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Cousin marriages and inherited blood disorders in the Sultanate of Oman

Claire Beaudevin

Introduction

This chapter uses the case of inherited blood disorders (IBD) as a lens to examine the impacts of a global biomedical discourse of genetic risk in cousin marriage in the particular context of implementing genetic services in the Sultanate of Oman, and against the backdrop of a regional public health agenda regarding IBD in the Gulf states. IBD currently represent the very core of the emerging medical genetics services in Oman, as well as in several of the other oil-rich Gulf countries (Bahrain, Qatar, United Arab Emirates, Saudi Arabia). Oman has experienced profound and rather extraordinary social upheavals since the coup that gave the current sultan access to the throne in July 1970. One of them is the healthcare system itself, created *ex-nihilo* during the past few decades. In 1970, there was only one (US-missionary) hospital in the country; in 2000, the healthcare system was ranked 1st among emergent countries for its 'performance according to the impact on health', and 8th for its 'global performance' (World Health Organization 2000).

IBD have now been made a priority in the creation of genetic services in Oman. Indeed, IBD are new diseases in the country, recognised as diagnostic categories only during the 1980s; previously, there were no laboratory facilities for diagnosing IBD, and no facilities for managing IBD. Living with sickle-cell anaemia or thalassaemia implies a routine of diverse medical interventions: blood transfusions, treatment reassessment, check-ups and specific blood tests are often necessary on a monthly basis. Besides, the pyramidal organization of the Omani healthcare system also requires patients to go to regional hospitals or even to the capital for treatment (Beaudevin 2013a), as there is only a handful of IBD-specialized units in the country. The public sector provides free healthcare, including certain complex and expensive procedures that can only be performed abroad, for Omani passport-holders, but not for the (mainly male) migrant workers from Asia who comprise 25-30 per cent of the population. The numerous private health institutions do not provide advanced care for people living with IBD — notably regular transfusions and repeated treatment of pain crises — or large scale screening for IBD — for the disease, or to identify unaffected carriers who risk having an affected child if they marry another carrier).

This chapter is based on anthropological research (Beaudevin 2010, 2013b) that focused on the social dimensions of living with sickle-cell anaemia and thalassaemia, their medical management, and the public health policies related to them. For this research, I conducted long-term fieldwork using ethnographic methods: I spent time with scientists, patients, families and officials, in public and private hospitals and clinics, in and outside the capital (Muscat), in official meetings and conferences, at patients' homes, and with the IBD patient association, etc.

In what follows, I begin by discussing diverse expert and lay discourses about consanguinity, genetic proximity and the local concept of *al-aqārib* ('the closest ones'), in the context of a global medical discourse that stigmatizes consanguineous couples, to show that consanguinity has complex meanings and does not map onto a single social reality in Omani society. I then turn to discuss expert and lay understandings about genetic risk, to detail the on-going medicalisation of cousin marriage that is occurring as a consequence of the Omani public health discourse and incipient policy for managing risk of IBDs in the Sultanate. There are real issues for patients and families in understanding the genetic risk for IBDs, but the common association of cousin marriage with risk for IBDs and the concern with stopping cousin

marriage as a means of preventing IBDs is misleading in the light of the high prevalence of IBD carriers in Omani society.

Expert Discourses

Consanguinity as a 'Genetic Burden'

In the early 2000s in Oman, consanguineous marriages characterised around 56 per cent of couples. More precisely, 24.1 per cent of married couples are first cousins, a proportion comparable with neighbouring Saudi Arabia, for example (El-Mouzan et al. 2007). There are no more recent figures, but the proportion may now be less, since fecundity has decreased from 6.6 children per woman in 1990 to 3.13 in 2007 (Ministry of Health 2008) — subsequently to the implementation of the 'national birth spacing initiative'.

Omani medical doctors are trained during 6 years in the Sultanate's two colleges of medicine, but must then study abroad if they wish to obtain their specialist medical qualifications. Most spend several years in the USA or the UK, and a smaller number study in Germany, France, Canada or Australia, where they are exposed to international views about consanguinity that are embedded into their medical training. These views are both ideological and scientific — ideological because they stem from European and North American historical discourses depicting consanguineous marriages as biologically hazardous and socially exceptional (Ottenheimer 1996; see also Kuper, this volume). The common scientific medical definition considers individuals to be linked by consanguinity when they share a least one ancestor, up to the great-great-grand-parents (Susanne et al. 2003). This link is associated with a higher risk of recessively-inherited conditions in children compared with children of non-consanguineous couples; thus, marrying a relative is often considered a genetic 'burden'. However, consanguinity rates are notoriously difficult to establish. Social definitions of kin, extended family or tribe do not always correspond to an underlying genetic relatedness. In Oman, for example, contemporary civic status was created only in the 1980s, and so sharing a name (isonomy) does not necessarily indicate shared biological ancestry or traceable tribal origin. Consequently, epidemiological studies of the effects of parental consanguinity on infant health are often based on approximations of consanguinity rates, and are further complicated by the fact that many different factors influence birth outcomes (see Bittles, this volume). Moreover, the abundant literature produced by medicine, public health and biological anthropology on the matter shows a global tendency to stigmatize the 'cultural behaviours' that lead individuals to choose a spouse among their family members. This has not, however, resulted in globally uniform policy responses; public health goals range from targeted genetic counselling in some countries (Modell and Darr 2002; World Health Organization 1999) to the eradication of this matrimonial practice in others (Mégarbané 2002).

Medical practitioners in Oman are thus caught in the crossfire: on the one hand, they are part of a society where over half of the couples are cousins and over a quarter are first cousins (Nair et al. 2008; Rajab and Patton 2000), and where these alliances are valued by families. On the other hand, the authorities discourage these marriages and the internationally-trained medical practitioners have learned in medical school that consanguinity is dangerous. This generates a wide range of sometimes conflicting representations, from 'consanguinity as economic choice' to 'consanguinity as genetic burden' (Bonte 2007; Khlaf 1989; Bonte 1994).

Some doctors express extremely critical views. This Omani in his late sixties, living in Muscat, was a young doctor when the current sultan took power:

'I saw a woman, from a rich family. Educated. A very well-known family. One of the daughters was sick [with sickle-cell disease], homozygous and her father wanted her to marry her cousin. He is educated... (*sigh*) I told him: "do you realize the kind of grand-

children you will get?!” [...] Marrying one’s first cousin, this is not Muslim. The Prophet did not say it. And the diseases and the cousin marriages increase. And there is no social stigma on these marriages, even from the government’. (Interview, Muscat, November 2008)

The available official figures do not show any increase in the frequency of cousin marriages, contradicting this doctor’s statement. I would also, however, not be as affirmative as this doctor about the lack of stigma from the government. The image of cousin marriages in the media is rather negative. Further, doctors systematically investigate parental consanguinity in cases of congenital abnormality; a mandatory declaration form is available in all maternity units and contains a specific field about consanguinity assessment. In 2003, the regional press (Vaidya 2003) announced the visit to Oman of a renowned European geneticist, who publicly affirmed the impact of consanguinity on the prevalence of genetic disorders in Oman. The negative biomedical view of consanguinity is even endorsed by anthropological publications examining matrimonial behaviours in Arabia and related health matters through the unique lens of the ‘consanguineous marriage’ (see for instance Al-Kandari 2007).

Consanguinity as ‘Causing’ Inherited Blood Disorders

Some doctors I observed and interviewed in Oman try to teach patients that cousin marriage is a dangerous practice. The explanatory model of disease that underlies this stand is ‘disease as a sanction for prohibited social behaviours’ (Zempléni 1985): thus, IBD cases are attributed to the grand-parents’ and parents’ matrimonial choices. For these caregivers, convinced that cousin marriage is a causal factor in the prevalence of IBD, marrying a cousin is incomprehensible, even more so among the most educated groups of the population. An Indian radiologist working in a public hospital in Muscat told me, ‘Even if you talk with educated people, it does not change anything. I know doctors who married their first cousin. It’s culture. It’s deeply rooted. Some even get married without being tested. In India, cousin marriage is forbidden’ (Interview, June 2008).

Omani scientists publish notable figures: 7 per cent of Omani newborns are affected by a genetic disorder and a quarter of these cases are due to consanguinity (Rajab and Patton 2000); 10 per cent of Omanis carry an IBD mutation, half of them because of consanguinity (A. Rajab, personal communication, April 2008). These figures are not easily verifiable, but consanguinity cannot be responsible for all IBD cases. Since the frequency of unaffected carriers of IBD (people with IBD traits) is quite high, cousin marriage does not significantly increase the average shared risk of every Omani of having affected offspring.

Since systematic screening for IBD carriers is expensive and arduous, public health specialists tend to focus on defining target groups. In this context, the emphasis is often put on the dangerousness of consanguinity despite its relatively low impact on IBD prevalence in the country. Though they are presented as ‘scientific’, the criteria used to define these target groups are partly ideological. In the 1990s, a doctor employed by the Ministry of Health started a ‘tribal data-base’ linking IBD prevalence in specific families with families’ tribal origins, with the aim of assisting future IBD screening campaigns by identifying ‘high-risk’ family groups and tribes. The protocol for this data-base, published in a leading peer-reviewed medical journal, reveals an underlying assumption that the ‘tribe’ is essentially a biological unit deprived of social dimensions. In this publication, this assumption is justified by defining the tribe as a ‘genetic as well as social unit’, historically intermarrying (supposedly among a paternal lineage, that is, one with the same name indicating common male ancestry) to preserve access to water resources. This data-base is partly rooted in historical inaccuracies: it is based on a tribal nomenclature written in the early 1900s by a British administrator (Lorimer 1908); it ignores the political fusions and fissions that occurred in the tribal system

since then, as well as the above-noted common disjunction between tribal name and genetics.

This data-base is probably the most striking indication that cousin marriages and consanguineous marriages in general are targeted by emergent genetic public health activity. It is all the more striking for it draws on historical social categories that identify specific tribes with specific diseases. In Doha airport in 2005, I met a young Omani woman who, on learning about my research, immediately exclaimed:

'Ah, *faqr al-dam* [indigence of the blood, i.e., here, inherited anaemia]! ... this is a problem, mainly because of people marrying relatives. You know, there are families where these marriages led to peculiar diseases. The *al-Hinayy*, they are known to have blood disorders; and the *al-Maskarī*, this is mental disorders...'

Lay discourses

Blood Ties and Closeness

There is no Arabic equivalent term for consanguinity. Dictionaries translate it by uncommon phrases such as *rābat al-dam* (blood ties) and by phrases referring to social as well as genetic ties, as *sala al-qarāba* ('kinship relation', which can also encompass alliance) or even *ʿasabiyya*. The latter term — coined by the Arab historian Ibn Khaldūn in the 14th century (see Ibn Khaldūn 2004 for an English edition) — focuses on solidarity and loyalty ties that can exist in or outside the kinship network.

Likewise, in Omani common sense usage, consanguinity as biomedically-discouraged cousin marriage is considered one type of proximity (*qarāba*) within a broader whole of manifold *proximities*. *Qarāba* is an 'experience-near' practical kinship term (Eickelman 2002) that does not refer to etic analytical categories. This broader whole is called *al-aqārib* (sing. *al-aqrab*), i.e. 'the closest ones'. These are individuals whose proximity is spatial, social, genealogical or all of these at the same time. Thus, neighbours one visits regularly are *aqārib*, as are one's tribe's members (at least those with similar social status) and, above all, the close family members. The nuclear family is called *al-ahl* (people) or *al-hayyān* (*hayy* means neighbourhood). However, as Amal — an Omani teacher in her thirties — states, *al-aqārib* first designates people to whom one is linked by blood or alliance:

'*al-aqārib*, for me, those are all the close relatives: uncles, aunts, cousins, nephews and nieces, brothers-in-law and sisters-in-law. Mainly cousins, actually... Anyone who is my blood relative; there are some close ones and more distant ones: as my parents' uncles or even more distant, cousins of cousins, for example' (informal conversation, October 2008).

Biomedical representations are also pervasive within Omani society, notably through the daily use of the English language: most of the patients I met seemed to understand the biomedical meaning of consanguinity. As a result of this integration of biomedical terminology, most lay discourse about consanguinity only refers to first or second cousin marriages. In a conversation held in Arabic, the meaning of *al-aqārib* is thus contextual: when a nurse asks someone who carries an IBD trait if s/he and her/his future spouse are *aqārib*, and when women discuss future spouse choices for one of the family children, the *signifié* is different.

Safety and Backwardness

First cousin marriage in its specific parallel patrilineal form allows an individual to marry his/her closest relative inside the paternal lineage, i.e. the child (*bint ʿamm* or *ibn ʿamm*) of his/her father's brother. A significant body of literature deals with the cultural, social and economic aspects (notably preservation of the paternal lineage legacy) of this matrimonial

strategy (see e.g. Bonte 2007). Another pragmatic reason, emotional and material safety, has been described in many societies — in Oman, by Christine Eickelman in the 1980s (Eickelman 1984), where her observation remains relevant despite the massive rural exodus that has since occurred. Therefore, discouraging such marriages on public health grounds in contemporary Omani society has consequences that go way beyond health or economic aspects.

Contradicting some health professionals' assertion, Omanis are not ignorant about the risks to children of intra-family marriages: cousin marriages may be numerous, but the idea of the dangerousness of a 'lack of external blood' is ancient. Saif, a tribal leader in his late seventies, living in a rural area, told me about his youth (i.e. before any public health presence in Oman): 'In some families, we saw their number decreasing. Less children. Dead children, etc. Thus we used to say "they should marry outside, those people. The tribe is drying out" [*al-qabīla al-latī bathīf, najtanbūhā*], so we avoided them' (Interview, Muscat, June 2008). He then explained that exceptional measures can be taken in such cases: 'One tribe used to want this, to marry outside, but it was not allowed. One day, in the other tribe, a girl was born with a crooked eye, handicapped. However, the tribe asked for her, thinking she could bring in good things'. Indeed, Omanis did not wait for the arrival of biomedicine to observe correlations between disorders in and endogamy. Nonetheless, — before 1970 and nowadays — they evaluate the risks in ways not always congruent with genetic counselling rationality.

Cousin marriage is practiced in the Sultanate but not unanimously supported. Some Omanis, following medical advice or wishing to move away from burdensome matrimonial practices, frankly express their opposition. In these cases, marrying a relative is presented as a backward decision, as in the words of Hamad, whose wife is affected by sickle-cell anaemia: 'In Saudi Arabia, they intermarry. This is the reason of the number of sick people there. They do not want to marry outside of the family' (Interview, Seeb, May 2008). Hamad identifies cousin marriage with the Saudi neighbour, i.e. with the country many young Omanis have an aversion to, because of what they call its 'traditionalism'.

Oman's recent history — of internal political conflicts, complex interactions with European powers and tribal dynamics (see for instance Valeri 2009) — has produced a social dichotomy that also reflects the country's topography. While the interior of the Sultanate (*al-dākhiliya*) is identified with religiosity and attachment to the past, the coastal areas — especially the capital — are considered progressive and developed (Beaudevin 2013a). Hence, many Omanis tend to consider cousin marriages a backward peculiarity of the Interior. Abdulrahman, a young Omani from the Interior, affected by sickle-cell anaemia (as are several of his siblings), laments his parents' lack of foresight before they married: they are first cousins, he suffers this disease, and for him, the causal link is obvious. He even asserts, 'The Ministry of Health does not do anything to decrease the number of births of affected children. It's not complicated: they should only say, "if you marry a relative, this is dangerous for the children"' (Interview, al-Khoud, May 2005).

Omani Marriage Medicalisation Policies in the Pipeline

IBD in the Gulf and in Oman

Genetics has been a regional public health matter in the Gulf for about a decade, energetically discussed in local media, as shown by these newspaper articles' titles: 'Arabs have highest rate of genetic disorders' (Muslim 2006), 'Incidence of genetic blood diseases in Oman among highest worldwide' (Al-Tauqi 2012), 'Congenital anomalies high in Oman' (Vaidya 2003). As the commonest inherited disorders in the region, IBDs are targeted by recent policies. Several countries neighbouring Oman have chosen to implement mandatory premarital screening for

IBD: in the United Arab Emirates since 2006, in Qatar since 2009 and in Saudi Arabia since 2004. Newborn screening is also a regional choice: systematic and mandatory in Iran since 1997 and in Saudi Arabia since 2004. In Abu Dhabi (one of the United Arab Emirates), a pilot-study of neonatal sickle-cell screening was launched in 2002 (Al-Hosani et al. 2005). Medical termination following an IBD diagnosis was legalised in Iran in 2003 (Hedayat et al. 2006). It is also allowed in Saudi Arabia, but the authorities advocate pre-implantation genetic diagnosis, considered more in accordance with Islamic jurisprudence (Al-Aqeel 2006; Al-Odaib et al. 2003).

The Dubai-based Centre for Arab Genomic Studies (CAGS), created in 2003, is a leading network for the regional development of research and public health policies regarding genetics. In 2004, CAGS started to construct a Catalogue of Transmission Genetics in Arabs (CTGA) aiming at making an inventory of genetic disorders in the region.

Omani health professionals often mention Cyprus as a brilliant example of the quasi-eradication of IBD by voluntarist public health policies. One Omani surgeon told me, 'I heard from a haematologist yesterday that in a European place I don't know, an island, they managed to get a zero incidence. We should do this!' (Interview, Muscat, May 2007). Another doctor, in the University Hospital, spoke admiringly but inaccurately of this strategy: 'In Cyprus, they got a law. They go so far as to sterilize people' (Interview, al-Khoud, December 2008).

In Cyprus in the 1940s, the high prevalence of beta-thalassaemia mutations (about 15 per cent of the population; Angastiniotis et al. 1986) called for prevention policies to avoid bankrupting a healthcare system unable to afford daily care for thousands of new patients (Weatherall 1998). The prevention program that was implemented involved the religious authorities, made premarital screening mandatory and allowed medical termination. By the 1980s, the incidence of thalassaemia had decreased by 97 per cent. Although these figures are impressive, few Omani health professionals know the reason for this result: 80 per cent of the pregnancies of affected foetuses had been terminated (Angastiniotis et al. 1986). As mentioned above, medical termination for IBD is allowed in several of Oman's neighbouring countries but not yet in the Sultanate.

In Oman, IBD are specific to Omani nationals, partly because prospective labour migrants must undergo severe mandatory health check-ups and also because of marriages regulations. If the Omani population is not *per se* a genetic isolate, the geography of the Sultanate and its extremely restrictive regulation of bi-national marriages give it an undeniable peculiarity. The legal limitation of these marriages is part of the industrious production of national identity, a process started by the current sultan in the 1970s. An initial 1980 Royal Decree prohibited marrying a non-Omani, but has been gradually relaxed: in contemporary Personal Status Law, marrying a Gulf Cooperation Council (GCC) national is allowed (the GCC comprising Saudi Arabia, Bahrain, Oman, Kuwait, Qatar and United Arab Emirates). Since 1993, marrying a non-GCC national can be allowed by a special dispensation from an *ad-hoc* ministerial committee, but the process commonly lasts for more than 3 years — and disregarding this rule can lead to deprivation of Omani citizenship. Meantime, governmental discourse tends to discourage consanguinity, believing — erroneously, given the prevalence of IBD traits in the general population — that banning cousin marriages would solve the IBD problem.

Regarding IBD — and genetics more broadly — the Omani government stands at a crossroads. Given the concomitance of dwindling oil resources and the growing prevalence of IBD, the Ministry of Health started some years ago to conceive a national screening policy, aiming at spotting individuals carrying the IBD genetic mutations. However, decisions are not made yet regarding the practical organization of screening. Several screening and counselling experiments are currently on-hand in public institutions, mainly in the capital area and on a vol-

untary basis: electrophoresis equipment has been purchased for several primary health care facilities and any Omani can request a blood test for free. Many come with some of their siblings or with their future spouse. The entire process lasts about 2 weeks, with a final mandatory visit to the healthcare centre to be given the results by one of the few nurses trained in genetic counselling.

IBD Screening: for Whom, and Why?

An important technical consideration influences IBD policy-making: population screening is simpler, and cheaper, than genetic testing, since it does not involve genomic investigations *per se* but a characterization and quantification of haemoglobin variants, used as a proxy for genetic status for IBD. Detecting IBD-carriers only requires haemoglobin electrophoresis, which is a widely known, relatively cheap and easy-to-perform laboratory technique. Most of the patients, families and health practitioners I met favoured mandatory IBD screening, which young Omanis have discussed in internet forums since the early 2000s (English Sabla 2004). There is however no consensus on who should be screened. IBD are not minority-specific disorders in the Sultanate, but are widespread all over the country. The 'tribal database' mentioned above is not (yet?) an official screening tool.

Some advocate screening adolescents at school, but my observation is that currently blood tests are often omitted during mandatory medical check-ups for Omani school children. Since more than 95 per cent of women give birth in hospitals (Ministry of Health 2008), it would be possible to create a systematic neonatal screening program, but doctors are concerned that parents will forget the carrier status of their children decades later, when the spouse selection process would start. Moreover, there are practical concerns about neonatal screening: detecting abnormal haemoglobin is impossible with simple tests in infants before 6-8 months and would thus incur significant laboratory expense.

Looking at the experiences of neighbouring countries, many patients and caregivers favour premarital screening, given that almost all births in Omani society occur within marriage. In 2008, premarital tests for HIV/AIDS and hepatitis B, already compulsory for the few foreigners authorised to marry Omanis, became mandatory for Omanis. This implies the existence of a 'prenuptial medical frame' into which IBD screening would be integrated. Yet, as a haematologist very relevantly told me, 'there is a timing in marriage here, and it is difficult to slow it down' (Interview, al-Khoud, December 2008).

It may seem surprising that some families are reluctant to request screening during the engagement negotiations. However, planning a marriage is a significant symbolic and financial investment: choosing a spouse is a long process that can sometimes be similar to a reciprocal 'investigation' conducted by families. The aim is to ensure the future couple complies with the *kafā`a* rules that their status similarity is sufficient. In Oman, *kafā`a* is both sustained by Ibadi jurisprudence and Personal Status Law (article 20). And yet, it stands in contradiction to the Fundamental Law (article 17) that prohibits any kind of discrimination. Most of the time, *kafā`a* is assessed on a financial and social status basis, but health matters can also constitute additional criteria (see Al-Azri 2012 about these criteria and their everyday application in Oman). In principle it is thus acceptable to request information about a future spouse before the dowry is brought to the groom's house.

Policy-makers in Oman have also not yet defined the ultimate goal of a potential screening program. As Claire Julian-Reynier comments, there are different issues at stake:

'The interest of heterozygous individuals screening is different from the one of disease screening. First, it means the identification of high-risk couples; secondly, informing them about their risk; thirdly, giving them access to prenatal diagnosis or pre-implantation genetic diagnosis for further pregnancies'. (Julian-Reynier 2003,

my translation)

Moreover, screening for high-risk couples is really only practicable in social contexts where prenatal examinations and pre-implantation genetic diagnosis (PGD) are available to complement the screening, which is not the case in Oman. PGD is available in Saudi Arabia for couples who carry IBD mutations, but Oman currently has no public infrastructure to support the use of assisted reproduction technologies. Furthermore, for some doctors, the country's scale complicates the situation differently, as this doctor involved in the new national genetics centre remarks:

'There is a PGD lab in the plans [of the genetics centre], but people have no idea of realities. It's just like for bone marrow transplantation: everything seems too perfect. There is always a risk to miss affected embryos and the best European success rate are around 30 per cent [...] In Saudi Arabia, they have 50 million inhabitants [Oman has 2.8], it is absolutely different' (Interview, Darsayt, April 2008).

Amniocentesis and chorionic villus sampling also are currently unavailable in the Sultanate, mainly because of the scarcity of appropriate cytogenetic facilities. The university hospital and the Ministry of Health lab where such analysis would be possible are overwhelmed by requests from all over the country, mostly related to voluntary adult IBD screening and pre-bone marrow transplantation check-ups. As a result, couples who can afford it sometimes choose to obtain PGD abroad — the current price of the procedure is approximately 20 000 US\$ in the United-States.

The bioethics of medical termination in Muslim societies is a complex issue beyond the scope of this chapter. In Oman, it is theoretically allowed only if the pregnant woman's life is endangered (Ministry of Health and Unicef 1999). In practice, although it is rarely performed, medical termination may be offered when foetuses suffer severe cerebral or cardiac abnormalities (and not for IBD or Down syndrome); doctors may advise couples they believe able to afford the expense to go abroad for termination, providing precise lists of hospitals. Since the late 1990s, the Ministry of Health has been considering legalizing medical termination on the grounds of parental suffering, neonatal pain and mortality and health expenses (Ministry of Health and Unicef 1999).

The Omani healthcare system thus provides couples with only limited choices in the management of their risk of having affected children, despite the fact that a national mandatory screening program is an official priority in the current governmental 5-year plan. Health and educational facilities dedicated to disabled children are also extremely scarce in Oman.

Lay Perceptions of Genetic Risk

On being identified as carriers, individuals must anticipate not their own future sickness but the potential birth of an affected child, in a process which implicates an entire family and its procreative choices. In this process, IBD are considered to be deficiencies (*faqr al-dam*, i.e. 'indigence of the blood'), since they put a serious strain on one's own 'value on the matrimonial market' (Fassin 2000) and on that of one's children. Risking giving birth to an affected child is thus partly also risking not finding a spouse for him/her, i.e. fathering a pariah.

Being a Carrier

A new social category appeared in Oman with the use of haemoglobin electrophoresis: that of 'carriers' of IBD, whose 'abnormal haemoglobin' level is elevated but not pathological, and who were socially invisible beforehand — since there is no exterior sign of their genetic status. For carriers of an IBD mutation, the idea of being the vehicle of a disease that could —

or perhaps already does — affect one of their children is often difficult to understand. Indeed, sickle-cell and thalassaemia mutations, in heterozygous form, very rarely cause symptoms. Admitting their inheritability and their role in the birth of an affected child has to be experienced as an act of faith.

Rayan, a 30-year old Omani, tells about the moment she discovered she was a thalassaemia carrier:

'I had to undergo thyroid exams, they took blood for this, in the university [hospital]. And after two weeks, they told me I had no thyroid problem but I had *ānīmīa thalāsīmīa* [one of the Arabic phrases for beta-thalassaemia], I was a carrier. They did not tell me anything, did not prescribe any medication, nothing. They only told me I should do some tests before getting married and I shouldn't marry a carrier. They were students, and this was a scary story [she laughs and seems embarrassed]. First, I was really frightened. I didn't understand why they were talking about. Then, they explained me again and I understood' (Interview, Mawaleh, December 2008).

Rayan's difficulty in understanding her genetic status, something she does not feel in her body, is partly related to the ambiguity of the phrasing through which she first learnt she was a carrier:

'Drawings, that would be useful. The doctor could fist they what it is, thalassaemia, what it means to have this disease, something about my own situation, the way I got it. Not only, "You got it. Do not marry someone like you. No need of treatment. Good-bye." If she had explained in a better way, I would have understood, I wouldn't have been so terrified. She tells me I'm a carrier of thalassaemia, I hear 'pregnant'... [the Arabic term *hāmal* means both 'carrier' and 'pregnant']. I didn't know *hāmal* meant this too' (Interview, Mawaleh, December 2008).

The disturbing intangibility of the idea of having a mutation but not being ill means people sometimes reject the biomedical discourse. This is all the more likely when there are no affected people in family, when healthy children embody the 'biomedical mistake'. Once the inheritability is thus obliterated, the management of risk is no longer necessary. One young father of a sick infant, in despair, exclaimed, 'No one is sick in the family! I do not understand!' (Direct observation, Muscat, December 2006).

Interpreting Numbers

Though autosomal recessive inheritance is a simple mechanism for geneticists, making it clear and understandable for non-specialists is arduous. I frequently observed scenes that could be aggregated thus: a health professional explains the risk as 'one risk upon four' (rarely as '25 per cent'); parents hear this figure, but conceive it as 'given once and for all', i.e. the birth of one affected child would guarantee the subsequent births of three unaffected siblings. Every pregnancy is a new throw of the dice, but is thus not taken into account. Indeed, the single occurrence is seen as protective of other family members. This conception of risk echoes the notion of social recessivity of disease, in Zempléni's phrase (coined in another context): 'The best known examples are elective disorders attributed to certain authorities or divinities who protect the community under the sole condition that they physically invade one member of each generation' (Zempléni 1985). This form of risk perception has been described in the Caribbean too, where some families, rejecting genetic aetiology, question the 'unicity of a sickle-cell child [...]: why him and not the others?' (Benoît 2004)

Another common interpretation of numerical risk entails its gradual relativisation: for some parents, whatever risk has been announced by health practitioners, and without questioning the genetic aetiology, the birth of several unaffected children somehow 'cancels' the

risk. A 'stroke of good fortune' thus eliminates the everyday reality of the risk. This has also been described elsewhere, such as in the infectious disease department of a French hospital, where the absence of vertical transmission of HIV from mother to child is a 'local reassurance' for staff members (Desclaux and Egrot 2003). Moreover, a risk value is meaningful contextually, and is not acceptable in the absolute. Rayan, the young woman mentioned above, asked me to explain to her again the recessive inheritance where both partners in a couple are carriers. Once I finished, she exclaimed, 'Ah! But then it's not 50 per cent? it's 25 per cent?! If I had known it was 25 and not 50, I wouldn't have said anything and the first guy who proposed me wouldn't have run away!' (Interview, Mawaleh, December 2008).

Looking for a Spouse

Few interviewees had experienced premarital IBD screening partly due to the small scale of the pilot programs in the country, and partly due to a frequent mix-up: the relatively recent genetic screening is commonly confused with screening for sexually-transmitted diseases, which also requires a blood sample. Thus, mentioning tests during the pre-engagement period of a marriage negotiation is often considered as an ill-concealed accusation of deprivation towards the other family.

Another misunderstanding that can occur during this period arises from the biomedical discourse, mentioned above, that erroneously presents consanguinity as the main cause of IBD. Many Omanis, having integrated the message that consanguinity is dangerous, decide not to get tested on the grounds of this aetiological model, thinking that not marrying a cousin is therefore the best prevention. Umm Safiya, a young Omani woman, told me that a '[test] is not needed for those who marry outside of their family' (Interview, al-Khoud, April 2008).

The status of carrier can constitute a 'damaged identity' that periodically resurfaces (Atkin and Ahmad 1998). Indeed, as 'epilepsy is dormant between seizures, carrier status [...] is dormant between two reproductive episodes' (Parsons and Atkinson 1992). Finding a spouse is the first of these moments and represents a dilemma, for the future couple's parents, between divulging their child's genetic status and risking not finding a spouse — especially if carrying a mutation is considered pathological in their community. Being a carrier makes the individual 'discreditable' since their 'differentness is not immediately apparent and is not known beforehand' (Goffman 1986). The dilemma for parents thus lies in the decision to 'discredit' their child or not. Rayan, who is carrier of a thalassaemia mutation, relates how she chose her husband, after having been told about the risk:

'I wasn't engaged yet at that time and I decided to put this first. My husband, I told him to get tested before we decided anything. [I wonder if she asked by herself] Oh yes, it was me! My parents? Impossible. They would have kicked my ass if they had known that I asked him such a thing! They didn't know. My husband is the third one. The first one ran away even before getting tested, maybe he did not understand, maybe he thought I was sick [she laughs]. The second one didn't get tested and said "it's nothing, we get married and we'll see." And my husband, him, the third one, he got tested. He's not a carrier (interview, Mawaleh, December 2008).

Rayan was so scared of stigmatization (including from her own family) that she did not risk asking her parents to impose screening upon potential sons-in-law:

'I was scared they would think I was sick, I couldn't have children, or things like this. And that they would have said "Allah will provide" and wouldn't accept my fiancé to get tests. Allah, Allah, always Allah. OK, but we also have minds... My parents would have dared to say to my fiancé's family "she wants a house, she wants a diamond", but they would never have said "she wants a blood test" (interview, Mawaleh, December 2008).

Yusuf has a son affected by sickle-cell anaemia. His cousin tells me that before Yusuf got married, Yusuf was informed about his carrier status but had no choice at that time — everything was already decided and impossible to cancel. The perceived inescapability of the marriage process after engagement weighs down IBD mutation carriers more heavily than their potential 'genetic responsibility' (Novas and Rose 2000) towards future children.

For people affected by IBD, finding a spouse is of course even more difficult. Their coping strategies are various: some, like Abdulrahman (a sickle-cell anaemia patient) abandon the idea of getting married because of the risk of having affected children. In 2008, he just was offered in marriage a cousin unable to find a husband because of a partial paralysis affecting her legs. Abdulrahman first agreed but then categorically withdrew his consent, after learning she was a sickle-cell mutation carrier and wanted children. Asila, a mother of two affected by a mild form of thalassaemia, chose to marry a very religious man, someone she told me 'would never divorce [her]', and decided not to inform him about her disease before the birth of their first child.

Salma is a young sickle-cell patient who had already forced two potential husbands to get tested and refused their proposals after their carrier status was confirmed. Her story casts light on the collective management of risk inside families:

'With my husband, finally, we didn't get tested. Because in case it has been positive... we couldn't have got married and he absolutely wanted to marry me. If you ask me why I let him do this... I think that twice, it was too much. I was scared. And my parents told me not to do the tests, because they really liked him and wanted him as a son-in-law. He didn't want to say to him "she wants a house, jewellery and a blood test" (interview, Seeb, December 2008).

In her work about African-American mothers who carry sickle-cell trait, Shirley Hill shows that it is partly erroneous to base public health policies on the assumption that women's duty is to avoid transmitting the trait to their children. Imposing a screening test on the future husband, or abandoning their wish to be parents 'may be viable strategies for groups with access to and confidence in medical knowledge and with patterns of marriage, childbearing, and gender relations coincide with the assumptions of the health belief model' (Hill 1994).

Asila's choosing secrecy and Salma's eventual succumbing to social and emotional pressure show that gender asymmetry persists among affected individuals.

The Social Context of Childbearing

The possible recurrence of an IBD within a family after the birth of an affected child has to be contextualized within local representations of a 'normal' family. Rayan, pregnant, holds her 1-year old and tells me, 'I can't wait! [I seem puzzled, she laughs.] I'm in a hurry to give him four! Yes, the four standard children. But my husband wants six, or maybe twelve. The Omani family... [she laughs] But I told him it won't be with me! I think four is ok' (Interview, Mawaleh, December 2008). In many families, any procreative 'pause' imposed on a woman by the birth of an affected child or by the evaluation of risks to future pregnancies is actually a 'breach' of this woman's fertility. Such pauses may threaten women's social status, since the father of several affected children can easily obtain a divorce or take a second wife.

Many carrier couples have more children despite the birth of an affected child. This risk-taking attitude partly reflects the procreative pressure of contemporary Omani society. However, there is not a broad consensus on this, as the following conversation between Yusuf (Y.) who recently had an affected son, and his sister (S.), who is also a nurse, shows:

S. [to me] — When their first daughter was born, I was staying with them and I knew they both were carriers. We were scared. I pushed my sister-in-law to get the

daughters screened. Thank God, they are ok. But the boy... he got oedemas... I understood.

[she turns to her brother and asks :]

S. — So. What is your plan?

Y. — I will wait.

S. — Wait for what?

Y. — ...

S. [calling me to witness] — I know this family with four affected children. And they don't do anything. No birth spacing. [euphemism for birth control, originating in the name of the 'National Birth Spacing Initiative' launched by the Omani Ministry of Health] (Interview, Seeb, May 2007).

Fatma, whose two sons have thalassaemia, could afford a choice. She tried to control the risk, without breaching religious law: 'For my third son, I asked a sheikh in Saudi Arabia if it was allowed to do termination for thalassaemia. He said yes. Thus, when leaving to India for the amniocentesis, I got myself prepared to this. But he's not sick' (interview, Sūhar, April 2008).

Some families appear as 'risk takers' (Shaw 2009) who may seem to not take the risk seriously. Yet, their decisions are not necessarily misunderstandings of genetic aetiology. Rather, the criteria on which reproductive decisions are made are not inevitably those favoured by biomedicine: the preservation of social structure seems more assured by maintaining the matrimonial system than by avoiding giving birth to affected children. As Sylvie Fainzang states: 'preserving health is not the only rationality, and divergent rationalities do exist, "alternative" to utilitarian rationality' (Fainzang 2001).

Concluding Remarks

In this chapter, the case of inherited blood disorders in Oman offers a lens through which to investigate the implementation of genetic services and the expert and lay representations of heritability and consanguinity. The 'young' Omani healthcare system, created *ex-nihilo* since 1970, is the scene of conflicting discourses about cousin marriage. Health practitioners are torn between international public health views learned in Western universities and that often demonize this practice, and local perceptions that approve it for social, economical and historical reasons. Moreover, the very concept of consanguinity does not echo a single, simple and finite social reality in the Omani society, where proximity is composite — it includes blood ties, but also entails alliances and shared territories.

Ethnographic fieldwork with doctors and patients in Oman's public healthcare facilities showed the variety of local modes of risk construction and perception. For patients, the novel availability of genetic information about potential spouses and in-laws creates new dilemmas during the spouse selection process. It also raises questions about how genetic information should best be communicated to patients, given the potential stigmatisation of carriers, and the misunderstandings of statistical risk information that are possible. It also shows how, even when patients understand the risks, alternative (non biomedical) rationalities can prevail throughout marriage negotiations and in the matter of reproductive decision-making.

Examining the wider context of policy debate concerning the management of IBDs in the country also reveals the irony of a focus on consanguineous marriage, a practice that has considerable social significance, in a population where the prevalence of IBD carriers is high and which is also genetically 'closed' due to restrictive bi-national marriage policies. In this context, banning cousin marriage would not have a significant impact on the prevalence of IBD.

Compared to its neighbouring countries, the peculiarity of the Omani context lies in its current public health situation regarding genetics: the Sultanate is still in an ongoing process

of policies implementation, since no decision as been made yet regarding the national screening strategies. The Cypriot ideal of quasi eradication of an IBD appears tempting for many health and public health professionals, but the means used in this achievement — mandatory premarital screening and legalization of medical termination for IBD — are problematic in the Sultanate. The medicalisation of spouse selection is certainly on hand in Oman, but its final form still has to be determined.

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