UK Pakistani views on the adverse health risks associated with consanguineous marriages

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Abstract This is a qualitative study exploring the perceptions of members from the Pakistani/Kashmiri community living in Luton, UK, on the adverse health risks associated with consanguineous marriages. Rates of stillbirths and infant mortality are higher than the national average in Luton and the existing evidence base suggests that these higher rates may be associated with consanguinity (especially first cousin marriages) in highly consanguineous populations, such as the Pakistani/Kashmiri ethnic group. This qualitative study included 9 focus groups and 10 one to one in-depth interviews ($n=58$) with members from the Pakistani/Kashmiri community in Luton during 2012. Audio-recorded transcripts were analysed using framework analysis. Emerging themes included a limited knowledge, opposition to evidence and need for a more culturally sensitive health services approach. Findings from the focus group and interview discussions indicated that participants had a limited and varied understanding of genetic risk and indicated a lack of discussion within the community regarding genetic risk. They also opposed evidence that may link consanguineous marriages with infant mortality, stillbirth or genetic disorders that led to disability. The participants stressed the need for culturally sensitive and locally constructed services for information on genetic risk and services. These findings may be used to address higher rates of infant mortality and adverse health impacts associated with higher rates of consanguinity in Luton and elsewhere, through a partnership approach, improve upon current services and develop culturally appropriate services.

Keywords Consanguinity · Genetic risk · Infant mortality · Stillbirth · Community engagement

Introduction

The cultural practice of consanguineous marriage (or cousin marriage) refers to marriage between close biological relatives and has been linked with an increase in genetic risk leading to stillbirths, infant deaths and genetic disorders (Bennett et al. 2002; Hamamy et al. 2011; Modell and Darr 2002). Evidence highlights a 2–3 % risk of genetic disorders in children of unrelated couples which goes up to 4–6 % in children of consanguineous couples and a strong association with rise in autosomal recessive disorders (Bennett et al. 2002; Darr et al. 2013; Hamamy et al. 2011; Shaw 2009). While most people with recessive genes show no signs of disease due to the presence of at least one healthy copy of the gene, a person who inherits two copies of the same rare recessive gene variant will express the disease (Bittles 2010a). The children of two healthy carriers of the recessive gene have a one in four chance with each pregnancy of having an affected child with the rare genetic disorder linked to the recessive gene (Bittles 2010a). This risk increases further when families marry within close relatives over successive generations, resulting from a clustering of rare gene variants within the runs of homozygosity, which increases in children of close relatives (Ahmed et al. 2012; Bittles 2008; Woods et al. 2006).

Consanguinity is relevant to UK health care as there are now large settler populations from South Asia, the Middle East and sub-Saharan Africa (Ahmad 1994; Bittles 2009; Hoodfar and Teebi 1996) who practice consanguineous

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marriages. The Pakistani/Kashmiri community¹ is one of the largest ethnic groups in the UK (ONS 2011) and is highly consanguineous (Shaw 2009). Autosomal recessive disorders are also higher amongst this group (Taylor 2013b), with Pakistani babies accounting for 30 % of autosomal recessive disorders among all babies born in the UK, while accounting for only 4 % of total births (Modell and Darr 2002). The impact of consanguinity on potential genetic risk is increased through endogamy in sub-populations (Al-Gazali et al. 2006). Endogamy is distinguished from consanguinity in that it refers to marriage within a closed group, who are not necessarily related, but belong to a population sub-group, like a kinship network (Bittles 2010a). Within the Pakistani/Kashmiri community, there are kinship networks such as *biraderi* that are used to determine a hierarchical preference for marriage partners within the community (Ajaz 2013; Darr and Modell 1988; Shaw 2000). The results from a large cohort study in Bradford (Sheridan et al. 2013) showed an increase in congenital anomalies amongst children of consanguineous parents, but could not obtain information on the underlying impact of population sub-groups like *biraderi*, prompting some criticism, which argued that these endogamous unions can potentially increase or significantly impact the genetic risks associated with consanguinity in the UK (Ali et al. 2014; Bittles 2013). While the large cohort study in Bradford suggested that genetic anomalies were higher in their sample despite controlling for deprivation (Sheridan et al. 2013), evidence suggests that levels of deprivation have a significant impact on infant mortality and stillbirth rates (Weightman et al. 2012; Wood et al. 2012), which may be of relevance for determining impacts of consanguinity in other areas with high consanguineous populations.

There has been previous research on consanguinity with the Pakistani/Kashmiri community in different parts of the UK, in Birmingham (Ali et al. 2012; Sanderson et al. 2006), Manchester (Ravenscroft et al. 2011) and Bradford (Darr and Modell 1988; Sheridan et al. 2013). Some studies have identified a lack of knowledge about consanguinity and genetic risk (Ali et al. 2012; Emery and Hayflick 2001; Fry et al. 1999; Shaw and Hurst 2008) or sought to explore the impact of consanguineous marriages, including potential social

benefits (Bhopal et al. 2013). Studies exploring genetic risk perceptions found opposition to existing evidence by the community, which was perceived as contributing towards anti-Muslim sentiment (Ali et al. 2008, 2012). These studies have not only tried to explore the genetic impact of consanguineous marriages but also have tried to identify approaches to improving information on consanguinity and genetic risk (Darr et al. 2013). A community based or family-based approach is being offered as best practice to improve genetic services and information delivery to Pakistani/Kashmiri communities, aiming to utilise the exchange of information within extended familial networks (Darr et al. 2013) in Leeds/Bradford. The success of such initiatives rests on local contexts of knowledge about consanguinity and genetic risk and the community's willingness to accept and address adverse health impacts (Salway et al. 2012). Luton has a similar Pakistani/Kashmiri demographic to Leeds/Bradford (Communities and Local Government 2009), yet, prior to this work, there has been limited research done in Luton related to consanguineous marriages and its impact on health. The findings from this study focus on the Luton context. Understanding the local contexts of ethnic sub-groups and the wider determinants of health and perspectives on consanguinity, including levels of knowledge of genetic risk and consanguinity, is an important first step to ensuring that national or international strategies on health improvement are locally relevant.

The research site

Luton is home to one of the largest Pakistani/Kashmiri communities in England and Wales, making up the largest ethnic group in Luton (29,353 ~ 14.4 %) after the White British/Irish groups (ONS 2011). Given that the Pakistani/Kashmiri community is demographically similar to that of Bradford and Birmingham, it is also expected to be highly consanguineous; certainly, evidence from this research suggests that consanguineous marriages are common within Luton's Pakistani/Kashmiri community (Ajaz 2013). This community is also amongst the most deprived within Luton, as Pakistanis/Kashmiris make up a large proportion of the areas rated poorly on the Index of Multiple Deprivation (Luton Borough 2004, 2011). Previous research in Luton has not addressed the impact of consanguinity directly, with research focusing mainly on Pakistani/Kashmiri identity formation (Ali 1999), forced marriages (Khanum 2008) and children with complex needs (Kaur-Bola 2009), where consanguineous marriages were discussed as a subsidiary issue. This study has taken place at a time when interest in consanguinity has increased due to statistics showing higher than the national average rates of stillbirths, infant mortality and genetic disorders in Luton. Luton Borough Council and Public Health Luton have

¹ While community is a contentious topic in sociology and anthropology (Amit and Rapport 2002), here it is used to refer to the Pakistani/Kashmiri diaspora in the UK who have similar languages, religion and migration histories (Din 2012). Previous research carried out with the Pakistani community in the UK shows that a large majority are actually from Azad Kashmir (Ballard 2013). Previous research carried out in Luton supports this point and indicated that many (although not all) of Pakistani settlers in Luton prefer to be identified as Azad Kashmiri (Ali 1999). This point is supported by this research and hence the sample for this research comprised of participants who identified themselves as Pakistanis and those that referred to themselves as Kashmiris. Hence for the purposes of this research, the sample was described as Pakistani/Kashmiri.

reported that infant mortality in Luton is higher (7.5 deaths per 1,000 live birth) than the national average (4.6 deaths per 1,000 live births)² and is highest in the Pakistani community (Taylor 2013b) where consanguinity has been identified as a modifiable factor (Taylor 2011; Taylor and Whiterod 2011). The number of stillbirths in Luton is also higher than the national average, although consanguinity was not statistically linked (Taylor 2013a); others have indicated an impact of consanguinity on increased stillbirths (Al-Abdulkareem and Ballal 1998; Alper et al. 2004; Bittles et al. 1993). Existing evidence on infant mortality and stillbirths, as well as genetic disorders in general, indicates that there may be an association with consanguinity (Bennett et al. 2002; Darr and Modell 1988; Zlotogora and Shalev 2010); however, the extent of the impact is variable on levels of relatedness, sampling techniques and controls for non-genetic factors (Bittles 2010b, 2012; Hamamy et al. 2011). A meta-analysis of 46 studies on consanguinity and links to early deaths showed a statistically significant 1.3 % higher number of infant deaths in children of first cousins than those born to non-consanguineous couples (Bittles 2012). Stillbirths were also higher by 0.5 % in first cousin progeny (Bittles 2012), and recent data continue to show increased stillbirths (Bellad et al. 2012; Sørbye et al. 2014) as well as increased infant deaths (Charafeddine et al. 2012; Sørbye et al. 2014) in children of consanguineous parents compared to non-consanguineous couples.

In response to these statistics, the Luton Borough Council formed a Scrutiny Task and Finish group on Infant Mortality, which as part of its recommendations has called for an increase in research looking into the impact of consanguinity within Luton, and work in this regard has now commenced. This is one of the first research studies to look at the Pakistani/Kashmiri community's knowledge of genetic risk and links to consanguinity. It was important first to understand the Luton Pakistani/Kashmiri community's knowledge of genetic risk which can in turn contribute towards understanding the best approach(es) to delivering information and services on genetic risk in Luton and other areas of similar demographic where research into the impact of consanguinity within ethnic groups has not advanced as much as areas like Bradford and Birmingham.

Methods

This was a qualitative study that included focus group discussions and in-depth interviews with a total of 58 local

community members, including 27 married to their cousins and 31 who have never been married to a cousin.

Recruitment and ethics

The sample was recruited from the local Pakistani/Kashmiri community and included participants that were in consanguineous marriages and those that were not in a consanguineous marriage (Ali et al. 2008; Hussain 1999; Shiloh et al. 1995). These groups were further subdivided by gender and age (17–29, 30–49, 50+ years old). Most participants were from Dallow and Biscot Wards belonging to similar socio-economic groups, with both wards amongst the most deprived wards in Luton (Luton Borough 2004, 2011). Both in-depth interviews and focus group discussions were used to explore community views to not only add validity and depth to data (Hennink et al. 2011) but also follows best practice of similar work (Ali et al. 2008; Bywaters et al. 2003; Kaur-Bola 2009; Khanum 2008). The participants included 24 males and 34 females, with representation from all age groups. While the original design was to carry out focus group discussions with non-consanguineous participants and in-depth interviews with consanguineous participants, a pragmatic decision to include focus group discussions with some consanguineous participants due to their limited availability was made to enhance participation. The discussions included 6 focus group discussions (FGD) with non-consanguineous participants and 3 focus group discussions and 10 in-depth interviews (IDI) with consanguineous participants, and data was collected between March and July 2014 (see Table 1. for detailed information about discussions).

The approval of the University of Bedfordshire Institute for Health Research Ethics Committee was sought prior to recruitment. Once approval was received, the participants were recruited at local community centres, mosques, shops and the university, and through snowballing, by asking participants to identify other potential participants (Hennink et al. 2011). Participants were offered £20 as a goodwill gesture for participation and to cover for travel costs. Before any data was collected, the participants were given information sheets to learn about the research, advised of their freedom to withdraw at any stage and asked to sign an informed consent form designed to meet both the NHS and WHO requirements for a qualitative study (NHS 2013; WHO 2013). In addition to the consent form, participants were asked to also verbally consent to allow tape recording of the discussions; this was particularly important as some older participants had signed their consent in Urdu, and the verbal consent was (in those instances) taken in Urdu, to ensure

² More recent data shows that infant mortality rates have dropped slightly in Luton (7.1 per 1,000 live births); however, they remain above the national average for England and Wales (4.5 per 1,000).

Table 1 Details of interviews and focus groups

Discussion ID	Date held	Location in Luton	Total participants	Audio (time)
Discussions with non-consanguineous community members				
Males 16–29 FGD	25/4/2012	University of Bedfordshire	5	80 min, 44 s
Females 16–29 FGD	20/4/2012	University of Bedfordshire	9	74 min, 02 s
Males 30–49 FGD	24/5/2012	Local charity centre ^a	4	63 min, 51 s
Females 30–49 FGD	10/7/2012	Local community centre 1	4	96 min, 47 s
Males 50+ FGD	8/3/2012	Local community centre 1	3	51 min, 59 s
Females 50+ FGD	7/3/2012	Local community centre 1	6	87 min, 37 s
Discussions with consanguineous community members				
Male 16–29 IDI 1	28/7/2012	Local community centre 1	1	54 min, 01 s
Female 16–29 IDI 1	16/3/2012	University of Bedfordshire	1	62 min, 18 s
Female 16–29 IDI 2	12/7/2012	Local community centre 1	1	61 min, 43 s
Female 16–29 IDI 3	12/7/2012	Local community centre 1	1	33 min, 13 s
Female 16–29 IDI 4	12/7/2012	Local community centre 1	1	36 min, 47 s
Male 30–49 IDI 1	19/4/2012	University of Bedfordshire	1	53 min, 26 s
Male 30–49 IDI 2	24/5/2012	Local community centre 2	1	69 min, 15 s
Male 30–49 IDI 3	20/7/2012	Local community centre 1	1	60 min, 48 s
Female 30–49 IDI 1	7/3/2012	University of Bedfordshire	1	52 min, 18 s
Female 30–49 IDI 2	19/4/2012	University of Bedfordshire	1	78 min, 57 s
Mixed 30–49 FGD	9/6/2012	Local charity centre	5	68 min, 37 s
Male 50+ FGD	8/3/2012	Local community centre 1	6	59 min, 03 s
Female 50+ FGD	7/3/2012	Local community centre 1	6	86 min, 18 s

This table provides a full list of all of the discussions, dates and locations of when and where they took place, as well as the length of discussion in minutes

FGD focus group discussion, *IDI* in-depth interview

^a Actual location names anonymised for privacy protection

no participant had consented on the forms without understanding the written language.

Data analysis

The focus group and individuals' in-depth interview discussions were semi-structured and were designed to last an average of 60 minutes. Participants are not identified by name, consistent with the confidentiality promised to the participants; instead, they each have been ascribed a pseudonym. The discussions were audio recorded and transcribed by MA. As English was not the native language for all participants, some of the discussions were held in Urdu and Punjabi (and in some cases Pahari, a dialect of Punjabi). This presented an added complexity in transcription of discussions, as words had to be translated on the go, and in order to avoid pitfalls of representation of the participants by a translator (Temple and Young 2004), it is usually recommended that the researcher is a better option to conduct such interviews, if they could speak the same language (Esposito 2001), which was the case in this research. The narratives were extracted verbatim, thus ensuring key ideas were logged and avoiding the loss of meaning (Chapman et al. 2009). The data were stored and organised using QSR Nvivo 10 computer-assisted qualitative data analysis software. A framework approach (Ritchie and Spencer 1994) was used to analyse

the transcripts which involved familiarisation with the data, identification of the main themes and sub-themes, followed by coding, indexing and charting of the discussion findings (Silverman 2010).

The theme-based approach to framework analysis in Nvivo 10 ensured that narrative extracts from different discussions were charted under relevant themes and sub-themes in one place, with hyperlinks to direct quotes in the transcripts as well as the audio recordings, which again ensured that the participants' spoken words were utilised verbatim and their meaning was not amended or lost. The themes and sub-themes were thus revised as each transcript was coded and analysed to remain consistent with the participants' meanings. The data were then charted into matrices, based on the major themes, with different excerpts arranged across all the discussions under their relevant themes. The final analysed data were parsed again to ascertain the overall meanings being derived by the participants in relation to the major themes.

Triangulation

Data triangulation was ensured through collecting data from both consanguineous and non-consanguineous community members, and methodological triangulation was achieved through data collection using both focus groups and in-depth interviews. MA transcribed the discussion and conducted

initial analysis; both NA and GR independently confirmed the audio recordings and transcripts, as well as the coding scheme, charted matrices and final themes for quality control purposes and investigator triangulation (Guion 2002).

Findings

The findings from the focus group and individual in-depth interview discussions are presented thematically below. In order to maintain the participants' meanings and perspectives, their narratives are presented verbatim and the presentation of the findings is guided through their words, giving a representative account of the discussions. Comparisons are made between the age groups and consanguinity status where relevant. The participants' understanding of consanguinity and genetic risk, their perspectives on the evidence linking consanguineous marriages with infant mortality and genetic risk of adverse health effects, as well as their outlooks on delivering of culturally sensitive care are discussed below.

Understanding consanguinity and genetic risk

A majority of the respondents had previously heard of the link between consanguinity and genetic risk, primarily from the media. As well as the media, a minority of participants mentioned (unspecified) health promotion campaigns as their source of information. All respondents explained that the consensus portrayed was that consanguinity led to increased "problems in kids" and "genetics". However, when asked to explain what was meant by genetics, let alone genetic risk, the majority of participants had a minimal understanding. Those participants who had gone through at least a secondary education were aware of genetics, at least in a general sense that it had something to do with their parents and heredity.

Like, (it's) inside me. What I am, what makes me.—Abid, non-consanguineous men, 16–29 FGD
(Genetics is like) your genes, your parents' genes.—Saima, non-consanguineous women, 16–29 FGD

As the responses below from Muneeb and Zainab Bibi highlight, the ways in which some older participants described genetics were simplistic and were usually linked with something to do with blood and pointed to heredity in a very generic way.

Yes blood relations. Genetic means your germs (sic). It has come out of germs. Like if you are marrying your paternal uncle's (son) then you would have same germs

as your uncle. This is genetics.—Zainab Bibi, non-consanguineous women, 50+ FGD

That there are some faults in it. Some people have done research in it, I watched it on television. They said that some disease forms in genetics. If you marry within close relatives, there is a change in their blood. It can happen in girl or boy. There can be many such diseases.—Muneeb, non-consanguineous men, 50+ FGD

The fact that some participants in the older age group discussions had never heard of the word genetics could have been due to the language barrier. All of the 50+ age group discussions were held almost exclusively in Urdu, but the literal translation of genetics in Urdu, *geeniyat* or *ilm-e-ikhlaqi*, is perhaps even less common than the English word, making it all the more difficult for these participants to understand genetics. However, a language barrier was not necessarily the case with some of the other participants, like Farhan, a participant in the mixed consanguineous 30–49-year-old group discussion who stated, "(I've) never heard of that word (genetics)." The group discussion that Farhan was a part of was held with parents of children with disabilities, making it more likely that he may at some point have spoken to a genetic specialist,³ yet he claimed to have never heard the word before.

Most of the responses around genetics were non-specific in nature, owing to the lack of understanding of the term. Still, when probed about any potential risk associated with cousin marriages, some of the participants related the presence of disabilities in children of consanguineous couples as a possible risk, which again was something that they had absorbed through the media.

There was a thing in the media. If you continuously marry cousins, somewhere down the line there may be an effect (genetically). But I don't know.—Zain, non-consanguineous men, 30–49 FGD

Yes, I've heard it from people, I've seen it on TV a few times. I've read it in books, that if you marry within cousins, then you get girls being born and all that, but I don't believe in that. This is that person's luck or fate, and that's what happens.—Samar, consanguineous female, 16–29 IDI

Only a minority of respondents had actually heard about cousin marriage and genetic risk through their doctor, but the discussion was short-lived on the insistence of the participant and then never revisited by the doctor.

³ All patients diagnosed with a genetic disorder are offered genetic counselling through the local genetics service. Although it was not clear how many of the participants had attended an appointment with a genetic specialist, one focus group discussion with five participants, was held through a local disabilities charity which provides genetic risk information to patients, parents and carers.

Yes my doctor he mentioned that you know this was way back in after I got married and (had our) first kid, and he said you know, you are married in cousins and this is very dangerous what you people do and you don't understand (sic)... And he said yeah there could be more diseases and stuff. And I said how you know? Raise your facts. He said it's being studied that's why I am telling you. I said ok you know leave that conversation to another time mate and we left.—Imtiaz, consanguineous male, 30–49 IDI

The only specifics about genetics came from Soha in the 16–29 female focus group discussion, who was a science student undertaking a genetics course at the time. Soha mentioned the limitation of the gene pool as a result of continuous cousin marriages through successive generations.

They just didn't wanna accept it, it's common ancestors, you have a limited gene pool, all these statistics are out there, but they don't want to accept it. Because it damages their culture. The queen carried, they all carried haemophilia and they all married cousins.—Soha, non-consanguineous women, 16–29 FGD

Zain from the men's 30–49 FGD also mentioned negative aspects of consanguinity which he believes: appear when there are cousin marriages over multiple generations. This was echoed in Ikram's response below from the men's 16–29 FGD, talking about the impact on successive generations.

There (in Bradford) it's quite common, (they) marry their cousins, they said like, they did a study, within they found out like, especially because it wasn't just first cousin marriages, it was second generation, third generations, they all marry their cousins, because of that, their kids were born with like, some of them were born with defects or learning disabilities, you know. And that could be one of the problems as well.—Ikram, non-consanguineous men, 16–29 FGD

While Zain and Ikram's words may represent a lay understanding of illness causation, it may in fact be closer to the genetic science of consanguinity, as in the rise in the number of homozygous regions in successive generations of consanguineous families (Bittles and Black 2010; Cherkaoui et al. 2005; Woods et al. 2006). Still others like Laiba acknowledged the need for better understanding of risk and spoke of an increased (genetic) risk level when there had been no “cross” marriages outside the family in the generation before, showing the other end of the spectrum for lay understandings of genetic risk.

There should be more awareness against it (genetics). Especially in instances where there has been no cross

marriage (outside cousins) in the generation before, because when they have that cross marriage and then their kids have cousin marriage, then you have less side effects.—Laiba, consanguineous female, 16–29 IDI

Laiba also happened to be only one of two participants who hinted at a possible link to infant mortality and stillbirths. Although, her estimation of the risk for disabilities is vastly incorrect and indicative of the lack of clear understanding of risks associated with consanguineous marriages.

I have heard, in fact I know that this happens, 90 % of the time children are disabled. And in some (cousins), couples cannot have children, they die.—Laiba, consanguineous female, 16–29 IDI

The other participant to speak specifically about risks of infant deaths and stillbirths spoke about it being an issue within her extended family.

I have family members who are married to cousins who have four to five miscarriages and I often wondered if that was linked to the fact that both of these individuals, their mothers were related and their fathers were related, cousin wise (sic).

Researcher: Were they miscarriages or were they stillborn?

Stillborn. And I think she had one to two miscarriages and two to three stillborn because she was trying so hard to have children. Although she has children now, but in the back of my head I always thought that (it was because they were cousins)—Nosheen, consanguineous female, 30–49 IDI

Soha, the science student, was also the only person to mention specifically the possible risks of not just cousin marriages but also marriages within the *biraderi*, pointing towards risks associated with endogamy (Bittles 2012; Hamamy et al. 2011).

A lot of Kotli (district in Azad Kashmir) people are intermarried. Not first cousins but still inter married. So, I would still check genetic risk.—Soha, non-consanguineous women, 16–29

Other respondents made reference to this potential risk unknowingly, and once as an argument against the risk posed by cousin marriages, as disabilities existed in the family of a couple who were not cousins, but when further probed belonged to the same *biraderi*. While belonging to the same *biraderi* may not necessarily have been the cause of disabilities in that family, endogamy has been reported to have an impact on genetic risk within a

community (Bittles 2012; Hamamy et al. 2011). However, most participants did not feel there was any health risk associated with marrying within the *biraderi* as opposed to cousin marriages, where only a few respondents felt the potential of risk.

My other *mamu* (maternal uncle) who is married outside the family and he has a physically disabled son. And my father's brother married outside the family has a physically disabled daughter.

Is it the same *biraderi*? (question from researcher)

Still Rajput but not very close.—Semra, non-consanguineous women, 30–49 FGD

But I never thought that that would have an impact on things like genetics. Like the whole *Malik Chaudhri* thing. What my parents told me is, it's (the *biraderi* names, titles) like to do with the jobs you do in Pakistan, from ages ago. It was classed that *Maliks* do this and others do that.—Nazish, non-consanguineous women, 16–29 FGD

Disputing the evidence

Majority of the participants, regardless of age, gender or whether they were in a consanguineous marriage or not, disputed the evidence of the link between consanguineous marriages and genetic risk. The focus of the discussion around this point were that stillbirths, infant deaths and disabilities were not specific to the Pakistani/Kashmiri ethnic group and existed within “White people” who did not marry relatives as the following extracts from discussions highlight;

White people do not marry in cousins and Muslims do. So first thing (they say) is that these disabilities are more in Muslims maybe it's because of first cousin marriages, so why are the kids of white people disabled? They aren't marrying in cousins.—Tahira, non-consanguineous women, 50+ FGD

It (disabilities) isn't because of cousin marriages; it can be like that anyway. Because there is so many, more of the English people, they have disabled kids and they don't marry cousins.—Ikram, non-consanguineous men, 16–29 FGD

This is one of the big debates, why are there millions of marriages that are outside, why are more people disabled in that sense? Why are there more disabled babies in outside marriages than cousin marriages? When you go to such places (disability centres), there's (not) only kids who's from cousin marriages. Why are there a whole set of ones from outside marriages? Why are they all disabled?—Sabeen, consanguineous female, 16–29 IDI

Furthermore, some of the respondents stated that there was little or no history of any issues in their own families even though most of them were married to their cousins.

She (his wife) said doctors mentioned this as well that you are married in cousins, first cousins and it could be dangerous you know. What's the danger? We have four kids now and my brother has 6 and then he got married again and he got another 4, (that's) 10 kids altogether (with no problems).—Imtiaz, consanguineous male, 30–49 IDI

I don't think there is anything conclusive that proves that marrying your first cousins is going to result in your kids being disabled. I mean my parents are first cousins, *alhamdulillah* (thank God) none of us are disabled. Yet, there's another member of our family who's married outside the family and she's got disabled kids.—Zain, non-consanguineous men, 30–49 FGD

These participants' take on presence of disabilities in other ethnic groups who do not marry within cousins has been countered by the service providers in Luton (Ajaz 2013) as the community simply not understanding the nature of the disabilities and the true cause behind different medical conditions. In fact, some participants completely denied any negative health effects of consanguineous marriages and also suggested that it could not be proven.

It's nothing wrong in it (cousin marriages). You are married with a cousin or not, it doesn't matter, but things that people say, that diseases are spread and all, in my opinion it doesn't happen.—Nargis, non-consanguineous women, 30–49 FGD

You can't prove it, that's the thing.—Abid, non-consanguineous men, 16–29 FGD

I think two years ago, there was an article in a local paper or something and it said in a year there's like a 100 something marriages in Luton that are forced, but they made that figure up. So obviously as a reader, I believed it. (But) I went to a conference where they had councillor Kurban Hussain, he pointed out to them, prove it, where do you get the figure? And they couldn't. And they made them apologise.—Asif, non-consanguineous men, 16–29 FGD

The responses from the lay community show that the reasons why some participants dispute the existing literature on possible links of consanguinity to genetic disorders lies in their limited and varied of understanding of genetics, their own observations of family histories, as well as a distrust of official reports presented on the matter based on prior experiences with media reports that may have been misleading. This does not however equate to denial of facts, as was suggested by Soha, as most participants have

explained their own reasons for doubting the evidence rather than a simple denial.

Perhaps there was another reason for the lack of belief in evidence linking genetic disorders to cousin marriages, as Laiba noted post-interview that she believes that people like to hide these disabilities, so as not to be stigmatised. When participants were asked about the possibility that perhaps the disabilities were not seen in other family members married into cousins was due to matters of confidentiality, the majority dismissed this idea. However, Adeel, 31, talked about how he was unsure of the exact nature and progression of his cousin and brother-in-law's genetic condition because they wished not to discuss it with anyone.

He never tells (us about his condition). Especially within the family, he never gives you the full picture. He just hints you here or there. To us, he doesn't tell us anything. The doctor can't either. So, we don't know really about him.—Adeel, consanguineous male, 30–49 IDI

Another participant, Imtiaz, 32, had mentioned during his interview that there was no history of disabilities or genetic disorders in his family; however, after the interview he stated that he in fact had a daughter who had a hearing problem from birth. It is possible that Imtiaz did not mention this during the interview for fear of stigmatisation, it may have been because of his perception of disability, but this could not be explored further as the participant was hesitant to continue the discussion.

Culturally sensitive information and services

Even though participants doubted the evidence linking adverse health effects with consanguineous marriages and were possibly hesitant to discuss existing disabilities within the community, they were very open to receiving more information about the potential risks of genetic disorders possibly related to cousin marriages and also about the health care services that are available currently to the community.

I think they need to be informed of the risk more. [Others agree] Definitely families of Southern Asian communities need to be informed of the risk that this carries, which I think they're not really subject to (currently). But they should be.—Faiza, non-consanguineous women, 16–29 FGD

Some participants also called for even more services to be made available for the community, both to encourage them to use health services more and also to improve research and the level of services available to deal with any potential issues with cousin marriages.

Things like free services. Like they get a free blood test or something. People will get off their couch (then) if they absolutely must get something done.—Taimur, non-consanguineous men, 30–49 FGD

I think there should be more research, definitely. They need to bring it out and they need to talk about it. They need to be very careful what they say, in front of the media. Keeping in mind that there are people out there who might just dismiss it because of how you put it in front of them.—Adeel, consanguineous male, 30–49 IDI

As the above participant response signifies, the community participants emphasised how any promotion or new services programmes should be delivered in a culturally sensitive manner, with an understanding of the importance of cousin marriages to the community. The importance of delivering culturally competent service in this regard is amplified by earlier responses of the community members where they showed doubts about studies and services, seeing them as an attempt to curb cousin marriages and the growth of the Muslim community.

If it's delivered in the right context. If it's done in a negative way, like don't get married to cousins, then people won't take that.—Zain, non-consanguineous men, 30–49 FGD

Some participants felt that this information was best delivered either by the religious leaders or in conjunction with them and discussions with the community, which again signifies the hesitation some in the community have towards the motives behind the evidence that is presented to them when it comes to cousin marriages.

It's better if community organises as we understand and get better things.—Yunus, consanguineous male, 50+ FGD

Yes, but there has to be consultation. Like in mosques, people who are in charge, there should be a consultation through them. Like if the government wants to take an initiative then they need to involve these people. Like you have explained it and if they are explained in a good way (too) then they can help as they have influence in the community.—Nargis, non-consanguineous women, 30–49 FGD

Discussion

The findings from the research highlight that regardless of personal experience of stillbirths, infant deaths or genetic disorders, there is a varied and mostly limited understanding of

genetics and genetic risk within the Pakistani/Kashmiri participants that took part in our focus group and interview discussions. For the majority of participants, genetic risk was related to inheriting “bad blood”, this finding is similar to other studies that also highlight a poor understanding of genetic risk related to consanguineous marriages amongst the Pakistani/Kashmiri community (Ali et al. 2008; Shaw and Hurst 2008). It is important to highlight that limited understanding of genetic risk is not specific to the Pakistani/Kashmiri community. Research with other ethnic groups has also identified poor genetic literacy (Chapple et al. 1995; Walter et al. 2004). However, it was of note that participants who had had previous contact with genetic specialists for treatment and/or counselling related to their children with genetic conditions also had limited knowledge, to the extent that one claimed to have never heard the word. They could not recall ever seeing a genetic counsellor, even though almost all patients (or parents of patients) that are diagnosed with a genetic disorder are offered genetic counselling in Luton. These responses show that the messages from health service providers are possibly not being absorbed.

The limited information the participants did have was varied and came possibly from a one-time discussion with their GP, or unspecified news reports or through programmes on television, in particular a then recently aired documentary titled “When Cousins Marry” on the Channel 4 series Dispatches (Rastogi 2010). Participants felt that this documentary and other media presented a negative view of cousin marriages highlighting the negative health outcomes associated with consanguinity and singling out the Pakistanis in the UK. Our findings highlight that participants feel consanguineous marriages are being pathologised and this may act as a barrier to acknowledging key messages about cousin marriages and genetic risk (Ahmad and Bradby 2007; Ali et al. 2012). Focusing solely on cousin marriage has also meant that the community possibly do not understand the underlying impact of endogamy within the Pakistani/Kashmiri population, who have a preference to marry within a kinship group or *biraderi* when and if a suitable cousin is not available (Ajaz 2013; Darr and Modell 1988; Tovey et al. 2005). This added complexity of consanguineous marriages as well as endogamous marriages possibly increases the risk of genetic disorders and infant mortality within the community as a whole (Bittles 2013).

Findings from this study corroborate existing research which highlight that the presentation of genetic risk that singles out a particular community, in this case the Pakistani/Kashmiris, also simply alienates them and results in the community refuting findings from studies that associate consanguineous marriages with negative health outcomes (Ali et al. 2012; Atkin et al. 1998). The participants explained their opposition to statistics on genetic risk related to consanguinity is based on the prevalence of disabilities amongst other ethnic

groups that do not marry within cousins. This highlights some misunderstanding about genetic disorders and the risks associated with consanguinity, which is associated with higher incidence of autosomal recessive disorders (Hoodfar and Teebi 1996; Woods et al. 2006). Certain severe autosomal recessive disorders may lead to death before birth or very early after birth (Bittles 2012; Sørbye et al. 2014; Stoltenberg et al. 1999), hence possibly never getting to an age where the children may become visible to the community in disability centres or hospitals. Another reason for being sceptical about the evidence on consanguineous marriages and genetic risk, as suggested from the participant responses, is the stigma associated with genetic conditions related to cousin marriage may force consanguineous couples to either refute genetic information or not relay the information to immediate family and the wider community (Bywaters et al. 2003; Croot et al. 2008; Paul and Spencer 2008; Shaw and Hurst 2009) thus preventing dissemination of information on genetic risk related to consanguinity, a fact corroborated by the local genetic counsellor serving the area (Ajaz 2013). This would appear to be different from the findings in areas like Bradford and Birmingham, where genetic risk information is being discussed in communities through familial network and has been successful in dissemination of this knowledge (Darr et al. 2013). The opposition in Luton is based on the fact that the discussion of genetic risk and consanguinity is in its infancy. Such an opposition, as illustrated by participants in this study, can have implications on service uptake and may require a more nuanced approach to service delivery, one which is not only inclusive and culturally sensitive but also relevant to the local context. The lessons learnt from Bradford and Birmingham will need to be applied to the Luton context and continue the successes of these strategies.

While the Pakistani/Kashmiri community in Luton is similar to that of Bradford and Birmingham, there has been little awareness and limited research on genetic risks associated with consanguineous marriages. The impact of local social determinants that may play a role in increasing health inequalities, including a bearing on infant mortality and stillbirth rates (Guildea et al. 2001; Olsen and Madsen 1999; Wagstaff 2000; Weightman et al. 2012), remains unexplored to date. As the discussions on consanguinity and genetic risk in Luton are just evolving, it is unclear yet if a wide ranging community approach or a more targeted family approach to promoting health information on genetic risk (Darr et al. 2013) will be successful. The situation in Luton calls for community engagement and increasing awareness on genetic risk and consanguinity in conjunction with local health care service providers and religious leaders. Towards this objective, and using evidence of good practice from other areas of the UK with

consanguineous communities (Ali et al. 2008, 2012; Darr et al. 2013; Salway et al. 2012; Shaw and Hurst 2009), work is already underway to address increasing rates of infant deaths and genetic disorders. The aim is to ensure that consanguineous couples can make informed pregnancy choices through delivery of culturally appropriate services (Hussein et al. 2014; Kohn-Wood and Hooper 2014).

Conclusion

This study is the first to examine Luton Pakistani/Kashmiri community views on the adverse health effects associated with consanguineous marriages. Findings from our focus group and interview discussions add to the existing literature. Although research on this area is further developed in other areas of large Pakistani/Kashmiri settlement, the work in Luton addressing the issue of consanguineous marriages and genetic risk is still in its infancy. Consequently, it is unclear if a community approach or a more targeted family approach to promoting health information on genetic risk, which is being contemplated in those other areas like Bradford and Birmingham, will succeed immediately in Luton and other similar areas, where there has been limited previous research. Initial steps in addressing this gap are to engage the community and co-construct a locally relevant and culturally appropriate genetic service and information campaign. Our findings can be used to add to the local commitment to address higher rates of infant mortality and genetic disorders in Luton through a partnership approach, improve upon current services and develop culturally appropriate services, and serve as a template for introducing such services in other areas with highly consanguineous population sub-groups, where there has been little previous research looking into the impacts of consanguinity.

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Compliance with ethics guidelines

Conflict of interest Mubasshir Ajaz, Nasreen Ali and Gurch Randhawa declare that they have no conflict of interest.

Ethics All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study. Ethical approval for this study was received from University of Bedfordshire Institute for Health Research Ethics Committee.

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