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Arranging marriage; negotiating risk: Genetics and society in Qatar.

ABSTRACT: This paper considers how the globalized discourse of genetic risk in cousin marriage is shaped, informed and taken up in local moral worlds within the context of Qatar. This paper investigates the way Qataris are negotiating the discourse on genetics and risk. It is based on data from ongoing ethnographic research in Qatar and contributes to anthropological knowledge about this understudied country. Participants were ambivalent about genetic risks and often pointed to other theories of causation in relation to illness and disability. The discourse on genetic risk associated with marrying in the family was familiar, but for some participants the benefits of close marriage outweighed potential risks. Furthermore, the introduction of mandatory pre-marital screening gave participants confidence that risks were monitored and minimized.

Keywords: genetics; beliefs; medical anthropology; Qatar; biomedicine

Introduction

The March 2011 ‘Doha Debate’ focused on the issue of marriage in the family with the motion: ‘This house believes marriage between close family members should be discouraged’. These globally televised debates sponsored by the Qatar Foundation and the BBC, were intended to provide an opportunity to discuss issues of importance to the Arab world. The fact that one of the debates focused on the medical implications of consanguineous marriage reflects the prevalent public discourse around the risk of cousin marriage. At the end of the debate, 81% of those attending voted to discourage unions between cousins.

This paper is derived from an exploration of Qatari encounters with discourses of genetics and risk. The private and emotional implications of the discourse on risk and cousin marriage are discussed here. How do Qataris understand the epidemiological discourse of genetic risk, particularly in relation to consanguineous marriage? Participants were aware of the genetic risk discourse as it related to marrying in the family; however, there was negotiation, with other risks being considered. When discussing illness and disability, a number of medical, genetic, environmental and social factors were taken into consideration. The research demonstrates how risk, consanguinity, morality, and gender intersect to help Qatari citizens make decisions through kinship. The project was not specifically about consanguinity, but rather a more general investigation into public understandings of genetics and notions of risk. However, as it continued, consanguinity became central to notions of risk in Qatar, and hence, the focus of this paper.

This research is situated amongst social scientific research focusing on how new medical technologies and knowledge, including those involving genetics, are received, accommodated and resisted within local moral landscapes (Inhorn 2009). Lay and public health/media discourses about genetic risk in cousin marriage do not always match up, as shown by ethnographic work in the UK, but less is known about the Middle East context. Our work endorses the approach taken by Shaw (2009) in her work on UK Pakistani families’

understandings of genetic risk. Despite the UK medical discourse on the elevated risk of consanguinity, the Pakistani people Shaw interviewed were not concerned about increased risk. Indeed, genetic risk was seen as irrelevant; thus, a 'differently constituted perception of risk' was present (Shaw 2009, 3). Shaw's use of Mary Douglas's work on risk as a framework for understanding British Pakistani couples' responses to genetic counselling resonates with our research approach. Thus, this research aims to map the perception of risk in Qatar; to develop a localized description of such understandings of genetic risk in a different context. In Qatar, the most common form of marriage is within the family and, thus, the context has important differences compared with the community studied by Shaw, where the marriage practice differed from the wider community. The Qatari government and medical practices are familiar with, and relatively supportive of, marriage in the family. This research adds to knowledge of public perspectives of genetic risk in consanguineous marriage by reporting from Qatar and endorsing in this context observations made in research with British Pakistanis.

The research is informed by current knowledge and analytical approaches to the topic in the Middle East region. A variety of scholars (i.e. Panter-Brick 1991, Raz 2005, Beaudevin 2013) have explored genetics and understandings of genetic risk in the Middle East. Raz (2005) explored what happens when this 'newly discovered scientific notion of 'fate' encounters its traditional and religious conception' (Raz 2005, xv), in this case amongst an inbred Negev Bedouin community in Israel. Particularly relevant as a study of genetic counselling in this social context is the preference for arranged patrilateral parallel cousin marriage and the religious ban on abortion. Beaudevin (2013) explored inherited blood disorders (IBD): serious genetic chronic conditions that affect red blood cells where the inheritance pattern is recessive. The Omani context she explored 'is a striking example of the way increased biomedical knowledge and the outcomes of its applications can affect a society' (Beaudevin 2013, 185). Panter-Brick's (1991) research examined parental understanding of genetic inheritance in Saudi Arabia and revealed that knowledge of genetics has 'profound ramifications on family relationships, which are perhaps the central element of Saudi culture' (Panter-Brick (1991, 1300). Scholarly works, such as those mentioned above have shed light on the way encounters with genetics alter social life and understandings in fundamental ways. While 'genetic research takes special importance in consanguineous communities where endogamy increases the prevalence of recessive genetic diseases, such communities often have traditional values that are incongruent with the "standard view" of genetic counselling' (Raz 2005, xvii).

The project

In fieldwork conducted over 12 months (February 2012-February 2013), accounts were collected about notions of health risk and, particularly, genetic risk. The site of the project was a school for children with special needs in Doha. Associated with the school and on the same site was a medical centre that focused on human genetic disorders, particularly those in children that lead to disability. Here, diseases were diagnosed and research conducted: the latter focused on gene discovery and autism, and gene discovery and epilepsy, in addition to identifying the disease-causing mechanism behind cognitive disabilities. The centre offered comprehensive research and care, which included counselling, education and childcare advice for parents of children with the diseases that were studied. The 2 S. Kilshaw et al. Downloaded by [Susie Kilshaw] at 02:07 29 January 2015 current research focused on the families of the pupils in the school. Pupils at the school were affected by some form of disability: some had diagnosed genetic conditions, others had conditions in which genetic factors were investigated as a contributing cause and many others had conditions where there was some uncertainty as to the cause. Conditions included: Down's syndrome, Batten disease, IDD, Autism, William syndrome.

We conducted primary interviews with 45 families to better understand their experience of having a young family member with a disability. Participants were invited to meet with the researchers by their social workers, who liaised with the families on a regular basis. This was deemed the most appropriate way to approach the families. On most occasions the mother and/or father was interviewed, but at times an adult sibling would arrive in their place. Interviews were conducted at the centre or at a meeting place at the request of the interviewee and lasted between 45 minutes and 3 hours. Follow up interviews were conducted with 11 of the families. The second author conducted the majority of interviews in Arabic, with the lead author (who is not fluent in Arabic) in attendance to help direct the interview. Using an interview script, the research assistant translated the responses to the lead author to allow for further questioning. Interviews were recorded, transcribed and translated at a later date. In addition to the main participants, professionals involved in the creation of genetic knowledge and those at the interface between the public and genetic discourse were interviewed including: social workers, geneticists, lab technicians, and those involved in medical screening programmes. The data for this paper are derived from preliminary analysis of material from 23 interviews and represents initial findings from ongoing analysis.

Because of the presence of the medical genetics centre at the same facility as the school, families of students were at the interface of public understandings of genetics. According to their website, the centre supplied ‘Provision of diagnostic and counselling services to patients and families with genetic disorders’ enrolled in the school and the ‘management and follow-up of patients with genetic disorders for a comprehensive oversight of their health-care.’ The centre’s website explains that the ‘main objective of the centre is the translation of research findings into clinically available testing for genetic diseases such as autism. To this end the centre works closely to develop new tests for genetic disorders as their genetic bases become identified’. Families had been exposed to genetics through general discussions by staff. Some had been more directly exposed through genetic testing, and genetic counselling was offered at the site.

The interviews included collecting basic demographic information about the family, marriage patterns, education and occupation. General questions about notions of health and illness and risk were asked. Questions were asked to probe notions of inheritance and genetics, i.e. ‘who provides the genetic material to a child’ as well as questions to explore how traits (i.e. intelligence, physical traits, and so on) were passed down through generations. The interview invited a discussion about the pupil and their disability, including diagnosis, theory of causation, and interactions with the medical profession. The interview also focused on broader themes about illness and/or disability in other family members. The authors also asked questions about genetics more generally to assess participants’ knowledge of and comfort with genetic discourse.

Genetic risk and cousin marriage

Consanguinity is usually defined as the intermarriage of two individuals who have at least one ancestor in common, the ancestor being no more distant than a great-great grandparent. Across the Middle Eastern region, the rates of consanguinity range in most societies from 20% to 55% of all marital unions (Bittles et al. 1991; Bittles 2012). In Saudi Arabia, marriages between relatives are reported to be as high as 57% (El-Hazmi et al. 1995) with up to 31.4% between first cousins (Panter-Brick 1991). The practice is declining in Lebanon, Saudi Arabia, Kuwait, Jordan and Israeli Arab communities and the Palestinian territories but is reportedly increasing in the United Arab Emirates (UAE), Yemen, Iran and Qatar (Bittles 2011, 62). A recent study

has found that 54% of Qatari marriages are consanguineous, with first cousin unions being the most common: 34.8% of all marriages and 64.4% of all consanguineous unions (Bener and Hussain 2006). Recent research in Qatar (Al-Ghanim 2010) has shown that consanguineous marriage continues to be common and the perseverance of this practice challenges fundamental assumptions about the correlation between modernization and social change.

In the Middle East it is not merely consanguinity but endogamy (Khlat 1997) that are practised. While the former indicates marriages between blood relations, the latter is a more comprehensive term that describes a societal preference for selecting a marriage partner from within a particular group, over generations (Sandridge et al. 2010). As a result of the practice, Middle Eastern Muslim populations have high frequencies of autosomal recessive disorders, homozygosity of autosomal and X-linked traits, and a plethora of new genetic syndromes and variants, the majority of them autosomal recessive (Inhorn et al. 2009). Other recessive conditions associated with parental consanguinity cause not infant death but long-term physical or intellectual problems, or both (Shaw 2009). The practice of consanguinity has been proposed as a contributor to the presence of health problems in the Middle East generally and Qatar specifically (Al-Gazali et al. 1995; Abdulrazzaq et al. 1997), especially autosomal recessive diseases (Teebi 1994; Hegab and Al-Mutawa 1996; Al-Fuzae, Aboolbacker, and Al-Saleh 1998; El-Shanti et al. 2006). In *Consanguinity in Context*, Bittles (2012) provides an excellent overview of the prevalence and effects of consanguinity whilst also providing a measured approach to shedding light on the 'past factual errors and misunderstandings that have bedeviled the subject' (Bittles 2012, 225). Current data indicate that, on average, first cousin offspring experience and additional 3.7% mortality from approximately 28 weeks gestation to 1012 years of age (Bittles 2012, 227). Children produced by such unions have an additional median risk of 3.3% in regards to birth defects (i.e. a total additional risk of 7% pre-reproductive morbidity or mortality) (Bittles 2012, 227). First cousins share one eighth of the same genes, meaning that they are more likely to have both inherited a faulty gene from a common ancestor, which they may both pass on to a child. Put simply, the risk of having a child with a genetic disorder is generally 23%, but rises to between 46% (or double the background risk) with first cousins (see Bennett et al. 2002; Bittles 2012). These estimates, however, do not allow for cases where such marriage has been practised for generations (see Sheridan et al. 2013; Bittles 2013). Risk is higher for offspring of repeated generations of consanguinity, which is often the case in Qatar. This paper considers the way Qataris weigh up the benefits of marrying close relatives despite the potential medical risks of doing so.

Discourse of genetics and genetic risk in Qatar

One of the most powerful and pervasive ways that the discourse on genetic risk was communicated to Qataris was through the introduction in 2009 of the mandatory premarital screening programme. For any Qatari couple planning to marry, engagement with genetic risk becomes a normalized practice of social life. When participants spoke of risk they referred to the screening programme and suggested that it gave confidence that potential genetic risks of marrying in the family could be eliminated. Participants were widely in favour of the programme; however, participants were overwhelmingly uncertain about what tests were involved and the meaning behind them. The general consensus was that it was about 'compatibility'; reproductive potential or a general health screening, with participants unaware of the specific conditions tested. The introduction of premarital screening seems to have contributed to confidence in the continuation of the practice. Indeed, this may be reflecting the ambivalence to a globalizing discourse of genetic risk and cousin marriage interacting with strongly held beliefs about marriage practices. Screening includes: sickle cell anaemia; thalassemia, testing of the clotting factor to discover Haemophilia (if there is a family history

or any medical indicators of the disease), syphilis, HIV (AIDS), hepatitis B and C and thus is not just for genetic conditions.

There is a degree of ambivalence in terms of the public health message of such risk. On the one hand there is the message that marrying in the family is risky and on the other hand there seems to be a notion that the practice is central to Qatari culture and should be protected. The Qatari Supreme Council of Health's website says:

By the development of genetic engineering and the accomplishment of the chromosomes' map, premarital medical screening has gained a number of advantages including...

- To control the prevalence of disability and the delivery of children with abnormalities;
- To maintain early detection and treatment and secure happy marriages;
- To maintain protection and safety for the whole society and the nation at large.

Thus, healthy and proper marriage is guaranteed and the married couple could be aware of the probable diseases that may inflict their children.

Screening can give confidence that risk is minimized and managed. Thus, despite the surrounding discourse about genetic risk there is an endorsement of the practice. Clinicians are aware that marrying in the family is common in Qatar and is seen as part of Qatari culture. There is a genetics lab at the main Hamad Medical Corporation (HMC) and a genetic counselling service. The centre that hosted this research project was one of main sites for genetics in Qatar where they 'focused on human genetic disorders, particularly in children, which lead to disability'. Public lectures organized by The Ministry of Social Affairs and Qatar University have focused on consanguinity and genetic disorders to increase people's awareness about the genetic diseases. The discourse of risk of marrying in the family was also disseminated in schools and on radio and television programmes. As Shaw (2006) has shown, the discourse of risk takes diverse forms even across a single national domain.

The religious context is relevant in that cousin marriage is allowed in Islam, yet some religious teachings suggest that this should be limited, i.e. should not occur generation after generation. In one Hadith, Prophet Mohammad says: 'Marry people who are not your relatives; do not marry your close relatives.' While listing the qualities to be sought in spouses to marry in accordance with the Sunnah, Imam Ghazali states that one should not marry his cousin. He quotes the following hadith: 'Do not marry a woman who is a close relative of yours because your child will be weak and puny.'¹ The prophet himself married his cousin 'Zainab' and he also married off his daughter 'Fatima' to his cousin 'Ali'.

Marriage in the family: outside observers

The practice of cousin marriage or, more broadly of 'marrying in the family' is one that has garnered a great deal of attention both within and without academia and within and without the Middle East. When discussing the research with the expatriate community in Qatar, the lead author found much curiosity about cousin marriage and arranged marriage. Despite living in Qatar for several years, most people's impressions of the host culture often centred on a taboo about cousin marriage, as well as an ignorance of actual marriage practices amongst Arabs. Cousin marriage has become the key marker of cultural difference, a 'sort of culture [that] is unacceptable in the twentieth century' (Cryer 2005 in Shaw 2009). In the UK, marrying a first cousin tends to be regarded as unnatural and biologically risky, immoral and evocative of

incest. It is also often regarded as illegal, as countering religious or civil law (Shaw 2009). Similarly, it would seem that arranged marriage was commonly and mistakenly conflated with forced marriage.

The global spread of biomedicine has brought with it a globalizing discourse of risk accompanying the practice of consanguinity. As Shiloh et al. (1995, 1301) suggest, such notions have ‘penetrated even in societies where this kind of marriage is common, and have been integrated into more general attitudes and beliefs about consanguinity’. Such is the case in Qatar where, despite being a dominant marriage pattern, the negative discourse of risk has been integrated into public discourse, possibly linked to the country’s continuing move toward modernization. However, this is not a straightforward integration, with individuals considering and negotiating risks. Indeed, at the individual, community, and state levels there is ambiguity about the nature of risk and how best to manage it. Thus, Qatar provides an interesting context to explore issues around the communication and reaction to discourses of genetic risk where, despite the global spread of biomedicine, a culture of transnational research, and a commitment to modernization: one can witness not only a continuing dedication to, but an increase in, the practice of consanguinity.

Attitudes of Western cultures and medical professionals toward consanguinity are often negative, ostensibly because of the impact on health (for example, see Shiloh et al. 1995; Bittles and Makov 1988). As Bittles (2012, 1) outlines, ‘major problems can arise when a term with a quite specific scientific definition becomes part of everyday speech ... Unfortunately, the terms inbred and inbreeding also fall into this category and, as a result, it has become virtually impossible to persuade members of the general public that inbreeding, and by extension marriage between biological relatives, can be anything other than harmful.’ This is despite the fact that there are many examples of deliberate inbreeding that have resulted in healthy and fertile stock (Bittles 2012) and that there is growing evidence that the deleterious effects of consanguinity are grossly exaggerated (i.e. see Shiloh 1995). Health workers in Western countries often exert pressure against the custom (Modell 1991). Shaw (2009, 49) states:

Public perceptions of risk are not neutral: a ‘climate of disapproval grounds the belief that certain deeds are dangerous’ (Douglas 1992, 27). Moreover, in the current political climate of Muslim/non-Muslim relations in contemporary Europe, the biological risk of cousin marriage provides ‘scientific’ grounds for disapproval of a marriage practice that singles out and blames a minority Pakistanis, or, by erroneous extension, ‘Asians’ or ‘Muslims’ for persisting in risky behavior, resisting cultural conformity.

Fatima: negotiating Risks; considering causation

Participants were aware of the discourse of genetic risk and a link with marriage practices. Fatima, who was related to her husband: ‘our grandfathers were brothers’, said of marrying in the family:

I think it strengthens the family relationships ... and no matter what the girl would still be among her family. I know some couples who are not related but their family relationships are still very strong. [Your daughter? What would you prefer?] The most important thing is that he is a gentle religious man.

Fatima is from a large Bedouin tribe known to favour consanguineous unions. Indeed, this tribe was often referred to as an example of the dangers of marrying in the family, as they are said to have a significant number of members with disabilities. Fatima referred to her son as having

'slight mental retardation', and said that they had undergone tests 'to see if it was genetic' but she reported that no one ever told her the results, so she was uncertain of the cause of his disability. Participants often expressed ambivalence and/or confusion about the process of diagnosis and testing. Fatima implied that she suspected an incident and medical intervention, including taking antibiotics and analgesives, in the early stages of her pregnancy might have caused her son's condition. Like Fatima, many participants were uncertain about the cause of their child's disability. They mentioned numerous possibilities including, evil eye, environmental factors such as pollution, mercury in vaccinations, and MMR (in the case of autism). Panter-Brick's (1991) research with 36 Saudi families found that despite an awareness of genetic risk, participants often accounted for illness and disability through explanation such as: 'evil eye', 'God's will' and illness or upset during pregnancy. Evil eye, also known as 'the look' (nathra) is cast by women, 'who may be jealous, envious or simply wicked, and who intentionally or unintentionally harm a child at a glance' (Panter-Brick 1991, 1297). In the lead author's ongoing work participants commonly refer to evil eye as a cause of miscarriage and illness more generally. Belief in the evil eye is prevalent throughout the Middle East (i.e. Spooner 1970; Ibrahim and Cole 1978; Meleis and Sorrell 1981), but we have found it to be a sensitive issue as it is seen as old fashioned or against Islam. Both of which are problematic in Qatar, which is focused on being seen as a modern nation. In light of this, the ease at which the women participants in the author's pregnancy and miscarriage project speak about evil eye is noteworthy. A number of participants suggested that the Gulf War and its associated chemicals had led to increases in certain illnesses and disorders. The mother's emotional and physical state whilst pregnant was cited as a possible cause of illness or disability, as is reflected in Fatima's discussion. In particular, if the mother was stressed, upset or if she experienced a shock, such as the death of a loved one. This resonates with the lead author's project on Qatari experiences of pregnancy where women suggest that their emotional state can affect the baby in terms of illness, disability or temperament.

Family members, particularly the parents of a disabled person, discussed a process of coming to terms with the condition mainly through faith in God. Discussions of faith also permeated theories of causation. Aisha described the cause of Down's syndrome:

It is something that is out of our hands. It is from Allah, the lord of the worlds. It is caused by chromosomal disorder. I don't know the reason... [What do you think is the cause?] I don't know. However, I was feeling down when I was pregnant with him... There is no one in the family nor my husband family. My husband is not a relative. ...The time before I got pregnant, I was upset. The stress continued for few months. I mean the whole pregnancy period was very stressful.

Ultimately, the conditions were seen as coming from God. The fact that the child's disability was divinely assigned gave participants comfort and allowed them to come to terms with their family member's disability and the demands of caring for them. As Aisha said: I feel that this baby is blessed. He came and everything good came with him.

Abdullah, the father of a severely autistic son, explained that he often tells his wife that:

We might have our health and wealth because of him. Allah gives you something and put something nice with it. Allah takes away something and makes it up for you with something better. I mean you might have a healthy child but when he reaches 20 or 22 years old, he dies suddenly in an accident. Yesterday I went to give my condolences to a person who lost his son in an accident.

Genetic explanations, ‘like theories that invoke germs or other environmental causes, provide a mechanism, but probabilistic concepts of chance leave a void that appeals to God’s will serve to fill’ (Shaw 2009, 147). Genetic mechanisms are often invoked at the same time, attributing genetic disorders to forces beyond human understanding. Featherstone and colleagues report that Anglo Britishers affected by genetic disorders often attribute this to fate of destiny, as if in a kind of biological predestination (Featherstone et al. 2006, 6970, 113).

Marrying in the family: medical risk

Whilst aware of the discourse of risk, many participants seemed unsure of the reality of such risks. Many used anecdotal evidence to support their uncertainty. Shaw’s Pakistani participants expressed scepticism of the thesis of cousin marriage causing disabilities ‘by making the accurate lay epidemiological observations that English people do not marry cousins but still have children with disabilities and the vast majority of Pakistanis marry cousins and have children who are perfectly healthy’ (Shaw 2009, 58). Similarly, Saudi families thought that a genetic illness should affect all children, rather than a few and should appear soon after birth; they stressed that other relatives had married cousins and ‘were blessed with normal children’ (Panter-Brick 1991, 1297). Qatari participants cited examples where cousin couples had many health children or referred to families where offspring had disabilities despite the parents being unrelated.

Wadha, a 33-year-old mother of nine explained that people often suggest that her son’s disability (harelip) is due to ‘inheritance’, but she refers to it as ‘fate’:

One of my sisters is married to my father’s sister’s son and all of her children are normal. Many cases of marrying within the family in our family and nothing happened.

In the miscarriage study, one participant suggested that the most common cause of miscarriage was due to ‘hereditary’ and later explained that it is likely due to a woman being married to her cousin. Although she herself was married to her cousin she explained that she did not worry ‘because at the end everything is according to God’s will. We have many [marriages within the family] and thanks God we don’t have any problems.’

Mona, the sister of an 18-year-old, suffering with homocystinuria said her brother’s condition was common in Qatar:

I did not know about it before but then I discovered that it is very well-spread, especially in some tribes ... among certain tribes who have the habit of marrying within the family ... I think it is important that people educate themselves. It is a disease that is caused by marrying within the family. However, my uncle mother side is married to a Syrian woman and they had a child who has this condition. I expect that it is genetic ... [I]t is a disease that it does not have to be in the father nor the mother but it appears in their children ... Not carriers. It is a defect in the gene itself. They say it is caused if an old person is married to a younger person or it is because of ‘marrying within the family’. There are only 90 cases in the clinic that I go to. All the cases are from certain tribes who are known to have the habit of marrying within the family. Although my father is not a close relative to my mother but they are in the same tribe and my brother is affected.

When her brother was diagnosed the doctors said it ‘was in the blood’ and the cause was ‘marriage in the family’. As a public health discourse, the consanguinity thesis ‘contains the

potential for stigmatizing difference or creating a “spoiled” self-identity’ (Goffman 1990), for individuals or groups who are ‘singled out as a risk on the basis of their marriage pattern’ (Shaw 2009, 55).

Maryam, the 43-year-old mother of Ahmed, explained that despite there being no familial relationship between her and her husband, most people assumed her son’s condition was due to a close marriage:

From birth, they keep asking me whether my marriage is within the family. When I say ‘no’, they get surprised. ‘How come the marriage is not in the family and you still had a child like this?’ It is linked in people’s mind that marriage within the family is the main cause of having handicapped or unhealthy children. I also see many people who are married within the family and still have very healthy children. I think it is better to marry from outside the family if they know that they have health problems in the family. ... I don’t know why this condition occurred to my child. There are risks but not as much as the risks of marrying within the family. If we say that 10% are the risks of marrying outside the family, 60% will be from marrying within the family. This condition is rare. When I had this baby I was young. I was in my twenties and this is what was shocking. ‘How come you had a Down child and you are still young and it’s your first pregnancy?’ In my case it is a defect in the division of chromosomes ... I panicked in every pregnancy. I expected that I would have a similar baby every time.

Shaw found that in some medical and lay circles, consanguineous marriage had become a popular general explanation for ill health; one that locates their poor health outcomes within their genetic and cultural background (Shaw 2009, 54) and that may overlook other factors.

Marrying out: risking harmony

Abdullah and his wife explained how their son has severe autism and they spoke at length about the difficulties in caring for him. Abdullah is related to his wife ‘my father and her grandfather were brothers.’ He continued, ‘this can be a factor to acquire inherited diseases’. His wife later said:

Yes. Marriage within the family increases the incidence of diseases. What is reason of the increase in autism rate?

Abdullah then added,

If you think about it, more autistic children are born every year...

After an evening of drinking tea, Abdullah, explained how one had to negotiate a variety of considerations and risks when one contemplated marriage for one’s children:

Look ... with regard to the psychological aspect, [marrying in the family] is good. If your sister is married to your cousin, this is better than marrying a stranger. Her children will be like ours ... A stranger did not take her ... For instance, you will feel free to visit them anytime ... it’s better than visiting a stranger’s home. If he is a stranger, the relationship would be formal between both families. His wife added: They have different habits; she would not be comfortable. Abdullah continued: Imagine that someone is married to... Someone from Emirates or Oman or some other place and she is from here ... their habits differ from ours. [Are Gulf Arabians not the same?] No they are not ... it is difficult in

the beginning, but later if she had children, she gets used to the new life. If you are married to someone who comes from another tribe ... your children will be different from your family ... You will move to another tribe; to another family ... Your name and your children's name will change ... They might have different traditions, habits, mentality, religion, and many other things ... Even the environment will change. You live in a big family and you are comfortable and suddenly somebody takes you to the other part of the world ... Many things will look weird ... Many are warning from marrying within the family for many reasons. One of the reasons is genetic diseases because many people marry within the family and actually suffer from such diseases. However, many are married within the family but do not suffer from genetic diseases ... I am 50% with and 50% against ... This is because many people who marry within the family have children who are physically and mentally weak. From the psychological aspect, marriage within the family is better because the husband will then care about my daughter, respect her but if he is a stranger ... That one is my nephew and was raised with me I know him and I know his personality and his habits ... but if he is a stranger, my daughter might not adapt to his family ... To his sisters to his mother ... But with her cousin: his mum is her aunt, her mum's sister ... She would not be lost because she knows the family very well. ... I prefer marriage within the family ... Yes. Marriage within the family has its cons and pros. However, the pros are more. I am against that the daughter marries from outside the family. The son is different he can marry from another family. It is hard for the girl to go outside her family ... she will not belong to her family anymore ... Her children name will change. I just don't like it ... My sons, it's better to let them marry wives from another family so they have better children who are healthy and everything. I feel it's hard to give my daughters away to another family.

At which point his wife laughed and exclaimed, 'this is discrimination!'

Marrying in and closeness

Abdullah's eloquently describes the way one had to consider and negotiate risks when contemplating a marriage partner for one's child. Marital links, largely controlled by women, constitute the mechanism by which consanguineal ties are manipulated, channelled, redirected, and intensified (El Guindi 2012, 551). Mothers explained the process of research and investigation, not only of the intended spouse, but also the family group more broadly: was the family 'good', honest, kind, faithful. Morals are held within families and thought to be inherited.

As Abdullah said,

I will be influenced by my father traits ... My genes are from my parents ... there are some things that you acquire from your parents like kindness, tenderness and a calm nature. This runs in the blood.

While 'outsiders can be admitted into the genealogy and do become members in ascent groups, they cannot share that group's honor and reputation. It is honor and reputation that is transmitted genealogically and which outsiders cannot share' (El Guindi 2012, 549). Thus, when considering a spouse for one's child one must consider carefully and, indeed, enquire subtly but robustly about their genealogy and the family's reputation. There is a preference for parallel first cousin marriage, specifically between a man and his father's brother's daughter (FBD), but other forms of cousin and close marriage occur. Marital preference reaffirms

endogamy and agnation. The value of marrying a cousin is that the parents will be known to one another and, thus, their moral behaviours and traits; making the prenuptial investigations and arrangements easier (Bittles 2012). Their preference is further characterized by a preference for parallel first cousin marriage, specifically between a man and his father's brother's daughter (FBD) *bint al-'amm* (the father's brother's daughter). As Bittles (2012, 66) emphasizes: there 'is the additional security of marrying a partner whose entire family background is known, so that any medical problems which might exist do not unexpectedly emerge after the wedding ceremony has been completed' (Bittles 1994; Khlal 1997; Hussain 1999).

Mothers explained that they were considering suitability and compatibility: sharing customs, practices and beliefs. If a woman married into a family that was very different from her own, she would not be happy. In forging marriages, women try to prevent conflict within and between lineages (El Guindi 2012, 551). Of utmost importance was a consideration for day-to-day interactions, as most daughters-in-law would live with their husband's family. Indeed, the reason why a cousin marriage was particularly valuable was because a daughter-in-law would also be a niece and so would be respectful to the mother. Familiarity and closeness meant greater harmony in daily life. The family has the considerable assurance of knowing and being related to her mother-in-law, thus reducing concerns regarding social incompatibility (Bittles 1994; Qidwai, Sued, and Khan 2003; Raz and Atar 2004). Marriages can be either 'close' or 'distant', but it is close marriage that is 'ideologically privileged, and given the precedence of agnatic relations over uterine, it is the patriparallel cousin who is the closest marriageable relative of all' (Holy 1989 in Clarke 2009, 39). Marrying 'close' has resonance: the nearest to a word for 'kinship' in Arabic, *Qarabah*, means, at root, 'closeness' (Clarke 2007); a relative is one 'close' (*qarib*).

As we can see from Abdullah's discussion, there is a strong rhetoric of protection (Bourdieu 1966, 227). From a male perspective, in many parts of the Arab world 'protection of one's womenfolk and one's own public standing, or "honour," which is intimately tied to them. That is to say that a man's duty of protection, on which his honour depends, paradigmatically applies to his womenfolk' (Clark 2009, 38). Despite an awareness of the potential medical risk of marrying in the family, although it is unclear how certain the risks were, there were thought to be risks of another kind if one did not marry within the family. Participants explained the importance of ensuring that a daughter was taken care of by her husband and his family. Anxiety about daughters leaving home was heightened if the husband's family were unfamiliar. As Clarke (2009, 39) comments, this 'preference for "closeness" is also an aversion to distance, to entrusting a "stranger" with one's own.' Cousin marriage protects women from the risk of marrying 'strangers', as evidenced by Charsley's (2005) work on Pakistani arranged transnational marriages: the marriage of a daughter in Britain to a trusted relative in Pakistan is a response to the risk of a woman's vulnerability to mistreatment.

This research supports Sandridge et al.'s (2010) claims of the potential advantages attributed to the practice including psycho-social benefits such as familial unity, decreased pressures on the bride in her new home, greater autonomy for women, a stronger marital bond with less risk of divorce, and a greater compatibility of the bride with her husband's family, property retention and effective transmission of the culture from generation to generation (Barth 1953; Khlal et al. 1986; Bittles 1994; Ottenheimer 1996). Sandridge et al. (2010) further elucidate that in a quickly developing nation such as Qatar, the benefit of the effective transmission of culture could create social stability, which in a period of turmoil and change could have enormous benefits. Participants explained that they had concerns about marrying in the family and referred to both medical and genetic risk and, sometimes, social risks. During Aisha's first

interview, she spoke openly about marriage in the family. She explained that diseases could pass from grandfathers to children. During a follow up interview she expanded on this:

Yes. This is well known. Prophet Mohammed, peace upon him, didn't recommend marrying within the family because it causes many diseases, which are inherited subsequently. If the mothers were sisters and they are married to their cousins who are also brothers. It is like you are building something on poor foundation. Everything will be destroyed. Many families have freed themselves from 'marrying within the family' perspective.

She spoke generally about families in Qatar who were 'very connected'. In these families, daughters were expected to marry cousins and, 'therefore, they get inherited diseases'. Aisha then instructed the research assistant, who had been conducting the interview, to tell the lead author that 'even Islam does not recommend marriage within the family'. She explained that some in her family do marry within and in the past it was rare for a woman to marry outside, 'but now it is different. I think the trend has changed in the last 2025 years.'

Next generation

There is growing sense in the younger generation that the practice should be discouraged because of the increased possibility of hereditary disorders in the offspring of such marriages, as reflected in the outcome of the Doha Debate as discussed in the introduction to this paper. This emerging research suggests that the younger generation are influenced by the discourse around genetic risk and are moving away from the practice. At the Doha debates, just five members of the 350-strong audience, made up of students from countries spanning the Middle East and North Africa, reported that they were married to or planned to marry their first cousin. However, we must also consider how much of this change is due to wanting to be perceived to be 'modern' and how this will affect actual practice. One family interviewed illustrates the way Qatari culture and marriage practices face rapid change. All six adult daughters were present at the interview, as well as the mother and father. The daughters, three of whom were married to cousins, all said that they would prefer their children to marry outside the family. One of the women, Mariam, said:

Well, we have this culture ... it is better to marry your cousin than a stranger. If anyone that wants to get married they say 'go and check your cousin'. So [your] cousin is the first choice. But these days they do have this check up or something ... like testmarriage test before anyone gets married either from a cousin or from another family they have to do this test.

Here, Mariam refers to the premarital screening programme, described above. She further explained that one of the reasons they tended to marry cousins is because you see them, you get to know them and she said,

From my point of view, yah, I prefer to marry my cousin, any of my cousins, to be honest! All three of us married our cousins. First cousins. Even my brother, he married our cousin. So thanks god, that we didn't find any problems, hamdullah, all of them are fine.

She continued, 'it is so popular, everyone is doing it, so it is not like it is strange.' 'When marrying a cousin, the first thing that comes to mind is that one worries about the potential problems in offspring,' Mariam explained as the others expressed their agreement. But they 'thank god' that they all have been fine. In the discussion that evening they made clear that

these issues were separate from their son/brother's disability, which they were convinced were not genetic.

During the interview, the lead author asked the family if they would want their children to marry in the family. Their response was surprising in that all the daughters present said 'no'. Mariam said:

For my son I wouldn't encourage it, I wouldn't stop it, but I wouldn't encourage it ... Now it is open and you are reading a lot. Marrying cousins causes diseases and stuff like this, so we decided no, halas, let us stop it.

The lead author then asked if the reason for the change is specifically because of the worry of subsequent health conditions:

Yes, well because it might happen ... when you get a baby, yes, I married my cousin, that is why I got a disabled child.

Thus, part of the issue was about blame and guilt. That if one were to produce a child with disability, then one would simply not know if it were to do with cousin marriage. Her sister agreed: And it is not just disability, here we have asthma ... I think asthma is to do with marrying in the family. Qatari negotiations of marriage are complex. As Parkhurst's (2014) research in the UAE reveals, wealth is a primary concern for many Emirati. Money, as an object, and the consideration of inheritance of goods and property influence the practice of consanguineous kinship, despite this not being openly discussed. The transfer of wealth among aristocratic groups could be teased out as supportive of consanguinity and yet the authors do not have material to support this.

Conclusions

In this research, which focused on public understanding of risk and genetic risk, the issue of consanguinity was ever present. A nuanced and sensitive investigation of the modern practice of cousin marriage is pertinent, particularly given the political dimension to research in the Middle East given the present climate. Even when studying or reporting upon what one might assume are relatively innocuous issues, we must be aware of the political climate. Some extreme right-wing American conservatives, for instance, seeking reasons for Arab and Muslim intransigence towards American foreign policy objectives, look to the region's notional fondness for 'clannish' 'cousin marriage', a stock, if dated, theme of the anthropological literature (Clarke 2007, 389 in Clarke 2009, 5).

Douglas (1966) argues that the modern preoccupation on risk is the way modern societies deal with danger something of concern for all cultures. Douglas's (1992, 14) assertion that risk perception is culturally shaped informs our research; despite its apparent neutral language risk is always moral and political. Douglas invites us to question why a society singles out some risks for attention and not others. Risk identification can be investigated to better understand a society's values and its social structures (i.e. Douglas 1992; Douglas and Wildavsky 1982). Of central interest here is the way that Qataris are weighing up and negotiating risks.

Returning to the 2012 Doha debate, Professor Alan Bittles, an expert on community genetics acknowledged there was an increased risk of birth defects in cousin marriages, but that increase is small. As Samar Fatany said, 'Families feel comfortable if their daughter marries within the family rather than marry a stranger, they do not know if she is going to be happy or safe if they

know nothing about her husband's background.' The authors would agree that participants were aware of the risk of marrying their children outside of the family and the social risks often outweigh the possible (and intangible) medical risks, at least for the older population. However, amongst the younger population, it appears that marrying in the family may no longer be the desired arrangement. With more opportunities for socialization between the sexes, younger Qataris are increasingly likely to meet and develop relationships. Increased exposure to biomedical discourse, particularly genetics, can alter society. The younger generation may be seizing such information to provide support for marriage partner preference. Alternatively, the younger generation may be more exposed to the discourse of genetic risk through education, premarital screening and the media and, thus, it may be that they are more influenced by it.

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Note 1. The scholars of the hadith literature divided the traditions into categories according to the degree of authenticity and reliability. The Qatari Religious Guidance and Advocacy Department referred to this as a 'hadith dha'aaf' (the weak traditions which are not so reliable). The sheikh said that although it has been proved from the medical point of view that marrying first cousins is associated "with the birth of unhealthy children which we do also believe but we have no evidence from Quran and Sunnah and we can't rely on 'hadith dha'aaf'". People do, however, refer to this hadith regularly when they speak about cousin marriage.

References

Al-Fuzae, L., K. C. Aboolbacker, and Q. Al-Saleh. 1998. "Beta-Thalassaemia Major in Kuwait." *Journal of Tropical Pediatrics* 44: 311-312.

Al-Gazali, L. I., H. A. Dawodu, K. Sabarinathan, and M. Varghese. 1995 "The Profile of Major Congenital Abnormalities in the United Arab Emirates (UAE) Population." *Journal of Medical Genetics* 32: 713.

Al-Ghanim, K. 2010. "Consanguineous Marriage in Qatar: Marriage Selection in a Society in Transition." World Academic Union (World Academic Press), Proceedings of 2010 International Conference on Humanities, Historical, and Social Sciences (CHSS 2010) Singapore, 26-28 February, 2010.

Abdulrazzaq, Y. M., A. Bener, L. I. Al-Gazali, A. I. Al-Khayat, R. Micallef, and T. Gaber. 1997. "A Study of the Possible Deleterious Effects of Consanguinity." *Clinical Genetics* 51: 167-173. Barth, F. 1953. "Principles of Social Organization in Southern Kurdistan." *Universitetets Ethnografiske Museum Bulletin no. 7 Brodrene Jorgensen A/S-Boktrykkeri, Oslo*.

Beaudevin, C. 2013. "Old Diseases and Contemporary Crisis. Inherited Blood Disorders in the Sultanate of Oman." *Anthropology and Medicine* 20: 175-189.

Bennett, R. L., Arno G. Motulsky, Alan Bittles, Louanne Hudgins, Stefanie Uhrich, Debra Lochner Doyle, Kerry Silvey, C. Ronald Scott, Edith Cheng, Barbara McGillivray, Robert D.

Steiner, and Debra Olson. 2002. "Genetic Counseling and Screening of Consanguineous Couples and their Offspring: Recommendations of the National Society of Genetic Counselors." *Journal of Genetic Counseling* 11 (2): 97119.

Bener, A., and R. Hussain. 2006. "Consanguineous Unions and Child Health in the State of Qatar." *Pediatric and Perinatal-Epidemiology* 20: 372378.

Bittles, A. H., 1994. "The Role and Significance of Consanguinity as a Demographic Variable." *Population and Development Review* 20: 561584.

Bittles A. 2011. The global prevalence of consanguinity. <http://www.consang.net> accessed October 2013.

Bittles, A. H. 2012. *Consanguinity in Context*. Cambridge University Press: Cambridge, UK.

Bittles, A. H. 2013. "Consanguineous Marriages and Congenital Anomalies." *Lancet*: ii 382 (9901): 13161317.

Bittles A., and M. L. Black. 2014. "Global Patterns & Tables of Consanguinity." <http://consang.net> (accessed September 2014).

Bittles, A. H., and E. Makov. 1988. "Inbreeding in Human Populations: An Assessment of Costs." In *Human Mating Patterns*, edited by C. G. N. Mascie-Taylor and A. J. Boyce, pp. 153167. Cambridge: Cambridge University Press.

Bittles, A. H., W. M. Mason, J. Greene, and N. A. Rao. 1991. "Reproductive Behavior and Health in Consanguineous Marriages." *Science* 252: 789.

Bourdieu, P. 1966. "The Sentiment of Honour in Kabyle Society." In *Honour and Shame: The Values of Mediterranean Society*, edited by J. G. Peristiany, 193241. Chicago: University of Chicago Press.

Charsley, K. 2005. "Unhappy Husbands: Masculinity and Migration in Transnational Pakistani Marriages." *Journal of the Royal Anthropological Institute* 11: 85105.

Clarke, M. 2009. *Islam and the New Kinship: Reproductive Technology and the Shariah in Lebanon*. Oxford: Berghahn Books. Clarke, M. 2007 "Closeness in the Age of Mechanical Reproduction: Debating Kinship and Biomedicine in Lebanon and the Middle East." *Anthropological Quarterly* 80: 379402.

Cryer, A. 2005 "First Cousin Marriage: A Public Health Issue?" *Bio News* 337, <http://www.bionews.org.uk/commentary.lasso?storyid=2843>. Douglas, M. 1992. *Risk and Blame: Essays in Cultural Theory*. London: Routledge.

Douglas, M. 1966. *Purity and Danger: An Analysis of the Concepts of Pollution and Taboo*. London: Routledge. Douglas, M., and A. Wildavsky. 1982. *Risk and Culture: An Essay on the Selection of Technological Dangers*. London: Routledge.

El Guindi, F. 2012. "Milk and Blood: Kinship among Muslim Arabs in Qatar." *Anthropos* 107: 555.

- El- Hazmi, M. A. F., Al-Swailem, A. R., Warsy, A. S., Al-Swailem, A. M., Sulaimani, R., AlMehari, A. A. 1995. "Consanguinity among Saudi Arabian Population." *Journal of Medical Genetics* 32: 623626.
- El-Shanti, H., A. Saoud, A. A. Saddon, S. M. Leal, S. Chen, K. Lee, and R. Spiegel. 2006. "A Distinct Autosomal Recessive Ataxia Maps to Chromosome 12 in an Inbred Family from Jordan." *Brain Development* 28: 353357.
- Featherstone, K., P. Atkinson, A. Bharadwaj, and A. Clarke. 2006. *Risky Relations: Family, Kinship and the New Genetics*. Oxford and New York: Berg.
- Goffman, E. 1990 [1963]. *Stigma: Notes on the Management of Spoiled Identity*. London: Penguin.
- Hegab, S. M., and S. A. Al-Mutawa, 1996. "Congenital Hereditary Autosomal Recessive Alacrima." *Ophthalmic Genetics* 17 (1): 3538.
- Holy, L. 1989. *Kinship, Honour and Solidarity: Cousin Marriage in the Middle East*. Manchester: Manchester University Press.
- Hussain, R. 1999. "Community perceptions of reasons for preference for consanguineous marriages in Pakistan." *Journal of Biosocial Science* 31, 449461.
- Inhorn, M. 2009. "Reproductive Disruptions and Assisted Reproductive Technologies in the Muslim World." In *Reproductive Disruptions: Gender, Technology, and Biopolitics in the New Millennium*, edited by M. Inhorn, 183199. Oxford: Berghahn Books.
- Inhorn, M., L. Kobeissi, Z. Nassar, D. Lakkis, and M. Fakhri. 2009. "Consanguinity and Family Clustering of Male Factor Infertility in Lebanon." *Fertility and Sterility* 91: 11041109.
- Khlat, M. 1997. Endogamy in the Arab world. In Teebi, A and Faraq, T (eds). *Genetic disorders among Arab polulations*, 1st edition. New York, Oxford: Oxford University Press pp.6380.
- Khlat, M., S. Halabi, A. Khudr, and V. M. Der Kaloustian. 1986. "Perceptions of Consanguineous Marriages and their Genetic Effects among a Sample of Couples from Beirut." *American Journal of Medical Genetics* 25: 299306.
- Ibrahim, S. E., and D. P. Cole. 1978. *Saudi Arabian Bedouin: An Assessment of their Needs*. The Cairo Papers in Social Science. The American University in Cairo, Cairo, Egypt.
- Ottenheimer, M. 1996. *Forbidden Relatives. The American Myth of Cousin Marriage*. Urbana and Chicago: University of Illinois Press.
- Meleis, A. I., and L. Sorrell. 1981. "Arab American Women and their Birth Experiences." *MCN* 6: 171176.
- Modell, B. 1991. "Social and Genetic Implications of Customary Consanguineous Marriage among British Pakistanis. Report of a meeting held at the Ciba Foundation on 15 January 1991." *Journal Medical Genetics* 28: 720.

- Panter-Brick, C. 1991. "Parental Responses to Consanguinity and Genetic Disease in Saudi Arabia." *Social Science & Medicine* 33: 12951302.
- Parkhurst, A. 2014. "Genes and Djinn: Identity and Anxiety in Southeast Arabia." PhD Dissertation, Department of Anthropology, UCL.
- Qidwai, W., I. A. Sued, and F. M. Khan. 2003. "Prevalence and Perceptions about Consanguineous Marriages among Patients Presenting to Family Physicians, in 2001 at a Teaching Hospital in Karachi, Pakistan." *Asia Pacific Family Medicine* 2: 2731.
- Raz, A., and M. Atar. 2004. "Cousin Marriage and Premarital Carrier Matching in a Bedouin Community in Israel: Attitudes, Service Development and Educational Intervention. *Journal of Family Planning and Reproductive Health Care* 30: 4951.
- Raz, A. 2005. *The Gene and the Genie: Tradition, Medicalization and Genetic Counseling in a Bedouin Community in Israel*. Durham, North Carolina: Carolina Academic Press.
- Sandridge, A., J. Takeddin, E. Al Kaabi, and Y. Francis. 2010. "Consanguinity in Qatar: Knowledge, Attitude and Practice in a Population born between 1946 and 1991." *Journal of Biosocial Science* 42: 5982.
- Shaw, A. 2006. "British Pakistani Arranged Transnational Cousin Marriages." *Contemporary South Asia* 211222. Shaw, A. 2009. *Negotiating Risk: British Pakistani Experiences of Genetics*. Oxford: Berghahn Books.
- Sheridan, E., J. Wright, N. Small, P. Corry, S. Oddie, C. Whibley, E. Petherick, T. Malik, N. Pawson, Patricia McKinney, and R. Parslow. 2013. "Risk Factors for Congenital Anomaly in a Multiethnic Birth Cohort: An Analysis of the Born in Bradford Study. *The Lancet* 382(19 October): 13501359.
- Shiloh, S., H. Reznik, M. Bat-Miriam-Katznelson, and B. Goldman. 1995. "Pre-marital Genetic Counseling to Consanguineous Couples: Attitudes, Beliefs and Decisions among Counseled, Non-counseled and Unrelated Couples in Israel." *Social Science and Medicine* 41: 13011310.
- Spooner, B. 1997. "The Evil Eye in the Middle East." In *Witchcraft, Confessions and Accusations*, edited by M. Douglas, 311319. London: Tavistock Publications. Teebi, A. S. 1994. "Autosomal Recessive Disorders among Arabs, An Overview from Kuwait." *Journal of Medical Genetics* 31: 224233.