanis, in the examples provided – is represented as endangering the political identity of another collectivity – that of the Danes.

In the Netherlands too, Storms and Bartels note in chapter seven, politicians have also constructed cousin marriage as ‘forced marriage’, but a proposal to legislate against it on these grounds is in abeyance since the election of the current government. In these debates, there is an echo of the nineteenth-century concern, which was prevalent in the United States, that the marriage practices of ‘non-integrating’ linguistic and religious minorities would threaten social progress, concern that resulted in thirty-one states making cousin marriages illegal (Ottenheimer 1996: 113). In the Danish situation, as Liversage and Rytter show, one consequence is that some cousin marriages that the authorities would define as ‘forced’ take place instead in Sweden, while other couples may be separated for years while trying to prove their marriage was not forced.

The case studies in this section also remind us that any assessment of the impact of legislation or genetic risk discourse upon spouse selection must recognize that within Europe’s consanguineous minority populations, marriage patterns are already undergoing change. Turkish and Moroccan women in the Netherlands are aware of the genetic risk in consanguineous marriage, but this awareness – perhaps traceable to their countries of origin – is mediated by religious, social and cultural considerations, which, among younger women, indicate that arranged cousin marriages will become less common. Trends in consanguineous marriage across Europe are likely also be influenced by internal, national and interstate diversity in the socio-economic characteristics of Europe’s consanguineous minority populations. British Pakistanis, for example, are socio-economically heterogeneous, and also differ in socio-economic background, migration history and regional origin from Norwegian and Danish Pakistanis (Rytter 2013; Shaw 2014). Variations in government stances towards minorities, as already illustrated by the recent Danish policy, are also likely to influence trends in consanguineous marriage across Europe.

Part 3, 'Consanguinity and managing genetic risk', presents case studies of schemes aimed at managing the elevated genetic risk for consanguineous couples, thus promoting 'healthy consanguinity'. A number of genetic carrier testing and screening programmes aimed at particular endogamous or consanguineous communities are in place. These include premarital carrier matching for the ultra-Orthodox Jewish community (Raz and Vizner 2008; chapter nine, this volume) and for Arab-Bedouins in Israel (Raz 2005), and schemes for British Pakistani families with recessive conditions for which mutations have been identified (chapter five, this volume). Targeted ancestry-based preconception screening for carriers of cystic fibrosis and haemoglobinopathies, for which risks vary with ancestry, was piloted in the Netherlands for Dutch couples and those of immigrant-origins in Surinam, the Antilles, Turkey and Morocco (Lakeman et al. 2008, 2009). There is a diversity of opinion across these different contexts with regard to whether the increased genetic risk associated with cousin marriage is best confronted by education, counselling, prevention, or some combination of these strategies. The schemes also raise questions about the potential medicalization of partner choice and the effects on marital norms, including through health interventions that have the explicit objective of identifying carriers of particular conditions not in order to discourage consanguineous marriage but to promote 'healthy consanguinity'.

The first case study in this section is from Israel, which has an ethnically diverse population with many endogamous communities. Zlotogora describes an innovative state programme devoted to 'healthy consanguinity' via genetic counselling, in which the genetic counselling takes place not in hospital departments but alongside family doctors, nurses and counsellors working in the various, usually rural and peripheral, communities of Arab Israelis, Druze and Bedouin, all characterized by a high degree of consanguinity. Zlotogora discusses the construction of a genetic database containing information about the genetic conditions present in the community as an invaluable genetic counselling tool, enabling the medical impact of consanguineous marriage to be reduced without directly intervening in local marriage traditions. This is striking, because in places such as the UK, the creation of genetic databases – for example on consanguineous Pakistani families to enable family doctor-led genetic counselling – has generated ethical debate about patient confidentiality (see chapter five, this volume). Zlotogora comments that in Israel there has long been acceptance of the use of ethnicity /community of origin data, including for medical purposes,



with the frequency of particular genetic conditions varying in different communities. Indeed, the genetic database created initially for the Arab Muslim community has since been extended nationally as an important aid to state genetic counselling provision.

We then turn, in chapter nine, from a state-administered to a community-administered programme promoting 'healthy endogamy': that of the much celebrated carrier screening programme *Dor Yesharim*, founded in 1983 to prevent suffering caused by births of children with Tay Sachs disease in a community where marriages are arranged and there is a religious ban on abortion. Marriages are advised only where both partners do not carry a mutation for the same condition, but to avoid stigma individuals are not informed if they are carriers or not. Since the programme's inception, the number of Tay Sachs births has greatly decreased, and the programme has been hailed as a triumph as a result of its sensitivity to the norms of the community.

However, Raz argues, *Dor Yesharim* has been less successful in preventing stigma. Public messages stressing the negative aspects of knowing about and being identified as a carrier constitute a powerful directive message that reproduces rather than challenges stigmatization: being a carrier is so bad that you had better not know. The stigma is such that carrier matching is often sought late in the marriage-arranging process, only after matches that might have proved 'advisable' have already been ruled out on grounds of a family history of the condition. Stigmatization is strong enough to contaminate even 'presumed carriers'. *Dor Yesharim* primarily serves an orthodox community with specific social characteristics, but may also be utilized by modern religious Jews who may also access state genetic counselling with its emphasis on non-directiveness, individual autonomy and informed consent. It is here, Raz notes, that we witness tensions between 'communitarian' approaches, which may be 'culturally appropriate' but compromise western bioethical principles, and 'liberal' approaches to genetic counselling, as he has also discussed in his ethnography of genetic counselling in a Bedouin community in Israel (Raz 2005).

In the final chapter, Teeuw and colleagues discuss a scheme for preconception genetic screening of couples that could be offered to couples on the basis of their consanguinity, or even to all couples. Significantly, the recording of ethnicity data in the Netherlands remains a topic of political debate, reflecting eugenic concerns and fear of stigmatization (Jans et al. 2011). A tool that could screen the coding sections of the genome of both partners would enable risks

for recessive conditions to be identified; from this, the risks associated with consanguinity could be refined in individual cases. The key question will be whether to offer this tool, once developed, to all or only to consanguineous couples. As the companion chapter by Storms and Bartels in this volume shows (chapter seven), cousin marriage in minority communities in the Netherlands is both stigmatized and undergoing significant change. Teeuw et al.'s discussion of the conditions under which such a scheme could be implemented is exemplary in its reflexivity and awareness of the need to incorporate ethical and social perspectives in the development of reproductive genetic technologies.

In the afterword, Adam Kuper provides a discussion of the marriage of cousins in Victorian England, which is elaborated in his *Incest and Influence: The Private life of Bourgeois England* (2009). Kuper's account of cousin marriages in the Darwin-Wedgwood family reminds us that close kin marriages, including first cousin marriages, were common in upper-middle-class Victorian England; cousin couples could feel as close as siblings, already connected through family ties, without actually being siblings. This observation resonates with Tillion's that across the Maghreb the idea of marriage is 'with the female relative, who, while not a sister, most resembles one' (1983). But in Victorian England doubts were already emerging in the minds of people such as Charles Darwin concerning where to draw the line between consanguinity and incest, and about the potential biological risks of cousin marriage.

By stepping back to Victorian England, Kuper shows us that much of the contemporary discussion of genetic risk in cousin marriage has its origins in our recent past, in the intellectual and social background to the rise of modern genetics. This offers historical depth to our analysis of how the study of cousin marriage has shifted to focus on the construction of risk. In the emerging nineteenth-century research, we can already trace many contemporary themes. The issue of genetic risk was clearly a sensitive one: one attempt to establish the effects of cousin marriage on fertility and birth defects took the form of a proposal taken to parliament that the 1871 census of England should include a question on cousin marriage, but the proposition was rejected on the grounds that it would be prying. There is also a contemporary ring to the concern to establish the influence of environmental factors on birth outcomes and quantify the particular risks of close kin marriage in remote inbred populations. The historical account shows us that much of the contemporary discussion of cousin marriage is also part of our past, with

the significant difference that today's discourse tends to be focused on Muslim minority populations in Europe, and on 'tribal', 'traditional', 'rural' and 'uneducated' populations in other parts of the world.

## **Negotiation, Reflexivity and Representation**

This volume addresses leading questions for a socio-anthropological study of consanguineous marriages underpinned by the modern medical focus on managing genetic risk. As far as we know, it represents the first comparative exploration of the forms and effects of the discourse of genetic risk on contemporary practices of cousin marriage, in interaction with existing and emerging facilities for genetic counselling, screening and testing. The contributions to this book show that the concept of genetic risk in consanguineous marriage is now global, and it circulates not only where marrying cousins is a minority marriage pattern, but also in areas where cousin marriage remains common. They also show how this discourse takes diverse forms, in the views and messages of health professionals and in the views of lay populations. The scientific information is itself diverse, depending on what is included in the risk calculation, and is more or less alarmist depending on its representation. Yet the general effect of much of the reporting is to suggest that the risk is 'high', that it applies to all consanguineous marriages, and that it equates to 'cause' and 'doubling' the background risk. The risk discourse is frequently also a vehicle for social and political agendas. To demonstrate this, we invite our readers to ask themselves whether public discouragement of pregnancy in women older than thirty-four years would be socially and ethically acceptable, and then consider the fact that women over thirty-four and first cousin couples are generally considered to have a similar increase in risk.

As the case studies demonstrate, there is, nonetheless, no straightforward medicalization at work across these contexts. There is heterogeneity in formal medical provisions for managing risk and also in how consanguineous couples and intermarrying communities perceive and negotiate the implications of risk information (Shaw 2011). Sometimes people calculate risk in quite unexpected ways that do not correspond with the bilaterality of Mendelian genetics but, as in the South Asian and Turkish cases discussed here, reflect local understanding of closeness in patrilineal kinship. These accounts contribute to knowledge concerning how biology

(genetics) and relatedness (kinship) are not identical (Böck and Rao 2000; Franklin 1997; Meiser et al. 2001; Richards and Ponder 1996; Shaw and Hurst 2008). It would be interesting to compare these cases with change in the quintessentially South Indian 'Dravidian' pattern of cross cousin marriage (to the MBD) under the influence of the discourse of risk in close kin marriage. In interpreting change in marriage patterns, the discourse of genetic risk is, of course, just one factor among others, such as the move toward smaller families, wider contraceptive use, and the shift away from family arranged marriages to individual choice of marriage partners.

In the rapidly modernizing economies of the Gulf States, genetics service infrastructure is being established with varying levels of integration of services, inviting further comparative research on the relationships between service provisions, and professional and lay discourses of genetic risk in consanguineous marriage. Is the misleadingly equation of risk in consanguineous marriage with risk of haemoglobinopathies noted in the Oman case made elsewhere in the Middle East? What public discourses circulate and what provisions exist for the clinical diagnosis and management of rare recessive conditions? Are minority groups always the targets of stigmatizing discourse?

In the community and public health programmes aimed at identifying carriers and promoting 'healthy consanguinity' discussed in this volume, we see that 'culturally sensitive' strategies are not entirely free of stigma, and also raise questions of coercion and consent regarding access to and the holding of genetic information. Such approaches may be appropriate at the level of 'traditional' religious/ethnic communities governed by more 'communitarian' ethics, but are less appropriate in multi-ethnic populations in Europe where genetic counselling is governed by principles of autonomy and individual informed consent (Raz 2005; Simpson 2004). Tensions between inducing change informed by individualistic western ethics and being sensitive to local cultural norms are also present within educational aids designed by health professionals to inform about genetic risk in cousin marriage or to promote 'healthy consanguinity' (Raz 2003). While top-down interventions may be too coercive, leaving the management of genetic risk entirely to the community has also proven to be problematic (Raz 2009a). The management of risk as part of 'healthy consanguinity' thus requires a careful, on-going dialogue between policy-makers, health professionals, and networks of individuals genetically at risk (Raz 2009b). In multi-ethnic populations, moreover, in order to avoid stigmatization by

ethnicity, the question remains open whether a risk assessment tool for consanguinity, offered 'independently' of ethnicity, is the best means of informing couples' reproductive choices. Of note, the majority of the problems highlighted in this book are in fact manageable, but this requires moving beyond both the traditional celebration of cousin marriage as well as the modern, medically led discouragement of consanguinity. Our comparative approach thus has implications for professionals developing and providing genetic screening programmes for consanguineous couples in diverse global settings, because it underlines the importance of taking account of the far-reaching influences of the local political, social and cultural context instead of assuming that a single approach will be suitable for all. The future of 'healthy consanguinity', if this approach is indeed to gain prominence, depends on the successful balancing of the interests of health professionals and providers, as well as of individuals genetically at risk and their communities and networks.

We end with some reflections on the challenge taken up in this book. We have described an historical shift in perspectives, from a traditional anthropological approach to 'cousins' as a social category/genealogical position and 'cousin marriage' as a social phenomenon, to the contemporary focus in epidemiology, public health and media reporting on cousin marriage as (risky) 'consanguinity'. What we offer across the case studies in this book is a contemporary, hybrid perspective on cousin marriage, one that draws together the cultural representations of anthropologists (as well as laypersons) and the scientific representations of geneticists, and encourages reflexivity in both.

In the accounts presented here, cousin marriage is sometimes given alternative social and cultural representations/labels, for example in its presentation as 'forced marriage' and as being inimical to democracy. But we have also seen that in most contemporary accounts it is represented mainly through the medical lens of genetic risk, indicating a continuing strong linkage between nature and culture, between the biological and the social, to the extent that cousin marriage is frequently essentialized, reduced to the literal and ominous metonymies of congenital defects and genetic diseases. This continues despite new genetic studies showing that generalized estimates of the increased genetic risk in consanguinity are often exaggerated or otherwise presented in an alarmist manner. However, the popular medical representation of cousin marriage as risky, and the association of cousin marriage with 'non-integrating', 'conservative', 'traditional', 'undemocratic' peoples, continues to

provide an important source of lingering antagonism. In a world of cultural compounds, social fragmentation and rising individualism, cultural elements that appear to resist modernity and globalizing trends are a symbolic source of danger. 'Cousin marriage' may be another case in point in the list of modern-day taboos.

Indeed, in a global world dominated by mass media and impregnated with a declared transnational desire for ubiquitous human communication, cousin marriage may be seen as evading 'the civilizing process', resisting assimilation, defying pluralism, negating the plausibility of change and blind to multi-cultural differences. However, as the collection of case studies in this anthology demonstrates, to generally denounce cousin marriage is in itself a normative act of defying pluralism and multi-cultural differences. We argue here for a renewed reflexivity that considers the complexity of cousin marriage, avoiding generalized stereotypes in favour of a hybrid approach that is sensitive to both the social and cultural importance of cousin marriage and the health issues it raises.

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