Keeping it in the Family: A Two-Part Exploration of Views on Cousin Marriages and Genetic Counselling

by

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Author's Declaration

This thesis consists of material all of which I authored or co-authored: see Statement of Contributions included in the thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Statement of Contributions

Sultan Abdulkarim was the sole author for Chapters 1, 2, 5, and 6, which were written under the supervision of Dr. Samantha Meyer and were not written for publication.

This thesis consists in part of two manuscripts written for publication and currently under review by two journals. Exceptions to sole authorship of material are as follows:

Research presented in Chapter 3:

Sultan Abdulkarim: Conceptualization; developed search strategies; gathered the literature; screened literature; extracted data from literature; wrote and edited all drafts of manuscript.

Saba Soltani: Reviewed the literature as a screener; critically revised methods section to affirm accuracy of how screening process occurred.

Samantha Meyer: Conceptualization; provided feedback, edited, and looked through all drafts.

Jackie Stapleton's guidance was essential to developing search strategies.

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Research presented in Chapter 4:

Sultan Abdulkarim: Conceptualization; conducted initial search from social media; designed search strategies; scraped for all data used; analysed data; wrote and edited all drafts of manuscript.

Warren Dodd: Conceptualization; critically revised paper; provided feedback

Seçil Dağtaş: Conceptualization; critically revised paper; provided feedback

Samantha Meyer: Conceptualization; provided feedback, edited, and looked through all drafts.

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Abstract

A consanguineous marriage occurs between two people of close genetic descent. This practice is particularly common among Muslims in the form of cousin marriages, though it has historically taken place in many different communities, and in some cases, it still prevails in non-Muslim contexts. Though they take place among Muslims, there is no real religious basis for the practice; it is driven by social and cultural factors, as well as potentially misconstrued ideas of what the faith of Islam promotes. Reasons for practice vary across communities, with some specifying family ties, wealth, and ease of marriage.

The ancestral closeness between cousins in marriages has been associated with increased likelihood for offspring to develop diabetes, blood disorders, and other conditions. Hence, there is potential for medical harm to occur to children conceived in this partnership. Genetic counselling is a process whereby a couple is screened to assess the risk to any potential offspring. Reception to this process has been mostly positive, though with some caveats; studies have shown that there may lie the belief that whatever happens to offspring is at the will of a greater power, or that people are fearful of stigma or judgment, among other reasons for aversion to any part of the genetic counselling process.

The present work has two key aims and corresponding studies; a scoping review and qualitative analysis of views related to cousin marriages located on Reddit. First, given the social and cultural importance of cousin marriages and use of genetic counselling, study 1 is a scoping review conceived and carried out to determine the current research landscape for perspectives on genetic counselling for consanguinity. Following Arksey and O'Malley's framework for scoping reviews, over 1300 articles were screened, ultimately leading to the extraction of data from 44

articles. Education, religion, and gender were found to be correlated with perspectives on genetic counselling for consanguinity. Furthermore, research gaps were identified: The vast majority of studies were quantitative in nature with very few being qualitative, leaving a gap in methodology and need to understand differences in perspectives. Locations of studies were mostly regionally focused to Muslim majority countries, leaving a gap related to geographic area and the practice of Muslims in non-majority countries where cultural norms may differ. Finally, only one paper incorporated theory in its explanation of perspectives, creating an opportunity to outline findings in relation to existing theoretical frameworks.

To address these gaps, a social media-based qualitative study was devised (study 2). The primary aim of this study was to analyse how people discuss cousin marriages and genetic counselling and inform how awareness of genetic counselling practices can be promoted for cousin marriages, enabling couples who are cousins to make educated choices about conception of children. Basing the study in social media allows for potentially varied perspectives from Muslims around the world rather than a small concentration of countries, and to get an understanding of the drivers of perspectives around genetic counselling for consanguinity, briefly drawing on relevant theory at a structural level to explain some findings (i.e. medicalization). The study involved scraping data from Reddit using the following subreddits: r/MuslimNikah, r/MuslimLounge, r/MuslimMarriage, r/Islam, r/Progressive_islam, and r/Islam_ahmadiyya. After data collection, the collected posts (and respective comments) were manually screened for relevance to addressing the study aim. Data were then analysed inductively using discourse analysis. Discourse analysis tends to be particularly focused on wording, arguments, and phrasing, so applying it in this case aided highlighting users' discussion points surrounding cousin marriages and genetic counselling,

aligning with the aim of the project. The results illustrate that while some users were against the practice of cousin marriages (i.e. expressing that practicers were akin to gamblers and irresponsible), those who were supportive of its practice or practitioners of it themselves cited dichotomies between religion and science, as well as fears of stigma towards their perspectives on cousin marriages. Those against cousin marriage cited comparisons between practicing cousin marriage and being 'anti-science'. This shows the diversity in perspectives and underscores why further education and genetic counselling promotion is needed.

The data can be used to inform future efforts to tailor promotion awareness and education surrounding genetic counselling in ways that appeal to those who may not see the use of it or disagree with it due to cultural or religious beliefs. When aiming for behaviour change, there can be tensions between drivers of that change (i.e. health promotion) and factors such as ideology, religion, and culture. The data contain several examples of the way people think of such factors (i.e. equating scientific concern with being anti-God), and this can be of service in sensitive promotion of genetic counselling awareness.

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I would also like to thank Saba Soltani for her help in screening articles for Paper 1 of this thesis, as well as Jackie Stapleton's in developing search strategies.

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Dedication

This thesis is dedicated to my mother, my father, and my sisters.

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Statement of Positionality

It is important to note my positionality in relation to cousin marriages. As someone who was raised as a Muslim in an Islamic society, I understand the commonness and even importance of cousin marriages within Muslim circles. My perspective is that as long as genetic counselling is sought after, which is already mandatory in various Muslim countries, then cousin marriages are a private matter that should not be interfered in. On the other hand, as a scientist, I do believe in the efficacy of genetic testing and I view it as a necessary step in the procession of a cousin marriage, and I believe that questions surrounding safety to offspring should be asked as it is in the benefit of both the couple and their children. Hence, I have my own understanding of these topics. The data collection process of this study included manual screening and coding text through discourse analysis. For manual screening, to mitigate my preconceived notions surrounding cousin marriages and genetic counselling, I made sure to include text regardless of whether I found it to be antithetical to my beliefs or even worded offensively, as long as it aligned with inclusion criteria. In discourse analysis, I focused on wordings and phrases used, with brief interpretation being used to describe the perspectives gleaned from the data. This way, in both cases of the manual screening and discourse analysis, focus was placed more so on the data than my own notions. As a researcher, I take a constructivist approach to my investigations, and that affected the conception of this work by making the focus of it be on people's statements and how they create meaning through discourse on cousin marriages and genetic testing.

Chapter 1. Introduction

Project Overview

An inevitable risk in the conception of any offspring is the chance for harmful genetic effects to occur (1). This risk becomes even greater when people of close genetic descent procreate with each other, thus leading to potentially even more dangerous consequences to their offspring (2). This type of coupling, typically termed consanguinity, may occur in various parts of the world (2). Consanguinity is increasingly recognised within the context of cousin marriages (3) more so than any other type of relationship between people of close genetic descent. This procreation has been reported to amplify the risk of genetic complications in offspring by approximately double the percentage relative to offspring from couples not of cousin/close descent (3). Cousin marriages (or consanguineous unions) are typically associated with Muslims relative to other communities (4), and reasons for its practice among Muslims range from maintaining generational wealth to keeping family ties secure (5). Hence, though the practice of cousin marriages does carry risk to offspring, there are cultural, social, and even religious reasons among Muslims that can influence people's actions surrounding cousin marriages. In turn, this can impact how Muslims perceive genetic testing as a buffer for cousin marriages to help determine risk to offspring. It is important to not only acknowledge the social reasons for undertaking this behaviour, but also to delineate the cultural drivers behind it. This delineation may also aid in the contextualization of information such as global consanguinity rates, associated complications of consanguinity, and the relevance of the role that genetic counselling plays in the aiding of cousin couples. The overall aim of this project is to examine how Muslims view cousin marriages and genetic counselling within the context of cousin marriages by reviewing the available literature on perspectives towards genetic

counselling and analysing online discourse surrounding cousin marriages and genetic counselling among Muslims specifically.

How Different Cultures Practice Cousin Marriages

Though the population of focus for this work is Muslims, the practice is prominent among other populations. Consanguinity is a longstanding practice, going as far back as Ancient Greece, where cousin marriages took place to maintain a family's status (6). In addition, cousin marriages have taken place in Amish communities, where it has been detected that consanguinity's practice has both been a driver of natural consequences, such as greater child mortality risk, while also being borne out of certain social drivers (7). Similarly, consanguinity has been found in India among non-Muslim populations, with a study even highlighting that factors such as residing in rural locations, being part of a wealthier bracket, and being of the Hindu faith were strongly associated with the practice of consanguinity (8). When it comes to Hindus specifically, there can be varying degrees of consanguineous unions (9): For instance, Hindus located in the northern part of India do not allow such unions, and they even limit unions between blood relatives by generations, namely five generations for women and seven generations for men (9). Those in the southern part of India, however, not only practice cousin marriages but also encourage unions between uncles and nieces (9). Finally, it has been found that consanguinity exists among Jewish people in Israel, though it is usually among recent immigrants and orthodox people of the faith who practice it (10).

It is important to note that cousin marriages themselves can vary, namely in the types of cousin marriages that can occur. For instance, outside of Islam, tribes in Australia have been found to practice three types of cousin marriages (11): Firstly, there is a cross-cousin type referred to as

‘Kariera’, whereby if a man’s sister is married to the mother’s brother’s daughter and her husband has a sister, the man marries the husband’s sister (11), in a way that creates an exchange of people for marriage. Secondly, there is another cross-cousin type, whereby the man marries the daughter of his father’s sister, called ‘Trobriand’ (11). Finally, there is a type called ‘Kachin’ where a man marries the daughter of his mother’s brother (11). There is a similar type to the latter that takes place in South India as well (11). In addition, among Arab communities, a similar (though not same) patrilineal type of cousin marriage to ‘Trobriand,’ is practiced, whereby the paternal uncle’s daughter is married, typically referred to as ‘parallel’ cousin marriage (12). This has been said to be preferred by Arab communities due to the notion of ‘honour’ being maintained (13), but also particularly due to historical unrest with battles across the areas (14); throughout time, there would be occasions where communities would be robbed and members would be taken, which led to the fracture of families. It has been stated that families based on cousin marriages (more specifically, parallel cousin marriages) fared better than other families due to their unity and the growing collaboration between family members (14). This same type of union is preferred across Afghan communities as well (14). In China, consanguineous families exist, albeit with some limits: It is generally preferred for marrying a father’s sister’s daughter, a mothers brother’s daughter, or a mother’s sister’s daughter, with marrying a father’s brother’s daughter being generally looked down upon (14). This is because in the case of a mother’s brother’s daughter, for instance, the marriage can strengthen ties with a separate family (albeit still linked) due to the family (the mother’s sister) being in a different house (14). In this sense, it is regarded as ‘pointless’ for one to marry a father’s brother’s daughter (14). Somewhat similarly, it is preferred in India that a cross-cousin marriage occurs, namely in that a mother’s brother’s daughter or a

father's sister's daughter is married to the male son of any given couple (14). The way in which cousin marriages work in India has been said to be influenced by linguistic factors; specifically, the father's brother's daughter or the mother's sister's daughter can considered one's sisters by virtue of the wording used to refer to them (the word used for them in several Indian languages often equates to them being a sister), so marrying them could be seen as a form of incest (14). However, when it comes to the Arabic language, the offspring of a parent's siblings are all deemed cousins linguistically, so there is no equation to incest (14). Among cousin marriages within South Indian Tamil communities, there tends to be more of a patrilineal kinship system, much like Arabs (15). However, matrilineal ties remain an important part of how familial systems work (15). In addition, those living in their home villages were more likely to engage in consanguinity (15). In Sudan, Christian communities prefer parallel cousin marriages whereby a mother's sister's daughter is married to the mother's son, while Muslim communities also prefer parallel cousin marriages, albeit ones where a father's brother's daughter is married to the father's son (14). This is correlated with more matrilineal and patrilineal proclivities among the communities, respectively (14). In Mayan culture, if two siblings of the same gender have offspring, then the offspring are considered siblings between each other as well, thus making any marriage between them incestuous and undesired; however, if two siblings of different genders have offspring, then it is deemed to be acceptable for the offspring to marry (16).

There have also historically been cousin marriages in the Netherlands, which took place for a variety of reasons (17): Based on historical data on cousin marriages, it has been determined that a reason for their occurrence was to maintain equal ties within one's social class and to maintain social standing, rather than potentially lowering it by marrying outside of the family (17). The

population was (and is) primarily a Christian one, and another reason for the occurrence of cousin marriages was that Protestants who had left the central church at the time wanted to maintain ties together, thus leaning on cousin marriages to ensure those communal connections were fixed (17). Being remote from other communities was also cited as a reason for cousin marriages, since geographical location had an impact on which types of kinship could be made (i.e. exogamous) (17). Other factors that impacted the incidence of cousin marriages included both members of a marriage being born in the same location, as well as being in rural communities (17).

A separate community where cousin marriages are common is that of Mennonites (18); Historically, they have been an isolated group, mainly due to their strong community ties and values. They typically live in small communities and when marriages take place in those communities, it is difficult to avoid marrying someone who is a cousin, which typically takes place due to the community size (18). Smaller groups may be created due to resulting population growth, leading to more communities with cousin marriages (18).

Similar to the Mennonites and the Amish is a group referred to as 'Hutterites,' who also live in isolated communities and practice consanguinity due to said isolation, in addition to a small population size (9). Some Indigenous communities across the United States and Canada have also been known to engage in consanguinity, such as Cree and Lumbee groups (9).

The focus of the present study is Muslim communities, though as demonstrated above, consanguinity is not something inherently Muslim so as not to misinform or mislead the public on what consanguinity is and how (and who) practices it. In fact, reasons and factors affecting cousin marriage practice may even differ between Muslim countries or communities. In Qatar,

much like Pakistan, there is a belief among people that consanguineous marriages end up strengthening family ties and that they ensure the safety of daughters (19). In addition, people whose offspring had genetic deficiencies (or people when asked in general) tended to attribute deficiencies in children to the 'will of a higher power' rather than to the consanguinity itself, thus separating the closeness of a relationship from the consequences to offspring (19).

Apart from Pakistani people, the majority of sampled Muslim Nepali women cited that their main reason for entering a cousin marriage was culture, with economic reasons, familial stress on the issue, and ease following (9). In addition, reasons cited among those in Bangladesh included maintenance of wealth, improvements of familial relations, and lower dowry payments (9), with there being an association between smaller dowry transfers and consanguinity (20). When it comes to wealth in particular and Arab Muslims, a level of prestige may be attached to historically long-lasting communities, thus those of 'higher status' are de facto barred from marrying anyone not within this same status (21). In Oman, factors such as the age of the woman when she got married, regional location, and employment status were associated with consanguinity (22), in addition to favouring a bigger family (23). Furthermore, in Turkey, it has been found that having lower educational levels, lower socioeconomic status, and lower age at marriage was correlated with consanguinity (24).

Cultural Drivers of Cousin Marriage Among Muslims

As noted above, given the association with Muslims, it may be assumed that cousin marriages are an inherent part of Islam. However, this is not particularly the case, and this assertion has been disputed academically. More specifically, it has been stipulated that there is no evidence in the holy book of Islam (the Quran) that supports the idea that cousins should get married at all (25).

On the contrary, there exists some Islamic text that actively opposes the idea of cousin marriages; for instance, there is a hadith (meaning statement by the prophet of Islam) that says the product of a cousin marriage may be differently abled upon birth (25). Hence, there isn't necessarily any concrete evidence to support the idea that cousin marriages have some sort of religious basis among Muslims, such as being written in the Quran. No basis can be found in Islamic history, as well; specifically, among all the important figures in Islam, the vast majority were in marriages with unrelated people, while only one figure married their first cousin and another married their second cousin (25). However, there is still a social culture that promotes the practice. For instance, in Iran one may find a popular saying referring to how 'the marriage between two first cousins is set in paradise'; this demonstrates the value in which some may find cousin marriages, regardless of whether there is a textual basis for them (25). In addition, it implies a religious association that's born out of culture, particularly because there is a reference to heaven, thus making the claim about cousin marriages based in religion as much as it is in culture. Hence, while cousin marriages are culturally based, this does not mean that people cannot misconstrue the basis of cousin marriages and believe that they are in any way informed by religion. Interestingly, a religious and historical connection that could be made to the practice is that the Prophet betrothed his daughter to her first cousin. However, this has not been a reason cited by Muslims who engage in cousin marriages (5). In addition, though it could be assumed that any cultural encouragement of cousin marriages would have progressively diminished due to education and reforms throughout history - for example, due to further understanding of the potential genetic complications associated with these unions, which has been demonstrated to be the case in countries such as Bahrain where education surrounding cousin marriages has decreased rates

overtime (26) - the opposite has been found to be the case in some cases. Rather, in regions such as Iran and Pakistan, consanguinity rates have been reported to be over half of marriages (27). In Iran alone, three generations of marriages were investigated only to find that the most recent generation had even more cousin marriages than the previous ones (27). This demonstrates that the practice of consanguinity is one that is potentially resistant to temporal and generational changes, highlighting its deep roots in culture that make it perseverant.

The reasons for a consanguineous marriage's occurrence may vary depending even on one's Islamic cultural background. For instance, in Pakistan, some groups engage in cousin marriages because they believe they are direct descendants of the Prophet of Islam, thus employing the practice to keep those ties to the Prophet 'untouched' (5). A 1999 study in Pakistan centred around reasons for consanguinity found that people's justifications were all based in culture and not religion; it was stated by participants that it was simply a tradition that has been maintained for time's sake, and that people engage in it to maintain strong family ties (5). Interestingly, another reason brought up was that of the dowry, in that marrying a cousin implies that due to family ties, there are not expected to be any issues about the amount of a dowry or any perceived shortcomings in the transference of it (5). Hence, there are also monetary factors to consider in why cousin marriages may occur. Some of the reasons can be deeply social; For instance, it has been cited that among certain groups in Pakistan, a reason to prefer a cousin marriage was that a marriage with an outside member could be perceived as there being something wrong with the person that may have affected their chances of a marriage within their own family, leading them to look elsewhere (5). So, a reason for cousin marriages' occurrence could be to maintain an image to the public. Some cited in-laws' familiarity with those getting married as being the

propagator of an ‘easier’ marriage, thus smoothing things out for the families rather than having to concede to a different, new family (5). Finally, another stated reason was that cousin marriages lead to less of a dependence on the appearance of the bride to determine marriage suitability, a fear that is mainly informed by cultural expectations in Pakistan for the bride to be of a ‘light-skinned tone,’ which is typically equated to beauty across the culture (5). Hence, while reasons for consanguineous marriages are cultural in nature, there can be a wide variety of different cultural reasons for why people may choose to engage them. Another reason that has been stipulated is that consanguinity is related to the economy of Pakistan, namely in that its stagnation may lead to a stronger desire to maintain community ties (28). While this specific study focused on Pakistan, there may be different reasons in different regions of the world. Generally, the notion of family support being a motivation for cousin marriages has been demonstrated in research (14). Research has also shown that lower socioeconomic status is associated with consanguinity, which makes it so that mortality is correlated with consanguinity, particularly when it comes to being prone to disease (14) due to socioeconomic status. For instance, a family with lower socioeconomic status may not be able to secure an exogamous marriage due to other families not wanting to marry into said status, hence making it easier for certain families to turn to cousin marriages (14). In turn, the close genetic nature of offspring could lead to further protection from infectious disease, leading to a form of ‘benefit’ from consanguinity (14,29).

It should be noted that there can be patriarchal contexts in the occurrence of cousin marriages, namely in how it can be used to ensure the patrilineage is carried on (30), effectively leading to women being used to maintain the lineage of the man they are betrothed to; It has been cited that women used in this way are typically viewed as inferior to men, and are inherently objectified

in the process (30). Some cousin marriages are entirely up to the parents of a woman (typically the father due to a patriarchal familial structure, as well as societal structure), and some of those marriages occur when a woman is still a child – she may be arranged into a marriage as a minor without regard to local laws and also to the age (30). Even as adults, there is not necessarily a regard for the age difference between the members of a consanguineous couple; the male cousin could be much older than the woman, and vice versa (30). The same goes for education, in that educational differences are not accounted for in a match between cousins (30). It has also been found that land is an incentive in cousin marriages, mainly in that it is to help maintain the wealth of the family as a whole, much like the economic reasons found in previously mentioned studies (5,17). This is especially important when a family would not have much to give as a dowry for an outside marriage, which further incentivizes both the family and the women getting married into a cousin marriage (30). The notion of wealth being an important factor in cousin marriages is especially the case in daughters being married off to cousins due to Islamic law; typically, any wealth owed to the daughter by inheritance is split with her husband, and it is regarded as better to marry someone already in the family to maintain that wealth rather than split it with an outsider (31). In some groups, it may be looked down upon to marry outside of the family, leading to a cloud of shame upon families that choose an exogamous marriage (30).

Views on and reasons for cousin marriages become more nuanced when practitioners of it are in Western societies. For instance, a study of kinship dynamics among British Pakistanis highlighted a cognitive dissonance between one's cultural upbringing and their surrounding community (32). For instance, it was cited that a British Pakistani father discussed how, in organising marriages for children, he faced a mismatch between his feeling that he is 'open' to the idea of marrying them

off to people outside of family and his innate feeling that keeping the ties within the family would be better than his children marrying an outsider (32). In addition, people can be selective about which cousin they marry depending on geographical location (32). In the aforementioned study, a participant discussed how they did not feel inclined to marry their British Pakistani cousin due to having been raised together and regarding them as a brother (32). Rather, they were more open to marrying a cousin from Pakistan to both guarantee familial acceptance of the marriage as well as to create both a physical and emotional distance between the two people that can potentially make the idea of a cousin marriage seem more personally tolerable (32). A potentially desired form of cross-cousin marriage is that of 'watta-satta', which involves an exchange of people (i.e. the husband's sister marrying the wife's brother and vice versa), intended to further maintain ties (32), much like the previously mentioned type referred to as 'Kariera' in Australian tribes (11). There tends to be quite a bit of discussion regarding how a marriage should be set up or how it should proceed (33); for instance, there can be negotiating regarding which son marries which type of cousin, namely as to whether the first son should marry the mother's brother's daughter or whether the second son should, with the other son marrying the father's sister's daughter and vice versa (33). While these marriages can be forced and patriarchal in nature, the culture among British Pakistanis can be quite different from this; more specifically, it could be that parents consider whether the cousins are a good match for each other rather than just saying they should get married because they are cousins, as well as whether their children even want to marry that specific person to begin with (33). Younger British Pakistanis have expressed support for the idea of marrying someone close to their family, and there is even a greater social culture surrounding a cousin marriage, whereby people speak about meeting their cousin spouse

through a lens of choice and romanticism rather than other practical viewpoints (33). Interestingly and opposite to British Pakistanis, consanguinity among Norwegian Pakistanis was found to be becoming lower in rate overtime, which has been attributed to being born and raised in Norway (33). However, when it comes to those who get into consanguineous unions, it has been linked to parents being in similar consanguineous marriages or being the types to make marital decisions for their children (33). Similar results were found in a study focused on Palestinians, where having parents in a consanguineous union made it less likely for people to reject the idea of consanguinity (34).

Global Knowledge and Rates of Consanguinity

Just as there is variety in the make-up of consanguineous marriages, differences can be found in the prevalence rates of consanguineous marriages on a global level; for instance, countries such as Kuwait, Saudi Arabia, Jordan, and Qatar have been reported to have consanguineous marriages across over half each of their populations (2), with Pakistan also having high rates. They are followed suit by countries such as Yemen, Oman, Tunisia, and Morocco, where the consanguinity rate is a third of the population at its lowest and half of the population at its maximum (2), which aligns with the notion that consanguinity is at relatively high rates in regions such as the MENA (Middle East and North Africa) region (35). The United Arab Emirates alone was reported to have a consanguineous marriage rate of over fifty percent as well (36), with marriage involving an educated husband being a factor. In Saudi Arabia, consanguinity is especially common among the daughters of a family, and there has not been a difference across generations for rates (37). In contrast, the country of Bahrain has displayed a decrease in consanguinity rates, from about a

quarter of the population to just above five percent, which has been attributed to education surrounding genetic consequences of marriages between first cousins (26).

Consanguinity's Associated Complications

Consanguinity has been associated with the development of multiple sclerosis and impeded educational development, but the central genetic impact is an increase in display of autosomal recessive disorders among those born out of consanguineous marriages (38–41). This is especially an issue across all regions that practice consanguinity, including the previously mentioned Arab countries, given their high rates of consanguinity, as well as the impact on mortality to offspring (42). Obesity and cardiovascular conditions have also been cited as potential consequences to the offspring of cousin marriages (43), along with sickle cell anaemia and thalassemia (44). Diabetes has also been cited as a major risk to offspring (45). Additionally, mental disorders (46) and deafness at birth (47) have been found to be associated with consanguinity. In Qatar, different immunodeficiencies have been found to be consequences of cousin marriages (48). In Saudi Arabia, blood disorders such as haemophilia have been cited as consequences to the offspring of cousin marriages (49).

Genetic Counselling Relevance

Given the many potential consequences to the offspring of consanguineous marriages as described above, there needs to be a scientific methodology or technology that has the power to identify such risks prior to a marriage; this is where genetic counselling (or testing) comes in, which is a process that helps identify risks to offspring in the case of two people procreating (50). In Western contexts, the conversation surrounding genetic counselling tends to be postnatal or during pregnancy, with a focus on evaluating genetics after conception (50). Within these

contexts, those within communities that particularly practice consanguinity (i.e. Hutterites, Amish, etc.) may elect to undergo a prenatal genetic counselling service to identify risks prior to conception (50). This is the same case in the MENA (Middle East and North Africa) region, where prenatal or preimplantation diagnosis is used to screen for the potential of illness in offspring of consanguineous unions (51). It has been encouraged to use this process to better educate consanguineous couples and provide them with the relevant prenatal knowledge they would need prior to conception (39). In Saudi Arabia, for instance, the process is accepted and widely used, with it being especially popular among couples who have already had a child with a genetic complication (51). The process itself is well-received by those in Saudi Arabia, Syria, Iran, and the emirate of Dubai, with it being required by law for all couples in Qatar since 2009 (51). This is not to say, however, that this has any bearing on whether people will heed the results of a genetic counselling session – all that is mandated is to undergo the process, not to halt any marriage or expect couples to not conceive children based on the results. There has been a call to explore and implement new technologies in the genetic counselling process that can help better identify genetic make-ups between consanguineous couples that can harm offspring (51), with reform calls going so far as to call for different ways to socially approach genetic counselling (52). For instance, a process focused on alerting extended family members as to their being carriers of genetic diseases that become more likely to be passed on in the event of a consanguineous union has been proposed, in the case one member of the family has been found to be a carrier (52). While genetic counselling is well-received in some countries (51), this is not a universal case; while some parents feel fearful of their sons and daughters marrying cousins due to the risk of genetic complications to the offspring, others may feel that the chance for a genetic complication is no

greater than in any other couple relative to a consanguineous couple (52). In addition, some may feel that their practices are being judged when a doctor says a cousin marriage is the reason for the disability, leading to feelings of alienation in the genetic counselling process (52). Some also feared stigma as a result of seeking genetic counselling, centrally because it would bring attention to their being in a cousin marriage (52). Despite these fears, many still saw the inherent value in the process, citing how it can help ensure couples as to what can happen with their offspring, or even confirm to couples that there is low risk (52). Given the stated fears, however, there has been a greater push to be sensitive in the dissemination of information during genetic counselling sessions by ensuring information is correct and plain, with proposals to engage consanguineous communities in knowledge sharing about genetic counselling being made (52).

Given the potential for varied responses to genetic counselling, the many complications that can occur from consanguineous marriages, and the sociocultural mechanisms behind how consanguineous marriages are carried out and perceived, it is clear that there is a need for more work as to people's viewpoints and thought processes with regards to genetic counselling and consanguinity. In addition, knowing these viewpoints can potentially provide some explanation as to why the practice remains high in some regions of the world (27). Considering that there were already existing studies within this space, it was important to establish a base from which to conduct a study, which is why a scoping review was conducted as Paper 1 of this thesis, which in turn informed the development of Paper 2, a Reddit-based qualitative study.

Methodological Reflections

In Paper 1, the scoping review, an initial inclusion criterion was that articles should not be about only second-cousins and that articles should centre first-cousin marriage. However, it was noticed

in the middle of screening that papers related to cousin marriage did not necessarily explicitly state which type of cousin marriage was focused on in studies, particularly in the abstract and sometimes even in full-text. Due to these papers typically being based in the MENA region, cousin marriage was likely treated as a given to be 'first-cousin marriage' or being inclusive of all types of cousin marriage, which is why inclusion criteria were changed to include papers that spoke of cousin marriage regardless of whether they specify first-cousin or not at both stages. To this effect, there is no differentiation between first-cousin and second-cousin marriage within the inclusion-exclusion criteria table located in Paper 1 for either stage. Ultimately, various articles that were included for extraction mentioned whether marriage was first-cousin only or a wider variety of types including first-cousin marriage. Despite restarting the abstract screening process, this likely impacted inter-rater reliability at the abstract stage. In addition, because of the requirement to look for genetic counselling perspectives within the context of consanguinity, it may have been difficult to distinguish between whether an article focused only on genetic counselling or genetic counselling within the context of consanguinity, particularly at the abstract stage. This also likely impacted inter-rater reliability at the abstract stage. However, this was addressed through discussion with the second screener, which helped mitigate further mismatches in the selection of articles. Meeting with the second screener and conducting trial screenings prior to both the abstract and full-text stage were essential in ensuring that we were on the same page about how to screen. Paper 2 was initially going to be a qualitative study with interviews; However, I pivoted from this direction due to being weary of the sensitivity of the topic, especially in that I could not assume that any people of the Muslim faith would be willing to discuss their perspectives on cousin marriages or associated genetic counselling. Canada is not

necessarily a country where this is widely spoken of, so it was reasonable to assume that people may not be open to talking about it, particularly within the context of being in a study where they may fear that their statements may be used against them. The direction I chose was ultimately to use social media, specifically Reddit, to gather the data for which I was looking. I made the pivot only after confirming data on Reddit were available by conducting searches using terms like 'cousin marriage' and 'genetic counselling' in the Reddit search bar. This search ended up showing me quite a few posts that would be eligible for inclusion in my study, and only then did I make the final decision to shift from interviews to Reddit data collection. I learned in my decision-making and thought process that before undertaking a search where I need to scrape social media, I should first confirm whether that data exist in social media to begin with. If I had proceeded with the study without first verifying data availability, then I would have wasted time that could have been spent on a more promising direction. It was important for me to be flexible in choosing the direction of my thesis because ultimately my goal, based upon the results of Paper 1, was to conduct a qualitative study, and I knew that qualitative data could be obtained through scraping social media due to my coursework experiences. There were certain limitations I had to consider, particularly with social media data ultimately being secondary, as I could not ask specific questions or probe into people's answers. However, the expansive nature of social media allows for a much wider variety of perspectives to be captured compared to what may be captured in an interview, especially when considering how people are more likely to provide unfiltered thoughts online relative to in-person or over a Teams call in front of a person. Hence, given these factors, the direction of social media was chosen, with Reddit specifically being chosen due to it having been used for other public health research (cited in Paper 2).

I used a Python-based scraper called PRAW to scrape data. In scraping of data for Paper 2, it was important to consider how to control the amount of data collected while also ensuring its relevance, particularly when considering that only one person would be screening the data. After my initial search using the Reddit search bar, I selected subreddits from which to collect data. The criteria for selecting subreddits was that they had to be Muslim-focused and that, from my initial search, they had to have more than one post come up. Subsequent to this, in each subreddit, I initially scraped posts by creating a list of keywords and having the search occur for each keyword. For instance, one search would occur for the word 'marry' in each subreddit and then 'cousin' in each subreddit. This was done for each keyword used. As a result, almost 130,000 posts and comments were scraped. This would have been impossible to manually screen for inclusion in my study, so I had to think of a way to limit the amount of data I collected while also ensuring data relevance. Based on comments provided by one of my committee members comparing this process to the process of a review paper, I recalled the types of search strategies that would be used for databases in collecting data for a scoping review. They would typically be combinations of words with 'AND' or 'OR' signifying which combinations of words to separate or keep together. This is called a Boolean search. I thought that using this search strategy would help in reducing the number of posts and comments collected because I could put in a combination of words rather than searching words individually. I ultimately decided on the following search string:

'cousin AND (marry OR marries OR nikah OR nikkah OR marriage)'.

This was because a big issue I faced with the previous search was that posts regarding cousins were being pulled, though without being about cousin marriage. In a similar sense, posts about marriage were being pulled, though without being about cousin marriage. Hence, ensuring that

each post contained both ‘cousin’ and a version of ‘marry’ made it so that only posts about cousin marriage (and their respective comments) were collected. Though a focus of this study was also on perspectives towards genetic counselling for cousin marriage, this was not included in the search string because any relevant data regarding genetic counselling would have to be in the context of cousin marriage. Hence, any relevant genetic counselling data would already emerge in the given search string. Using this search resulted in almost 30,000 posts and comments, a markedly lower amount than 130,000. This was much more manageable for manual screening.

Initially, the plan for analysis was to use thematic, narrative, and discourse analysis. This was to account for the varying types of data that may emerge given the diversity of social media discourse. However, after coding the data this way, I realized that all the coding I had done across all three analysis types ultimately referred to aspects such as word choice and language. This always fell under the umbrella of discourse analysis, after which I pivoted in the direction of analysis to be only discourse-focused. A benefit of doing so was to ensure that the analysis was focused enough for publication, and this was okay to do since it was a matter of reframing all non-discourse analysis codes to focus more on the facets of discourse analysis, particularly within the specific framework I had selected (Gee’s framework for discourse analysis, cited in Paper 2). In some cases, I labelled data by sourcing directly from people’s words, if they could be used in a way that could make sense for a label. In other cases, I labelled data with classifiers such as ‘conveying stigma’ based on things such as tone, whether people made statements that were targeted towards those in cousin marriages negatively, or other such indicators. The discourse analysis direction was also influenced by comments from a committee member and my supervisor-committee member, hence my methods and analysis were both supported by the

feedback of all my committee members. A significant lesson I learned throughout the conducting of this study is to seriously value the feedback of my mentors and to ensure that it is implemented duly in my work.

In Paper 2, it must be noted that despite every effort being made to ensure data were coded and included appropriately, my positionality as a Muslim researcher may have impacted the process of deciding which data were included after the completion of Reddit scraping. Though the data collected was from Muslim-focused subreddits, there were occasions where the data felt Islamophobic or inflammatory in a way that could potentially cause distress to me as the individual screening data. This could have inadvertently impacted what data were included in the study because I may have been inclined to discard all inflammatory texts due to their effects on me as the one screening. However, I felt no effect from reading any inflammatory texts that may have come up. I only had it as a strategy in mind to move away from the data for a brief period of time if I encountered anything distressing, after which I would return to manually screening it for inclusion in analysis. This strategy was kept in mind to ensure that all relevant data were retained, regardless of their inflammatory nature. Thankfully, it never needed to be used.

Coding for Paper 2 was markedly different than what would occur for other types of qualitive papers. Since this is a Reddit-based study, the way data appear is very different than data collected using other qualitative methods, such as an interview. Data appear as individual posts and comments, with series of them in threads. Coding was done post by post (or comment by comment) rather than line by line or with certain sections being coded. In cases where threads contained a post and a few comments that are quite short, the entire thread would be coded. Since people had the capacity to respond to others in ways that might be direct or targeted, seeing

threads of conversations provided me with a series of discussions or even dissent towards others' opinions in some cases, which was beneficial in the analysis of data. The type of discussions mimicked what would be in a focus group. Given that this study is focused on a culturally sensitive topic, and given my positionality as a researcher with shared cultural roots with the study, I wanted to create a balance between imposing my own interpretation of the data with also allowing the data to speak for themselves. Hence, the analysis section is written so that quotes are provided with brief interpretation of either an array of quotes or some specific quotes of interest. Quotes were selected based on the identified themes so as to ensure readers can note a match between the provided themes and their respective quotes.

Chapter 2. Study Rationale and Objectives

Paper 1. The Scoping Review

This paper is a scoping review that gathered peer-reviewed journal articles regarding perspectives on genetic counselling for consanguinity that were not population specific. Studies exist on the issue of perspectives towards consanguinity itself, particularly on the question of why a cousin marriage may be favoured (5), with similar studies existing for perspectives towards genetic counselling (52). Notably, however, both studies cited here are regarding Pakistanis specifically, with other studies being specifically focused on Qataris (19), Omanis (22), and more. Work on these topics is quite prevalent across Muslim countries, but it was important to establish a base from which to continue further research by identifying the current knowledge landscape globally and the research gaps that remain. Given the numerous locations in which studies have occurred (mostly Muslim-majority ones), the different populations assessed, and the varying methodologies used in these investigations, a review of the literature on perspectives on genetic counselling for consanguinity would consolidate this information and provide a base from which to carry out a study. The paper followed Arksey and O'Malley's framework for scoping reviews (53) and data was extracted from forty-four articles. The results of Paper 1 showed that education, religion, and gender were associated with genetic counselling perspectives, and that there was little-to-no use of a theoretical framework for investigating people's viewpoints. In addition, it found that the vast majority of studies were quantitative and regionally focused, with few qualitative studies on the issue. The studies focused on specific countries, with the vast majority being in Saudi Arabia. Since there were few qualitative studies that came out of the scoping

review, and because the studies were focused in on specific populations, a social-media based qualitative study was conceived, which brings me to Paper 2.

Paper 2. The Qualitative Reddit-Based Study

This paper uses social media to specifically document Muslims' perceptions regarding genetic counselling and consanguinity (cousin marriages), a process that has been employed for qualitative research (54). The reason this approach was chosen was to allow for more 'global' data to appear, as the studies found in the scoping focused on specific populations in Muslim-majority countries, while social media data had the potential to include data from other countries such as the UK, US, etc. In addition, the review found that the majority of studies focused on Arab Muslim populations, and using this wide-reaching method could include non-Arab Muslim populations as well. Furthermore, the topics being explored are of a potentially sensitive nature; harkening back to the point of stigma-perception brought up in a study (52), there is a chance that probing about the topic in an interview may discomfort people or make them feel judged. Hence, the social media approach allows for a non-invasive way of conducting the study. The study took place on Reddit, specifically in selected subreddits (Reddit's name for online communities). Subreddits (and posts) were included if there were conversations within them relevant to either cousin marriages or genetic counselling within the context of consanguinity, as well as the broader context of the people conversing being Muslims. The first step was conducting an initial search to see whether the data existed and within which subreddits, following previous methods used in social media-based qualitative research (55); this process helped uncover specific subreddits which were targeted for searches., Subsequent to finding the subreddits, specialised search strings were made for each subreddit to ensure that only relevant data was pulled, a practice

affirmed by previous investigations (54,55). Discourse analysis (56) was utilised as the central analytical method to focus on how people worded their statements surrounding cousin marriages and genetic counselling, as well as how meanings and social understandings were created surrounding the topics.

Objectives

Paper 1. The Scoping Review

What is the current research scope surrounding the general public's perspectives towards genetic counselling for consanguineous relationships and what are the gaps in research of those perspectives?

Paper 2. The Qualitative Reddit-Based Study

What is the discourse, as located in Muslim-focused communities on Reddit, surrounding cousin marriages and genetic testing?

Chapter 3. Paper 1: Perspectives on Genetic Counselling for Consanguinity - A Scoping Review

By Sultan Abdulkarim, Saba Soltani, & Samantha Meyer

Introduction

The practice of marriage between cousins is customary in several regions around the world. A separate term, inclusive of first-cousin marriages, has been used to refer to marriages between close relatives of any type. This term is that of 'consanguinity,' which has been used frequently in the literature surrounding these kinship practices to denote the relations between relatives (first cousins, second cousins, etc.) (1). This issue particularly befalls regions such as the Middle East and North Africa (MENA regions), South Asia, and Southeastern Asia, which are characterised by their high rate of Muslims. In some aspects consanguinity has also been described as a typical occurrence in particularly Arab-Muslim families (2). Biological children born from these unions are associated with a variety of potential birth defects or long-term health problems (2–5). Hypertension and diabetes have also been associated with the occurrence of consanguineous marriages (2). Anaemia and other sickle cell diseases are widespread in North Africa because of the high consanguinity rates in the region (5). Another hereditary disease associated with consanguinity is Mediterranean fever, which can be passed down through families and is an issue in not only the Mediterranean area but also the host countries that people from these areas immigrate to (5). Some other complications that can arise in offspring of consanguineous unions include heart disease and asthma, with even physical disabilities such as deafness being a risk (4).

This is not to say that offspring *always* come out with complications from consanguinity. On the contrary, if first cousins procreate then their child has double the risk for birth complications

compared to the general risk that their population has. Generally, this amounts to an increase in the risk for defects (6) typically by 2 or 3 percentage points. Though this is a small percentage, it is important to consider that regardless of the rate of the increase, any increase still poses a threat upon the life of the offspring. The risk increases threefold, however, when the parents of each first cousin are first cousins themselves (6). Thus, this is not only an issue of people's choices now but also placing these choices within the context of the cultural and historical beliefs surrounding them.

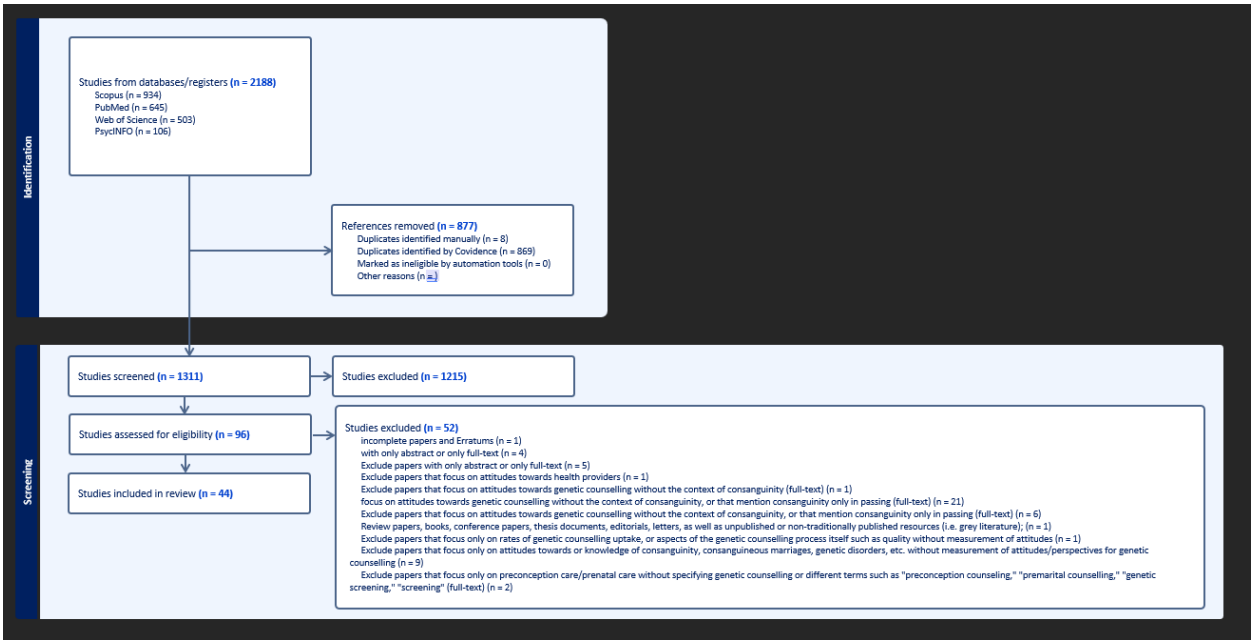
The aim of genetic counselling is not to eradicate these risks and suppress risk rates but rather to allow consanguineous couples the opportunity to learn more about the risks associated with their union, then make an informed decision about their future plans. This can be seen in recommendations set forth for genetic counselling practice, which stipulate that the process be focused on birth results and provision of *options* to couples (7). It is important to note that this is a matter based on the person's autonomy because this ultimately comes down to not only respecting people's personal choices but also being mindful of cultural practices, a point that has also been laid out as a suggestion for genetic counselling practice (7). Furthermore, the social aspects regarding genetic counselling have been put at the forefront of improvements in its practice, with the proposition of counsellors working with ethicists (8) to ensure the least strain upon the cultural values of the couples that seek counselling, while also ensuring that couples are informed of the risks associated with their relationship. Given the importance of the cultural context surrounding genetic counselling as well as the risks associated with consanguineous relationships, a review looking at people's perspectives on genetic counselling for consanguinity can pave the way for further improvements in practice.

The central objective of this review is to explore the current research landscape with regards to public attitudes towards genetic counselling for consanguineous relationships. In doing so, we fill a tremendous gap in knowledge surrounding consanguineous marriage practices and the attitudes that shape the use of services to mitigate risk. A significant goal for this to review is to account for people's views when it comes to the genetic counselling processes for their consanguineous unions to better understand why they might consider, or not, the use of counselling services. Moreover, obtaining these accounts might inform various stakeholders, such as the government, of the directions they can take to mitigate these attitudes for the sake of preventative counselling.

Methods

This scoping review was conducted with the PRISMA guidelines for Scoping Reviews acting as a base; however, of the 22 items applicable to scoping reviews, three were removed: Both critical appraisal items and the registration of a protocol (9). This is because the central focus of this review is documenting what we know about the topic at hand, then subsequently pointing out gaps in the research as opposed to evaluating methods.

Figure 1. PRISMA flowchart



We applied Arksey and O'Malley's (10) framework for scoping reviews that involved: developing a research question (what the current research landscape regarding public perspectives on genetic counselling for consanguineous relationships is), finding relevant studies, study selection, data charting, and report of results. Articles were collected using exhaustive search strategies in four databases: Scopus, Web of Science, PsycInfo, and PubMed. Search strategies focused on the themes of genetic counselling, consanguinity, reproductive behaviour, and perceptions. The keywords used can be found as supplementary material for this article.

Table 1. Inclusion-exclusion criteria of scoping review

Inclusion criteria	Exclusion criteria
Study Characteristics	

• Looking at attitudes towards genetic counselling for consanguineous couples through qualitative or quantitative research	• Exclude papers that focus only on rates of consanguinity relationships OR the genetic counselling process for consanguineous relationships without discussion of or looking into attitudes towards genetic counselling
Population	
• Include only studies that have a focus on consanguineous populations (full-text) • Include papers that discuss or look into the general public's attitudes rather than health professionals	• Exclude papers that do not have any focus on consanguineous populations (Full-Text) • Exclude papers that focus on attitudes of health professionals • Exclude papers about guidelines for how professionals should pursue counselling for consanguinity (i.e. cultural considerations, etc.)
Comparator / Context	
• Include papers that focus on adjacent concepts to attitudes towards genetic counselling for consanguinity (awareness, perspectives, knowledge, trust, etc.)	• Exclude papers that focus on attitudes towards genetic counselling without the context of consanguinity (full-text) • Exclude papers that focus on the assessment of a specific kind of

• Include papers that focus on perspectives/ attitudes towards genetic counselling ONLY within the context of consanguineous relationships (full-text) • Include papers that focus on attitudes towards genetic counselling regardless of context (abstract) • Include papers that refer to genetic counselling using different terms, such as “preconception counselling,” “premarital counselling,” “genetic screening” • Include papers focusing on attitudes towards/knowledge of preconception/prenatal ‘care’ or ‘healthcare’ (abstract)	intervention in genetic counselling for first-cousins without measurement of attitudes, perspectives, etc. • Exclude papers that focus on attitudes towards health providers • Exclude papers that focus only on attitudes towards or knowledge of consanguinity, consanguineous marriages, genetic disorders, etc. without measurement of attitudes/perspectives for genetic counselling • Exclude papers that focus only on rates of genetic counselling uptake, or aspects of the genetic counselling process itself such as quality without measurement of attitudes • Exclude papers that focus only on preconception care/prenatal care without specifying genetic counselling or different terms such as “preconception counselling,”

	"premarital counselling," "genetic screening," "screening" (full-text)
Other	
• Peer-reviewed research-based journal articles • Include only papers in the English and Arabic languages • Include papers with both abstract and full-text • Include only complete papers without Erratums	• Review papers, books, conference papers, thesis documents, editorials, letters, as well as unpublished or non-traditionally published resources (i.e. grey literature) • Non-English language and non-Arabic language papers • Exclude papers with only abstract • Exclude incomplete papers and Erratums

A second screener was trained by the main author screener before commencement of title and abstract screening. The training consisted of the explanation of inclusion and exclusion criteria to the second screener by the main author screener. This was followed by the selection of 20 articles for screening and the subsequent screening of the articles by both screeners. The training for title and subtract screening resulted in 100% inter-rater reliability (proportionate agreement) between the screeners. Training for full-text screening was identical, with 20 full-text articles being screened and 100% inter-rater reliability (proportionate agreement) being achieved.

At first, inclusion criteria were for specifically articles that mentioned first-cousin/consanguinity, including in the abstract. However, we noticed that some articles, particularly from nations like Saudi Arabia, discussed genetic counselling attitudes from the perspective of consanguinity without explicitly mentioning it in the abstract. This is likely due to consanguineous marriages there being viewed as equivalent to any other type of marriage. This resulted in changing the criteria to include all papers with attitudes to genetic counselling at the abstract stage so that they can be examined closely at the full-text phase.

Covidence calculated inter-rater reliability at both the title-abstract and full-text screening stages, both of which are indicated through Cohen's kappa. The kappa statistics for interrater reliability for screening meet an acceptable standard (11).

Table 2. Kappa statistics for inter-rater reliability of scoping review

	Cohen's kappa	Proportionate agreement
Title-and-abstract screening	0.61	0.95
Full-text screening	0.92	0.96

Data extraction was conducted after screening into a table in Excel. The table is included as supplementary material for this article. Details about each article (authors, findings, limitations, study design, etc.), along with the identification of theoretical bases for the investigations.

The primary research question aimed to explore the current research landscape with regards to the public attitudes towards genetic counselling for consanguineous relationships. In order to

meet the study aim, data were charted to specifically identify theoretical bases, study findings, study design, type of consanguinity, and study location.

Results

The following table is a summarised portrayal of the central findings of this review paper. It has been divided into two columns: “Factors and public perspectives related to genetic counselling,” with the second column being dedicated to “Findings associated with factors.” Prominent factors related to people’s attitudes were education and religion.

Table 3. Main findings of scoping review

Factors and public perspectives related to genetic counselling	Findings associated with factors
Positive or Negative Outlook	The majority of studies showed that participants had a positive outlook towards genetic counselling (12–18) Some studies showed that the population had a negative outlook (19,20)
Knowledge, Awareness, and Decision-Making	Most articles identified that most participants had little knowledge or awareness (20–25)

	Some articles identified that participants were mostly aware or had knowledge of genetic counselling (26,27) One article identified that family history of consanguinity can impact awareness (28) One article identified that medical students would go against genetic counselling results, while non-medical students would follow results (29) One article identified that only a third of those who underwent genetic testing did it due to awareness of medical benefits, with the remaining only doing it due to mandates (30) One article identified that counselling wasn't always associated with impacting decision making (31)

Education	This was identified as a significant predictor by various studies, with the majority pointing out that higher education was associated with greater acceptance of genetic counselling (32–43)
Religion	This was identified as a significant factor for rejection by multiple studies (24,33,41,42,44–52)
Gender	Some articles identified gender as a significant factor in people's perspectives towards genetic counselling (33,53,54) Some articles stated that gender was not significantly associated with people's perspectives (46,55) In one case, gender was associated with knowledge (26)

Only one article provided a theoretical basis for how it assessed people's perspectives clearly (43). This illustrates a *severe* gap in theoretical foundations for how we study people's perspectives,

especially when considering that a number of articles (n=13) list the finding that people who rejected genetic counselling results did so due to religion (24,33,41,42,44–52).

The vast majority of studies used quantitative methods, with only eight studies in total using qualitative methods in any capacity (both qualitative and mixed-methods). This shows a great disparity between approaches to the study of the public's acceptance of genetic counselling. More qualitative studies are required to fill in this gap in methodology, to shed light on participant's reasoning.

Table 4. Frequency of methodology types in scoping review

Methodology	**Frequency (# of articles)**
Quantitative	36
Qualitative	4
Mixed-methods	4

The majority of studies mention first-cousin coupling as the context underlying a study; However, looking at first-cousin attitudes vs double-cousin attitudes (e.g., if people's parents being cousins affects views compared to those who are first-cousins only) could provide further illumination on if there is any sort of threshold people have for consanguinity, and therefore their acceptance of genetic counselling.

Table 5. Frequency of consanguinity type

Consanguinity type	Frequency (# of articles)
First-cousin	31
Second-cousin	17
Double and other consanguineous types	4

Only four articles (out of forty-four) looked at the issue of genetic counselling perspectives within locations outside of the Middle East and North Africa. This shows that there is a lack of breadth in location choice, potentially leading to geographically-determined cultural beliefs that result in biases within people's perspectives on genetic counselling.

Table 6. Frequency of study location in scoping review

Study location	Frequency (# of articles for each country)
Saudi Arabia	19
Israel	5
Iran	3
Jordan	3
Oman	3

Lebanon	2
Multiple countries at once	2
Qatar	2
Australia	1
Bahrain	1
Canada	1
Palestine	1
UAE	1

Discussion

The majority of studies being in one region of the world aligns with global consanguinity rates – the highest rates of cousin marriages in the world can be found within the MENA region specifically. An illustration of the rate of cousin marriages in the MENA region can be seen through the Republic of Tunisia alone, where a study found that half of marriages across the nation were of a consanguineous nature (5). In addition, Morocco, at a lesser but still incredibly high rate, showed a rate of such marriages at approximately a third of all marriages, with immigration from said areas potentially being a catalyst for the presence of higher genetic anomaly rates in host countries (5). For some cases, it has been suggested that the rate of these relationships can be partially attributed to a desire from the people of these communities to marry those within the same family (56). This helps delineate the significance of the issue in not only a regional sense but also a global sense. If this is an issue that has been found to be prominent among Arab-Muslims, then it is reasonable to assert that Arab, Muslim, and Arab-Muslim communities across

the world may engage in consanguineous unions regardless of their physical location. Hence, while the studies in the review looked at mainly Arab-Muslim region of countries, this does not necessarily mean that these are the only possible locations where studies on genetic counselling for consanguinity can be conducted. Future research could be directed to not only other countries but also other ethnic and religious groups that practice consanguineous relationships within other countries.

Knowledge, education, age, and gender being the central determinants for perspectives uncovered through this review fits with general findings in this area of research. Several findings have been uncovered by studies that explored people's attitudes towards the genetic counselling process, particularly with regards to determinants and reasons for attitudes: For instance, it has been frequently found that educational level may be associated with the public's perspectives on genetic counselling (32–43). In addition, some findings have associated gender to differing perspectives on genetic counselling (33,53,54). This illustrates the characteristics that can influence acceptance of genetic counselling and helps to identify where education and promotion of counselling may be of benefit. However, this is not to say that those in consanguineous relationships necessarily lack knowledge and that education will be alone sufficient to promote the practice of genetic counselling among unions that carry risk to offspring. On the contrary, the science of genetic counselling is not ignored by those in such unions (31), and it has even been found that there is an awareness among consanguinity-practicing populations of the potential consequences of these marriages, a concern mitigated by other consanguineous couples around them (27). It has even been asserted that regardless of education, knowledge tends to be low across Arab populations (57). On the side of positive attitudes, a study in Qatar found that

approximately 40% of participants recognised the benefits that can arise from genetic counselling (54); the concerning aspect of this finding is that the other percentage do not see the usefulness of the counselling process, illustrating polarized perspectives within a single population and need to better understand drivers behind support, or lack thereof, for counselling. Several studies affirmed the importance of religion in attitudes towards genetic counselling (24,33,41,42,44–52). Ultimately, these findings were uncovered through quantitative methods and were not indicative of deeper reasons for people's perspectives on genetic counselling; Therefore, future research should employ qualitative methods to get to the grit of people's reasoning. A solution that has been proposed for this is for genetic counsellors to account for social factors into the way they counsel, helping mitigate any personal concerns those being counselled may have (58). Another concern that has been brought up with regards to counselling is that of privacy of results (32), which also plays into the separate concern of potential stigma (59).

This review contains the following potential limitations: 1) Though every attempt was made to ensure that no articles were missed by the implemented search strategies, it is possible that some articles may have been missed during the search process, particularly by how our inclusion-exclusion criteria were limited to only peer-reviewed articles. The expertise of a liaison librarian was invaluable in assuring that articles were not missed; 2) No protocol was submitted due to time-sensitive considerations that had to be made due to author circumstances, but every effort was made to ensure the methodology was robust in both the searching and screening stages.

Conclusion

This review's findings highlight the importance of not only diverse populations but also diverse study designs in research related to genetic counselling. While various studies look at the determinants of people's perspectives on consanguinity-related counselling, very few (if any) look at the deeper reasons that people may hold for their perspectives, with there being a large gap in qualitative research on this topic. Religion is assessed as a factor, but only as a one-off survey item rather than through people's experiences of religion, which are typically nuanced to each person. In addition, populations that practice consanguinity outside of the MENA region must be explored, such as people in religious communities or immigrant populations within Western regions. With these gaps having been detected, this provides direction for future endeavours within the practice of genetic counselling, primarily by emphasising the importance of taking into account people's individual and cultural concerns with regards to genetic counselling, as this information remains largely uninvestigated.

References

1. Albesher N, Massadeh S, Hassan SM, Alaamery M. Consanguinity and Congenital Heart Disease Susceptibility: Insights into Rare Genetic Variations in Saudi Arabia. Genes. 2022 Feb;13(2):354.

2. Hajjaji M, Khadmaoui A, El Bakkali M. The practice of consanguineous marriage and the risk of diabetes among offspring in the province of Tetouan (Morocco). Arab Gulf Journal of Scientific Research. 2023 Feb 27;42(1):30–43.

3. Khayat AM, Alshareef BG, Alharbi SF, AlZahrani MM, Alshangity BA, Tashkandi NF. Consanguineous Marriage and Its Association With Genetic Disorders in Saudi Arabia: A Review. Cureus. 2024 Feb;16(2):e53888.

4. Anwar S, Mourosi JT, Arafat Y, Hosen MJ. Genetic and reproductive consequences of consanguineous marriage in Bangladesh. PLOS ONE. 2020 Nov 30;15(11):e0241610.

5. Anwar WA, Khyatti M, Hemminki K. Consanguinity and genetic diseases in North Africa and immigrants to Europe. Eur J Public Health. 2014 Aug 1;24(suppl_1):57–63.

6. Hamamy H. Consanguineous marriages. J Community Genet. 2012 July 1;3(3):185–92.

7. Bennett RL, Motulsky AG, Bittles A, Hudgins L, Uhrich S, Doyle DL, et al. Genetic Counseling and Screening of Consanguineous Couples and Their Offspring: Recommendations of the National Society of Genetic Counselors. Journal of Genetic Counseling. 2002;11(2):97–119.

8. Nouri N, Nouri N, Tirgar S, Soleimani E, Yazdani V, Zahedi F, et al. Consanguineous marriages in the genetic counseling centers of Isfahan and the ethical issues of clinical consultations. J Med Ethics Hist Med. 2017 Dec 10;10:12.

9. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann Intern Med. 2018 Oct 2;169(7):467–73.

10. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. International Journal of Social Research Methodology. 2005 Feb 1;8(1):19–32.

11. Landis JR, Koch GG. The Measurement of Observer Agreement for Categorical Data. Biometrics. 1977;33(1):159–74.

12. Al Sulaiman A, Suliman A, Al Mishari M, Al Sawadi A, Owaidah TM. Knowledge and attitude toward the hemoglobinopathies premarital screening program in Saudi Arabia: population-based survey. Hemoglobin. 2008;32(6):531–8.

13. Aga S, Alghamdi Y, Alghamdi A, Khan M. Knowledge, awareness, and attitude of medical students concerning genetics and premarital screening. Journal of Nature and Science of Medicine. 2021 Oct 1;4(4):356–356.

14. Al Zeedi MASA, Al Abri ZG. Attitudes and impact among people with abnormal premarital screening test results in Muscat governorate's primary healthcare centers in 2018. J Community Genet. 2021 Jan;12(1):163–9.

15. AlOtaiby S, Alqahtani A, Saleh R, Mazyad A, Albohigan A, Kutbi E. Comprehension of premarital screening and genetic disorders among the population of Riyadh. J Taibah Univ Med Sci. 2023 Aug;18(4):822–30.

16. Eissa M, Patel AA, Farag S, Babiker NH, Al-Shahrani MS, Al-Nahari AM, et al. Awareness and Attitude of University Students About Screening and Testing for Hemoglobinopathies: Case Study of the Aseer Region, Saudi Arabia. Hemoglobin. 2018 July;42(4):264–8.

17. Teeuw ME, Loukili G, Bartels EA, ten Kate LP, Cornel MC, Henneman L. Consanguineous marriage and reproductive risk: attitudes and understanding of ethnic groups practising consanguinity in Western society. Eur J Hum Genet. 2014 Apr;22(4):452–7.

18. Zaien SZ, El-Houfey AA, Alqahtani H, El Sayed HAE, Elgzar WT, Essa RM, et al. Predictors of premarital screening and genetic counseling knowledge and attitude among deaf and hard hearing females in Tabuk, Saudi Arabia. J Med Life. 2022 Mar;15(3):379–86.

19. Cohen-Kfir N, Bentwich ME, Kent A, Dickman N, Tanus M, Higazi B, et al. Challenges to effective and autonomous genetic testing and counseling for ethno-cultural minorities: a qualitative study. BMC Medical Ethics. 2020 Oct 15;21(1):98.

20. Al-Qattan HM, Amlih DF, Sirajuddin FS, Alhuzaimi DI, Alageel MS, Bin Tuwaim RM, et al. Quantifying the Levels of Knowledge, Attitude, and Practice Associated with Sickle Cell Disease and Premarital Genetic Counseling in 350 Saudi Adults. Adv Hematol. 2019;2019:3961201.

21. Asadollahi H, Vakili M, Asadollahi R. Applying Rogers' framework to evaluate public awareness and knowledge of medical genetics in a developing country. J Community Genet. 2020 July;11(3):367–75.

22. Jaber L, Dolfin T, Shohat T, Halpern GJ, Reish O, Fejgin M. Prenatal diagnosis for detecting congenital malformations: acceptance among Israeli Arab women. Isr Med Assoc J. 2000 May;2(5):346–50.

23. Nikzadian M, Dashti F, Ostadsharif M. Compare the attitude to genetic counseling and obstacles in pregnant women with consanguinity and non-family marriage attending prenatal care clinics Al-Hadi Hospital of Shoushtar in 2015. Acta Medica Mediterranea. 2016;32(Special Issue 4):1535–42.

24. Zahed L, Nabulsi M, Bou-Ghanim M, Usta I. Acceptance of prenatal diagnosis for genetic disorders in Lebanon. Prenat Diagn. 1999 Dec;19(12):1109–12.

25. Zaien SZ, El Sayed HA, Ibrahim HA, Elgzar WT, Aboraiah MIH, Abdel-Mordy MA. Empowering deaf and hard hearing females toward premarital counseling and genetic screening: An educational intervention based on empowerment model. Afr J Reprod Health. 2021 Mar;25(s1):36–49.

26. Alhowiti A, Shaqran T. Premarital Screening Program Knowledge and Attitude among Saudi University Students in TABUK City 2019. International Journal of Medical Research and Health Sciences. 2019;8(11):75–84.

27. Thain E, Shuman C, Miller K, Sappleton K, Myles-Reid D, Chitayat D, et al. Prenatal and preconception genetic counseling for consanguinity: Consanguineous couples' expectations, experiences, and perspectives. Journal of Genetic Counseling. 2019;28(5):982–92.

28. Al Eissa MM, Almsned F, Alkharji RR, Aldossary YM, AlQurashi R, Hawsa EA, et al. The perception of genetic diseases and premarital screening tests in the central region of Saudi Arabia. BMC Public Health. 2024 June 10;24(1):1556.

29. Almannaei JAA, Alkhedri MA, Alawadhi RM, Saleh M, Alsherooqi MY, Mohsen JAS, et al. Attitude and Awareness of Bahraini Medical and Non-Medical Students Towards Premarital Screening. Bahrain Medical Bulletin. 2022;44(4).

30. El Sabeh M, Kassir MF, Ghanem P, Saifi O, El Hadi D, Khalifeh Y, et al. Consanguinity rates among Syrian refugees in Lebanon: a study on genetic awareness. J Biosoc Sci. 2021 May;53(3):356–66.

31. Shiloh S, Reznik H, Bat-Miriam-Katznelson M, Goldman B. Pre-marital genetic counselling to consanguineous couples: Attitudes, beliefs and decisions among counselled, noncounselled and unrelated couples in Israel. Social Science & Medicine. 1995 Nov 1;41(9):1301–10.

32. Ahram M, Soubani M, Abu Salem L, Saker H, Ahmad M. Knowledge, Attitudes, and Practice Regarding Genetic Testing and Genetic Counselors in Jordan: A Population-Based Survey. Journal of Genetic Counseling. 2015;24(6):1001–10.

33. Al-Eisawi Z, Jacoub K, Alsukker A. A large-scale study exploring understanding of the national premarital screening program among Jordanians: Is an at-risk marriage a valid option for Jordanians? Public Underst Sci. 2021 Apr 1;30(3):319–30.

34. Al-Shroby WA, Sulimani SM, Alhurishi SA, Dayel MEB, Alsanie NA, Alhraiwil NJ. Awareness of Premarital Screening and Genetic Counseling among Saudis and its Association with Sociodemographic Factors: a National Study. JMDH. 2021 Feb 17;14:389–99.

35. Alsulaiman A, Hewison J. Attitudes to prenatal and preimplantation diagnosis in Saudi parents at genetic risk. Prenatal Diagnosis. 2006;26(11):1010–4.

36. Altaany Z, Khabour OF, Alzoubi KH, Alkaraki AK, Al-Taani G. The Perception of Premarital Genetic Screening within Young Jordanian Individuals. Public Health Genomics. 2021 June 30;24(3–4):182–8.

37. Alwhaibi RM, Almuwais AK, Alotaibi M, AlTaleb HM, Alsamiri SM, Khan R. Health beliefs of unmarried adult Saudi individuals toward safe marriage and the role of premarital screening in avoiding consanguinity: a nationwide cross-sectional study. Front Public Health [Internet]. 2024 June 19 [cited 2025 Sept 28];12. Available from: https://www.frontiersin.org/journals/public-health/articles/10.3389/fpubh.2024.1379326/full

38. Bener A, Al-Mulla M, Clarke A. Premarital Screening and Genetic Counseling Program: Studies from an Endogamous Population. Int J Appl Basic Med Res. 2019;9(1):20–6.

39. Ghanim M, Rabayaa M, Alqub M, Hanani A, Abuawad M, Rahhal B, et al. Investigating knowledge and attitudes toward genetic testing and counseling among palestinians. Sci Rep. 2025 Feb 6;15(1):4446.

40. Hashemi-Soteh MB, Nejad AV, Ataei G, Ghasemi D, Siamy R. Knowledge and attitude toward genetic diseases and genetic tests among pre-marriage individuals: A cross-sectional study in northern Iran. IJRM. 2019 Sept 3;543–50.

41. Hassan AH. Public awareness and attitude toward premarital screening program in Jazan region, Saudi Arabia, an endemic area for hemoglobinopathies: A cross-sectional study. Afr J Reprod Health. 2023 Aug 31;27(8):65–75.

42. Ibrahim NK, Bashawri J, Al Bar H, Al Ahmadi J, Al Bar A, Qadi M, et al. Premarital Screening and Genetic Counseling program: Knowledge, attitude, and satisfaction of attendees of governmental outpatient clinics in Jeddah. Journal of Infection and Public Health. 2013 Feb 1;6(1):41–54.

43. Raz AE, Atar M, Rodnay M, Shoham-Vardi I, Carmi R. Between Acculturation and Ambivalence: Knowledge of Genetics and Attitudes towards Genetic Testing in a Consanguineous Bedouin Community. Community Genetics. 2003 Oct 17;6(2):88–95.

44. Alizary A, Ahmad K, Al Bakri A. Parental experience with an ocular genetic counseling services in Saudi Arabia. Saudi J Ophthalmol. 2023 Oct 24;37(4):296–300.

45. Al-Gazali LI. Attitudes toward genetic counseling in the United Arab Emirates. Community Genet. 2005;8(1):48–51.

46. Alkalbani A, Alharrasi M, Achura S, Al Badi A, Al Rumhi A, Alqassabi K, et al. Factors Affecting the Willingness to Undertake Premarital Screening Test Among Prospective Marital Individuals. SAGE Open Nursing. 2022 Jan 1;8:23779608221078156.

47. Al-Khaldi YM, Al-Sharif AI, Sadiq AA, Ziady HH. Attitudes to premarital counseling among students of Abha Health Sciences College. Saudi Med J. 2002 Aug;23(8):986–90.

48. Al-Kindi R, Kannekanti S, Shakman J, Lina, Al-Azri Z, Al-Kalbani N. Awareness and Attitude Towards the Premarital Screening Programme Among High School Students in Muscat, Oman. Sultan Qaboos University Medical Journal. 2019 May 11;19(3):e217-224.

49. Alkuraya FS, Kilani RA. Attitude of Saudi families affected with hemoglobinopathies towards prenatal screening and abortion and the influence of religious ruling (Fatwa). Prenat Diagn. 2001 June;21(6):448–51.

50. Josephi-Taylor S, Barlow-Stewart K, Selvanathan A, Roscioli T, Bittles A, Meiser B, et al. User Acceptability of Whole Exome Reproductive Carrier Testing for Consanguineous Couples in Australia. Journal of Genetic Counseling. 2019;28(2):240–50.

51. Sharkia R, Tarabeia J, Zalan A, Atamany E, Athamna M, Allon-Shalev S. Factors affecting the utilization of genetic counseling services among Israeli Arab women. Prenat Diagn. 2015 Apr;35(4):370–5.

52. van der Hout S, Woudstra AJ, Dondorp W, Sallevelt S, de Die-Smulders C, Paulussen ADC, et al. Consanguineous couples' experiences and views regarding expanded carrier screening:

Barriers and facilitators in the decision-making process. Eur J Hum Genet. 2023 Nov;31(11):1317–22.

53. Almasmoum HA, Tabassum A, Iqbal MS, Abo-Alshamat R, Aqeeli W. Knowledge and Attitude toward Hemoglobinopathies in Premarital Screening Program among the General Population in the Western Region of Saudi Arabia. Hemoglobin. 2022 Sept 3;46(5):277–84.

54. Al-Shafai M, Al-Romaihi A, Al-Hajri N, Islam N, Adawi K. Knowledge and Perception of and Attitude toward a Premarital Screening Program in Qatar: A Cross-Sectional Study. International Journal of Environmental Research and Public Health. 2022 Jan;19(7):4418.

55. Alawad N, Alangari A, Allhybi A, Masud N, Almuzaini F, Alshamari M, et al. Assessment of attitudes towards the use of preimplantation genetic diagnosis in a single center in Riyadh, Saudi Arabia. Journal of Genetic Counseling. 2023;32(5):1032–9.

56. El-Hazmi MAF. Ethics of genetic counseling—basic concepts and relevance to Islamic communities. Annals of Saudi Medicine. 2004 Mar;24(2):84–92.

57. Natarajan J, Joseph MA. Premarital screening for genetic blood disorders — an integrated review on the knowledge and attitudes of Middle Eastern university students. Middle East Fertility Society Journal. 2021 June 30;26(1):19.

58. Siani M, Ben-Zvi Assaraf O. A Qualitative Look into Israeli Genetic Experts' Insights Regarding Culturally Competent Genetic Counseling and Recommendations for Its Enhancement. Journal of Genetic Counseling. 2017;26(6):1254–69.

59. Baynam G, Gomez R, Jain R. Stigma associated with genetic testing for rare diseases—causes and recommendations. Front Genet [Internet]. 2024 Apr 4 [cited 2025 Sept 28];15. Available from: https://www.frontiersin.org/journals/genetics/articles/10.3389/fgene.2024.1335768/full

Chapter 4. Paper 2: Perspectives on Cousin Marriages and Genetic Counselling – A Qualitative Study

By Sultan Abdulkarim, Warren Dodd, Seçil Dağtaş, & Samantha Meyer

Introduction

The practice of cousin marriages has been said to be incredibly common among Muslims around the globe (1), particularly in the MENA (Middle East and North Africa) and South Asian regions. There are health concerns associated with cousin marriages, namely genetic complications that can arise in offspring due to the ancestral closeness of the couple (2). It has been found that in India alone, the prevalence of cousin marriages across the Muslim population can range from 15% in some jurisdictions to as much as 32.9% in others, with little change being detected over time across the late 20th century (1). Another area where consanguinity has been found is Iran, where in a single region of the country it was found that approximately 14% of all marriages were consanguineous (of close ancestry) in nature within a single year, which emphasises the persistent nature of the practice (3). In a separate case, it has been reported that among Muslim Arabs in Israel, cousin marriages are staggeringly at around 40% (4). A study in Qatar reported that around a third of participants had been in cousin marriages (5). This further demonstrates the persistence of cousin marriage practice and underscores how it remains engrained in various Muslim populations. Contrastingly, Jordan has witnessed declining levels of cousin marriages in recent, with the rate in 2018 being at approximately 28% (6).

While prevalence rates demonstrate necessary surface-level information to observe how much people engage in cousin marriages, they form only half the picture; it is equally important to highlight *why* people engage in these marriages. There may be factors that influence their

incidence. For instance, it has been found that for the men, factors such as their income, their father's career, and whether their parents were also in cousin marriages have been found to be associated with cousin marriage incidence (3). In addition, education has also been found to be a significant factor, particularly lower levels being associated with the occurrence of cousin marriages (4). Cousin marriages have been shown to be technically permissible in the religion of Islam (7); the social association between Muslims and cousin marriages has been widely documented, particularly in how they are perceived to strengthen familial ties and provide economic security (8,9). Maintenance of culture has also been stated to be a reason for the occurrence of cousin marriages, particularly across South Asia (10). It is important to highlight, as well, that in the pursuit of such perceived social benefits, cousin marriages may be forced between people, particularly when it comes to women within the Muslim community; it can involve the objectification and resulting 'sale' of a woman, in effect, if it meant families would be 'swapping cousins' to ensure males were married (11).

Genetic counselling has been typically used as a tool to inform couples of the likelihood of their offspring acquiring genetic complications, with the ultimate choice on whether to proceed with a cousin marriage being left to the people involved (2). In some cases, those within cousin marriages have expressed an aversion to such knowledge and generally independently predicted low risk to any potential children they may have (12). Hence, understanding the *why* behind cousin marriages is also important to informing the public about what cousin marriages may entail and how genetic counselling can ensure that couples are wholly aware of risks involved in such marriages.

While the aforementioned factors related to cousin marriages do reflect existing research on the topic, this is evidence gathered largely from quantitative studies and there remains an opportunity for an investigation Muslims' social reasonings surrounding cousin marriages and genetic counselling, which is the type of investigation that qualitative research affords by nature. Being aware of barriers and enablers of communication regarding cousin marriage and associated genetic counselling can inform future initiatives on how to sensitively address ideas regarding cousin marriage and convey the efficacy of genetic counselling as an educational and precautionary measure. Knowing the state of discourse among Muslims can inform how to word educational materials that promote genetic counselling for cousin marriages. While not every barrier to communication can be easily changed, such as barriers based more in personal cultural or religious belief, efforts can be made to communicate the efficacy of genetic counselling through a lens of religious permissibility, for instance, which could potentially lead to an increase in uptake of counselling, though this is also difficult to change. Improved sensitivity to religious and cultural sentiments throughout the genetic counselling process can help guide practitioners through behaviours that are more averse to outside interference, while also emphasising the aspect that this is a matter of educated choice, with exclusion of any pressure in decision-making or countering of personal beliefs. These practical outcomes might be informed by this work, the aim of which is to observe discourse in online Muslim-focused communities surrounding cousin marriages (and any genetic testing associated with cousin marriages, if mentioned) to inform future promotion and practice of genetic counselling for cousin marriages.

Methods

When considering a qualitative investigation, it is important to note that the issues of both cousin marriages and genetic counselling within cousin marriage contexts can be sensitive given the cultural context, particularly when considering the prevalence of cousin marriages among global Muslim communities. This can raise the question of how to navigate people's views in a more traditional qualitative investigation, such as through interviews. Hence, a qualitative social media study was undertaken, whereby the social media platform Reddit was scraped for posts and comments relevant to cousin marriages, with discussions surrounding genetic counselling within the context of cousin marriages also being included. Subsequently, discourse analysis of the text was conducted. The study design was informed by the work of Meyer et al. (13) and Rotolo et al. (14) in conducting qualitative research using Reddit. Data were collected by scraping comments from subreddits and manually screening for inclusion (13-14). The approach to discourse analysis was informed by the work of Alquayb (15) and guided by Gee's framework (16).

Data collection

Social media data were scraped using a sample of subreddits within the platform Reddit. A scraping tool named PRAW (Python Reddit API Wrapper) was used to collect threads within each identified subreddit (17). Prior to the procession of this study, an initial search of posts was conducted in Reddit to confirm availability of data to meet the research aim, following a process outlined by Meyer et al. (13). 'Cousin marriage' and 'genetic counselling' (as well as the American spelling 'counseling') were used as the keywords for the search. The resulting posts and subreddits were reviewed to determine which subreddits to include in the scraper, as well as which keywords could be used. This study's focus on Muslims' perspectives influenced which

subreddits were chosen for scraping (the data 'sample'). To ensure that the Islamic context was maintained, Muslim-focused subreddits found within the initial search were selected. This resulted in the following subcommunities being scraped: r/MuslimNikah, r/MuslimLounge, r/MuslimMarriage, r/Islam, r/Progressive_islam, and r/Islam_ahmadiyya. Posts from the initial search were reviewed to determine commonly used words that could be utilised to create a search string of keywords for the scraper. Initially, a longer search string where each word was searched singularly across the chosen subreddits was devised to ensure maximum data retrieval. Due to the search focusing on each word occurring on its own, this resulted in 130,000 posts and comments being retrieved. This would have been incredibly difficult to manually screen for relevance and subsequently analyse. As a result, a novel approach to searching the data was developed, employing an approach based on Boolean searches, much like search strategies used for systematic and scoping reviews, for which certain combinations of terms were searched. This was the final search string used for the study:

'cousin AND (marry OR marries OR nikah OR nikkah OR marriage)'.

The adjusted search strategy yielded 29,889 results, aligning with number of posts manageable for qualitative coding without the aid of large language models (see the work of Rotolo et al. (14)). Genetic counselling-related terms were not included due to redundancy and scraper restrictions, the latter of which namely were character limits associated with conducting a lengthy Boolean search. To elaborate on the redundancy, we need to go back to the initial aim of this study: to observe discourse in Muslim-focused online communities regarding cousin marriages and genetic counselling within the context of cousin marriages. Given that the search string used already focuses on cousin marriages, any genetic counselling-relevant views would have been captured

already since any genetic counselling perspectives should be within the context of cousin marriages.

Upon completion of scraping, a .xlsx (Excel) file was generated displaying the scraped posts and comments within the order the scraper pulled them in, as well as the order in which comments and posts were shown on Reddit itself. This was done by adding a 'depth' column to the scraper that added numbered marks for each post and comment to denote whether it was the starting post, a comment underneath, or a comment underneath another comment (while also identifying under which comment specifically). For instance, '-1' was used as a label to mark the post, '0' was used to label any comment underneath the post, '1' was used to mark comments in response to the comment labelled '0', 2 was used to mark comments made in response to the comment labelled as 1, and vice versa. This was relevant to discourse analysis to ensure the context of users' statements was observed, particularly in cases where a user comments on another user's comment rather than the main post.

Data were manually screened so that only data indicating views or statements on cousin marriages or genetic counselling for cousin marriages was retained. If a post was not focused on cousin marriages but the associated comments were, then the comments were included along with the posts (for context).

Posts and comments containing discussions of cousin marriages were included, while also allowing for any discussion of genetic counselling within the context of Muslim cousin marriages. As a result, 2702 posts and comments were retained for analysis.

Analysis

Gee's approach to discourse analysis (16) forms the central analytical tool utilised in this work, specifically his identified 'toolkits' of social language, conversations, and intertextuality (16). The social language toolkit focuses on the type of wordings and language used, the conversations toolkit focuses on the larger debate surrounding discourse (e.g. in this case being the larger debate on cousin marriage permissibility as indicated by the collected posts and comments), and intertextuality focuses on what people refer back to or quote in discourse (e.g. in this case, when someone refers to religious text). These toolkits form the lens through which analysis was undertaken and guided the analytical process by focusing on people's language choices and how they were situated within the grander debate surrounding cousin marriages, as well as what information was referred to for support, if any. The analysis was inductive in nature, while being informed by Gee's approach to discourse analysis. The structure of this analysis follows the structure of Alquayb's work in analysis of Reddit text (15), as well as Meyer et al.'s approach (13). All analyses were conducted in MS Excel.

Results

The central discourse noted in the results included values given to cousin marriages, namely in the form of disagreement with their practice. On the other hand, other users expressed that they felt the topic was being 'blown out of proportion' and that a mitigator for it (genetic testing) is already present. Some of the discourse also focused on stigma with regards to cousin marriage. Dichotomies between two 'sides' of the general debate surrounding cousin marriages were also highlighted, mainly being between East and West, as well as religion and science. Discourse

featuring elements of Islam, such as Allah or the Prophet, also emerged. A separate dichotomy that emerged was that of repeated cousin marriage across generations vs one-time cousin marriage. 'Sides' were situated within the context of a perceived wider debate about culture or allusions to sources of information (e.g. word-of-mouth and religious text).

Expressions of disagreement with the practice of cousin marriages

'Anti-cousin marriage' perceptions emerged from analysis. The following quote from a post indicates an opinion focused on the current state of cousin marriages in greater society:

"…it's genuinely concerning how normalized cousin marriages still are today. Scientifically, marrying a cousin doubles the risk of genetic complications in children. To know that and still proceed is so deeply irresponsible. What's even more troubling is that, for many families, cousin marriage isn't even a last resort, it's the first choice."

The post used wording such as 'irresponsible' to denote a value of recklessness to those who practice cousin marriage. They express disagreement with how cousin marriages are being 'normalised,' assigning an inferred value of cousin marriage being an 'uncommon practice' that is now mainstream. The wording used to describe how cousin marriage may be chosen as a 'first choice' as opposed to a 'last resort' infers a value of preference as to what constitutes an appropriate time for a cousin marriage. A scientific claim is alluded to for supporting their point.

Wording focused on the perceived normalisation of cousin marriages and derision of it being a 'first choice' for people is repeated across the following comments in response to the post:

"…it's sad how it has become the default in many cultures. It's many parents' first choice even though there are so many other options."

"It's crazy how it's the first choice."

These comments also express emotional reactions to the idea of cousin marriages being a 'first choice,' using words such as 'sad' and 'crazy' to express their disagreement, thus lending the practice of cousin marriages an 'alien' quality by inferring that the practice is bewildering.

"In many Muslim communities, marrying cousins has become the default, and marrying outside the family is often seen as less desirable."

The preceding quote infers that those who practice cousin marriages may not only be engaging them due to the practice being a 'default,' but also because an exogamous marriage is perceived as unwanted. The implication of an uncommon practice becoming mainstream is echoed here.

"This is not about being attracted or not, it's about…cultural patterns creating a situation where cousin marriage is prioritized above all else…they are, in fact, making a beeline to their cousins."

This comment situates itself within the grander conversation of tradition being followed over other elements, as indicated by how 'cultural patterns' are said to contribute to a case where cousin marriages are 'top priority.' The use of 'they' implies confers an 'other' value to those who practice cousin marriages.

The following comment was made in response to a positive statement in favour of allowing cousin marriages:

"And you're okay with gambling with the life of innocent children rather than taking basic precautions? Because that's the real risk here.."

The use of ‘gambling’ creates the assumption that those in cousin marriages are ‘playing with lives’ and taking uncertain chances, classifying them as ‘gamblers’ rather than people entering a union.

The following post was regarding a woman whose parents suggested to her that a marriage could be carried out with her cousin:

“We have been bought up in a joint household and she has always referred to me as "older brother". It feels weird for me to change that”.

The language focuses on the type of relationship between the user and their cousin, lending a sibling-like value to it that counters the notion of any marriage occurring.

“Think of having kids and medical issues as driving and accidents - driving is an inherently risky activity and you may do all the right things and still get into an accident. But that doesn’t mean you should start driving recklessly and exponentially increase the chances of you getting into a collision. The same way I think it’s irresponsible to increase the chances of having kids with medical issue when you can easily lower that risk by marrying an unrelated person”

The language in this quote echoes the point of ‘irresponsibility’ raised by other posters, with this user stating that any impact to the chances of offspring to develop genetic complications is irresponsible. They also create a comparison to driving recklessly, which not only repeats the sentiment surrounding responsibility but also infers that cousin marriage is an action that affects surrounding parties, as would be with driving recklessly.

Testing already exists and feeling that discussions are being blown out of proportion

In response to negative posts bringing up the point about cousin marriages and genetic risks some commenters stated that discussions about the issue are 'turning nothing into something'. These comments tended to bring up the point that genetic testing already exists, demonstrating a knowledge of available services. For example:

"You can get testing before following through with it to see if there'll be any issues"

"both could take a genetic test before marriage to ensure there are no issues."

"do genetic testing, check the odds of birth abnormalities. If low, reconsider, u r not a lesser man at all. But u r also not a lesser man for saying no.

"…there is genetic testing you can do today that can help you determine if there is a greater risk now."

These comments regularly alluded to the availability of testing and demonstrated an awareness of its efficacy. The use of wording such as 'see if there are any issues' and 'help you determine' lend a choice-based value to the practice of genetic testing, emphasising the autonomy of people in a cousin marriage.

Another type of discourse that emerged was centred around perceiving those in the position of being anti-cousin marriages as exaggerating the gravity of associated genetic risk. For example:

"The risk associated with marrying cousins is definitely overestimated."

"With that being said I don't get the hyper fixation on cousin marriages, loads of things increase of offspring 'defects' (if we can say that), but they are never spoken about, because cousin

marriages are in vogue (or infamous I should say) in our time it seems people put it in a category of its own."

"The danger of cousin marriages is overhyped… There are many other factors as well that increases birth defects, but societies still don't prohibit those marriages…We all have ancestors that married their cousins."

Comments used wording such as 'overhyped', 'hyperfixation,' and 'overestimated' to demonstrate that posts about the potential consequences of cousin marriages were 'overblown' in nature. They supported this by alluding to how 'many' factors can lead to genetic complications in offspring within any marriage, thus making an equation of cousin marriage to any other type of marriage.

Fear of stigma associated with cousin marriage, East-West dichotomy, and perceptions of being anti-science

The point of being fearful of potential backlash and stigma emerged from the data within the context of a Muslim, revealing that they were married to their cousin to members of 'Western society." For example:

"The issue arises because I feel like I will be looked down upon, made fun of and mocked for wanting to marry my cousin in western society"

"How would you explain to people in western society that you are marrying a cousin? I am marrying a cousin and we share the same last name. They might be finding this awkward. Did anyone marry a cousin?"

Both comments use wording that implies an East-West dichotomy, namely by emphasising that they are fearful of being seen as awkward or mocked by members of Western society as opposed to Eastern society. The grander context of 'East' being more accepting of cousin marriage than 'West' is also implied through the use of this language. The use of 'made fun of,' 'mocked for,' and the perception that the marriage may be deemed 'awkward' lend a stigmatic quality to perceived potential responses to the marriage from Westerners.

"*There is nothing wrong with that, and in fact it would be much more effective if Muslim Doctors do so, or at least doctors who can deal with the issue without attacking the religious beliefs of Muslims.*"

This quote was in response to a user stating that Muslim communities should be informed about the potential consequences of repeated cousin marriage across generations. The quote was suggesting that there is 'nothing wrong with informing them;' the use of the word 'attack' in reference to what is perceived doctors may do in response to cousin marriages indicates a fear of stigma for fellow Muslims from doctors outside of the community. The suggestion of 'Muslim doctors' to mitigate potential stigma implies that those not of the faith would be unable to measure their responses to a patient claiming they are in a cousin marriage.

The East-West dichotomy emerged in a form that echoed the aforementioned perceptions that the issue is 'overblown,' with criticism being levied against Western society as opposed to Muslims who oppose cousin marriages. It also emerged in the form of focusing on Western 'influence.' For example:

"*imo they make it a big deal in the West.*"

"To call a cousin marrying his cousin "inbreeding" is such a western idea. Inbreeding is someone marrying their sister/mother/daughter. Stop making the west your baseline for god's sake."

"Cousin marriage is not classified as incest. Genetical deformities are not a result of cousin marriage either…offspring can only develop defects if both their parents possess the allele which is then expressed in the phenotype…But of course this is the only reasoning for the westerns to designate this practise as incest, yet it's weak and makes no sense."

"It is honestly simply the influence of Western culture that people are so concerned about marriage to cousins."

The use of the phrase 'big deal in the West' infers that the potential consequences of cousin marriages are exaggerated by the West and assigns a dismissive value to information regarding genetic risk. This sentiment is further reflected in the comment stating 'the influence of Western culture' is why people may perceive cousin marriages to be risky, inferring that the West is interfering with the East's way of practicing their culture. The comment stating, 'stop making the west your baseline,' within the context of referring to cousin marriage as 'inbreeding,' implies that there is a negative connotation associated with terms like 'inbreeding' and that cousin marriage may be perceived as distinct from this description. A similar sentiment is echoed by the comment that states how cousin marriages are not 'incest' and how the 'West' attempts to designate it as such.

A claim of Muslims being against science also emerged in the data as being associated with cousin marriages:

"*It's crazy to me how many Muslims are anti-science and anti-intellectualism in general …It's wild we're still having this conversation today.*"

The use of 'how many Muslims are anti-science and anti-intellectualism' in this comment implies that the user perceives there to be a large amount of Muslims who express views they may deem to be pro-cousin (and therefore anti-science, in their view), assigning a 'lesser than' value to what they presume to be a large section of the Muslim population. The use of the words 'anti-science' and 'anti-intellectualism' creates a dichotomy between those who practice cousin marriages and those who do not, implying that those who do not practice cousin marriages are of higher intellect. Expressing how it is 'wild' that the 'conversation' is being had infers an outdated value to the concept of cousin marriage.

Involvement of 'Allah, Prophet of Islam, or Islam itself' in perceptions of cousin marriages

Perceptions involving religious elements emerged throughout the data. These views ranged from using religious concepts to support cousin marriage to using them to criticise cousin marriage. In some instances, users would make the claim that 'Allah is above all,' in response to statements regarding genetic risks that can come out of cousin marriages. This would usually be in defence of criticism against the practice of cousin marriages, though it would also include instances where people would bring up genetic complications. This type of statement could involve either Allah, a mention of the Prophet of Islam, or Islam itself as evidence of absolute 'permissibility' of cousin marriages. For example:

"Science is not your god Allah is. Allah allows what is good and forbids what is harmful and nasty. Allah made it [halal]. I don't care what science says."

This comment creates a dichotomy between religion and science by focusing on what entity is 'worshipped,' inferring that those who believe in scientific claims regarding the risks of cousin marriage are in fact worshipping science and leaving Allah. The phrase 'Allah made it halal' also applies an inalienable value to what Allah has allowed to occur, inferring that as long as it is permissible (or halal) then it is acceptable to practice.

"Simple, because Allah did not forbid it, and He is All Knowing, All Wise. Our knowledge is very limited so we should never think, that we know something better than the Creator."

In this comment, knowledge relegated to what Allah has made permissible; the use of the phrase 'our knowledge is very limited so we should never think' infers that Muslims should not seek out any source of knowledge that does not constitute information associated with what Allah has deemed acceptable or not.

"it's permissible and whatever Allah makes permissible we shall not discourage against it. There is nothing wrong with marrying your first cousin. Go ahead if you want to"

This was in response to a post from a user asking if it was acceptable for them to enter a marriage with their first cousin. This echoes the aforementioned sentiment that what Allah deems permissible can be done regardless of other factors, particularly through the wording 'whatever Allah makes permissible we shall not discourage against it.'

"Once its in the Quran or ahadith then there is no haram. There is no negativity of marrying your cousin. I have married my cousin. Our children are fine. And never would ALLAAH allow something that would cause more harm than good for humankind."

This comment alludes to religious text like the Quran and the Prophet's sayings (hadiths or ahadith, as the user termed) to support the view that there is no 'haram' (in this context, equivalent to 'barrier') to practicing cousin marriage. It also repeats the same sentiment that Allah's allowing of an act to occur is paramount through the statement that 'Allah would never allow something that would cause more harm than good.'

"Stop creating bidah in the deen. Allah made is permissible, are you superior than your Creator?"

For context, 'bidah' means 'innovation' in a negative context, and 'deen' means religion. This comment in response to a claim of genetic risk starts by asking the user to not bring their own ideas into religion (using phonetic Arabic), lending an 'outsider' and 'interfering' value to any perspective that implies an association with science. The phrasing of 'are you superior than your creator' infers that anyone who questions the practice of cousin marriages is essentially challenging Allah, thus making equating discussion of genetic risk to the disrespect of Allah's place.

Citing of the actions of the Prophet of Islam in his marriage to a first cousin was providing as a reason for cousin marriage's perceived inalienable permissibility. For example:

"It is allowed in Islam, infact the Prophet himself married his first cousin (Zainab bin Jahsh if I am not wrong). So you don't have to listen to the people."

"Do you know that Prophet Muhammad (s.a.w) married his first cousin ? Hazrat Zainab (ra), and also do you guys know that Allah had told Prophet Muhmmad (s.a.w) about this marriage and this was a great source of joy for Hazrat Zainab (ra) that her marriage had been arranged and ordained by Allah tala."

"The Prophet (SAW) married his first cousin, how can you be against cousin marriage or think yourself a lesser man if you do so."

For context, '(SAW)' and '(ra)' are terms to be said after some Islamic figures out of respect – in the case of '(SAW)' it is typically mandatory to say after mention of the Prophet. Across comments, the idea that the 'Prophet married his first cousin' tends to be used in the context of displaying the acceptability of cousin marriage, as affirmed by stating 'how can you be against cousin marriage' subsequent to mentioning the Prophet's marriage. The use of the phrase 'so you don't have to listen to the people' subsequent to alluding to the Prophet's marriage infers that the Prophet's actions are an absolute authority in determining permissibility of cousin marriages.

In contrast to the previous instances, a key point that emerged was the application of religious concepts in a way that supported mitigation of cousin marriage practice. For example:

"This isn't about adopting Western ideas or shaming tradition either, it's about using the knowledge and understanding Allah has blessed us with."

"I am of the belief that we should accept the knowledge/science that Allah has granted us."

The use of the wording 'knowledge that Allah has granted' or 'blessed us with' lends an Islamically approved value to scientific perceptions, inferring that knowledge or science is to be seen as aligned with what Allah deems permissible.

The following comments directly reference Islamic figures to demonstrate reasoning for why cousin marriages are not directly encouraged:

“But personally I wouldn’t do it bc of diseases and Statement of Umar regarding this Ibn Abi Mulaykah reported: Umar ibn al-Khattab, may Allah be pleased with him, said to the house of Al-Sa'ib, "You have become frail, so marry intelligent people unrelated to you."

{Talkhis al-Habir 1371} “There is not a group of people who do not bring forth their women to marry men other than their own men, nor do their men go forth to marry women other than their own, except their children will be fools (i.e. born with a mental defect)” [Adaab ash-Shaafi’ee wa Manaaqibuhu (pg. 99) Al-Shafi’i reports Umar ibn al Khattab (RA) to have said, “Whenever the people of a household do not allow their women to marry men outside of their line, there will be fools among their children.”

“In Islam, we’re taught to avoid harm wherever possible, and we now know the real genetic risks of cousin marriages. The Prophet (saw) said, “Do not harm and do not reciprocate harm” and that principle applies directly here.”

“Imam Shafi'i and other scholars discouraged it, they also warned against being excessive in it meaning to not doing it again and again and again. Something can be generally allowed and there can be individual exceptions to the case where It can be haram, harm is one of them.

Allusions to sayings of Islamic figures indicate an alignment between acknowledging genetic risks associated with cousin marriages and religious practice, further lending ‘Islamic approval’ to scientific concerns.

Difference viewed between ‘generational’ and ‘one-time’ cousin marriage

A key differentiation that was made was regarding concerns about a cousin marriage occurring with offspring of cousins as opposed to concerns with the first generational marriage between

cousins. In essence, they would make the claim that the 'real issue' is with repetition of cousin marriages rather than just a single one in a lineage. This was always said in an attempt to show where the 'problem' lied in cousin marriages. For example:

"Cousin marriages across multiple generations is the problem, and it's only when you guys recognize that there is a genetic issue in the family and still go ahead and do it."

It is important to note that the user stating the above was within the context of the issue being 'overblown,' downplaying a post that took issue with any cousin marriage occurring even with the doubling of risk as opposed to multiplying over generations. This sentiment was repeated across other comments as well, with wording such as 'the problem happens' or 'can possibly be harmful' being used to refer to when cousin marriages occur with each generation:

"The risk of genetic issues with children becomes actually a lot greater if cousin marriage happens repeatedly."

"Marriage to cousins can possibly be harmful if it is done over many generations continuously."

"Intergenerational cousin marriages result in higher rates of genetic issues."

"the problem isn't one set of cousins getting married every now and then, it's the societal practice of cousin marriage, leading to generations of cousin marriage, multiplying the risk to the next generation over and over again every time it happens."

"Cousin marriages are dangerous especially if you have multiple generations of it."

"But if you're one of these families where literally cousins always marry cousins over generations then, yeah that's bad."

“The problem isn’t cousins marrying each other it’s when you continue to do this generation after generations.”

“Cousin marriage isn't bad. But if you repeat the process generations after generations then, it will be a risk.”

“What makes it bad is repeating it over multiple generations where the risk compounds.”

These comments were given in response when comments regarding genetic risk were dismissed by those in strong support of cousin marriages. The use of phrases such as ‘what makes it bad,’ ‘the problem isn’t (x) it’s (y),’ ‘can be harmful,’ and ‘is dangerous’ in association with intergenerational cousin marriage lends a higher degree of ‘badness’ to repeated cousin marriages as relative to a single cousin marriage, inferring a preference between the two based on perceived genetic risks to offspring.

Discussion

This study sought to explore the ways in which Muslims perceive cousin marriages and genetic counselling as discussed on Reddit with the goal of informing mechanisms for better informing individuals and fostering the uptake of counselling. The results paint a clear picture of online public discourse on the issue: First and foremost, there can be a separation made between religion and science, in that there may be people who believe that science is only interfering in the practice of their religious culture, which potentially creates a barrier for education on genetic risks associated with cousin marriages. An explanatory framework for this finding could be that of medicalization, in that the institution of medicine may be viewed as encroaching upon people’s

lives and has an influence upon the way they practice their lives, including cultural practices (18). Given that the point of 'Allah being God, not science,' was made with reference to cousin marriages, it could be perceived that the role of any questioning of cousin marriage is to replace cousin marriages with exogamous marriages exclusively, effectively making science a threat to the existence of the cultural practice. This is especially important to note when considering how it has been found that consanguinity is not Islamically promoted through any religious text (19). This shows an area of mismatch between religious and scientific views that genetic counselling could be capable of targeting by being sensitive to the cultural practice of cousin marriage while also acknowledging how it fits within a religious context. Some users, however, used religious text to show support for the ways in which cousin marriage could be dealt with to the benefit of couples, rather than believing that it is 'absolutely' permissible. Future practice and promotion of genetic counselling could provide information on how it fits in the religion of Islam and how its use has nothing to do with 'disrespecting' or 'crossing' Allah, as implied by some of the data. The aid of religious scholars could be employed to serve this aspect of genetic counselling, as evidence for the compatibility of genetic counselling with Islam would naturally prompt more Muslims to take advantage of the service.

Discourse surrounding stigma - where people felt as though they feared any potential negative reactions to their cousin marriage - was also an important insight, and consistent with past literature (20). It also highlights the importance of genetic counselling, and the promotion of counselling, being sensitive to Muslims' beliefs to ensure comfort with and acceptance of the service. If there is a fear surrounding discussion of cousin marriage, even one's own, then it can stifle any sort of communication regarding its use, particularly surrounding genetic risks that may

arise. If a person feels that they cannot discuss it due to a societal difference, especially to a medical professional, then they may be unaware of available services that can help identify any chances of complications to offspring. In this case, comments responded by telling the user to keep it to themselves because the marriage 'would not be understood.' Hence, this discourse emerging is a significant example of the kind of consequences that can occur when people feel stigmatised or that they cannot talk about their marriage, which in turn has the potential to affect whether they access, or are even aware of, genetic counselling services.

Disagreement with the practice of cousin marriages tended to focus on a perceived normalisation of the practice and derided the practice as a whole; noting this discourse is essential to this the aim of informing future genetic counselling practice and promotion, as the posts and comments used wording that plays into stigma. For instance, the suggestion that cousin marriages among Muslims can only be a technical process and should 'only be a last resort' misses on how relationships can come about naturally between Muslim cousins due to the cultural normalisation of such relations. Suggesting that the marriages should only be a 'back-up plan' invalidates relationships and creates a societal environment where practicers of cousin marriage are unable to speak about themselves, therefore potentially making them averse to seeking a doctor's aid in determining any potential risk to offspring, similar to the preceding point on the potential impact of stigma. Referring to those in cousin marriages as being inherently 'irresponsible' and as 'gamblers' suggests that they are inherently causing harm to children. However, while there is an increase in genetic risk to offspring of cousin marriages (21), this does not directly equate to direct harm as it depends on the percentage of risk as well as other factors such as whether their parents were cousins. The purpose of genetic counselling is to identify the risk and educate couples on

what could happen to their offspring (22), so it is unnecessary and potentially alienating to use any name-calling and may defer individuals from learning about and using services. Genetic counselling practice and promotion could potentially target not only practicers of cousin marriages, but also deriders of the practice, to ensure that the population is aware and educated adequately on the subject so as to minimise stigmatic perceptions. The point of availability of genetic counselling is brought up by those on the other side of the aisle in the emergent discourse. This discourse was important to note because it demonstrated the type of thinking and discussion surrounding cousin marriages that the practice and promotion of genetic counselling may address. If people can understand and be aware of the efficacy of genetic counselling, then there could be a change in the way cousin marriages are practiced (namely that people will be more cognizant of the potential risks associated and see the value in testing for said risk).

The perception that 'cousin marriages are made to be a big deal in the West' harkens to collectivist behaviour (23) where those in the East may be strongly opposed to anything Western in a way that places focus upon acting as a group against anything seen as 'Western' rather than acting upon information received that could be beneficial to health regardless of its source.

Similar thinking is echoed in the way anti-science and anti-intellectualism are brought up by a comment and thrust upon the Muslim community as a whole. Users who used religious concepts to express unmitigated support for cousin marriages created an antagonism between their perception of the religion of Islam and its permissibility of cousin marriages with the scientific concerns regarding genetic risk to offspring. This opposition is reflected in previous literature surrounding 'conservative' interpretations of the religion and their conflict with science (24).

Ethical considerations in the genetic counselling field have brought up the importance of specialised communication (25), so the pointing out of these strings of thinking and language could inform future genetic counselling practice on how to approach discussions as well as promotion. Finally, recognising people's knowledge surrounding the consequences of repeated generational cousin marriage as opposed to a pair of cousins marrying for the first time in a lineage (26) demonstrates a line of thinking that could be used for promotion regarding genetic counselling. More balanced thinking should also be promoted regarding cousin marriage and genetic counselling, particularly in how people may view all cousin marriages as 'bad' when in reality it depends on chances and risks that only a test would be able to detect.

Limitations

This study was not without its limitations. Though every effort was made to ensure data collection was thorough and complete, there may have been instances where some posts were not collected by the scraper. The iterative search process used and allowing various posts and comments to be pulled could have mitigated this limitation, primarily by ensuring that as many posts as possible were pulled. Posts made by deleted accounts, as well as deleted posts with undeleted comments, may have been missed by the scraper; However, during manual data screening, some instances of deleted posts were noted, which affirms that the scraper did work to pull those posts in some capacity. Attempts were made to ensure that the search strategy and strings used were as robust as possible, to which an iterative process was imperative, this process being what led to a Boolean search strategy being chosen. The search string created was much like what would be found in a systematic review for a database, potentially reflecting the type of rigor that would be expected

for a review paper (27). Another potential limitation from this work is that, as is the case with any social media-based study, there is always the chance that online 'trolls' or 'bots' made comments or posts that were unduly included as part of the final dataset. The only mitigation against this possible is human judgment of posts in manual screening, and the majority, if not all, of the posts were written with indications of human involvement (i.e. typos, autocorrect, misuse of words, punctuation, etc.). As the study is not representative of Muslims in general and includes Muslim-focused online communities only, there may be voices that were not captured in the data. For instance, some of the literature on consanguinity has shown that upkeep of familial relations can be a driver of cousin marriage (5); However, this did not emerge in the data.

Conclusion

This study observed the discourse surrounding cousin marriages and any associated genetic testing in Muslim-focused subreddits. The findings highlight various strings of thought that display the ways in which people view the genetic risks associated with cousin marriages, the societal and cultural associations they make with both cousin and marriages and science, as well as fears of stigma for being within said marriages. Future works can focus on direct improvements in the genetic counselling process as well as health promotion initiatives that target different facets of cousin marriages, such as people's religious and cultural ties to the practice.

References

1. A. H. Bittles RH. An analysis of consanguineous marriage in the Muslim population of India at regional and state levels. Annals of Human Biology. 2000 Jan 1;27(2):163–71. doi:10.1080/030144600282271 PubMed PMID: 10768421.

2. Bennett RL, Motulsky AG, Bittles A, Hudgins L, Uhrich S, Doyle DL, et al. Genetic Counseling and Screening of Consanguineous Couples and Their Offspring: Recommendations of the National Society of Genetic Counselors. Journal of Genetic Counseling. 2002;11(2):97–119. doi:10.1023/A:1014593404915

3. Heidari F, Dastgiri S, Akbari R, Khamnian Z, Khanlarzadeh E, Baradaran M, et al. Prevalence and Risk Factors of Consanguineous Marriage. European Journal of General Medicine. 2014 Dec 1;11(4):248–55. doi:10.15197/sabad.1.11.81

4. Vardi-Saliternik R, Friedlander Y, Cohen T. Consanguinity in a population sample of Israeli Muslim Arabs, Christian Arabs and Druze. Annals of Human Biology. 2002 Jan 1;29(4):422–31. doi:10.1080/03014460110100928

5. Sandridge AL, Takeddin J, Al-Kaabi E, Frances Y. CONSANGUINITY IN QATAR: KNOWLEDGE, ATTITUDE AND PRACTICE IN A POPULATION BORN BETWEEN 1946 AND 1991. Journal of Biosocial Science. 2010 Jan;42(1):59–82. doi:10.1017/S002193200999023X

6. Islam MM. Consanguineous marriage and its relevance to divorce, polygyny and survival of marriage: evidence from a population-based analysis in Jordan. Annals of Human Biology. 2021 Jan 2;48(1):30–6. doi:10.1080/03014460.2021.1877354 PubMed PMID: 33470846.

7. Aissaoui F. CONSANGUINEOUS MARRIAGE BETWEEN SHARIA, LAW AND MEDICINE. Journal of Law and Sustainable Development. 2024 Aug 8;12(8):e3887–e3887. doi:10.55908/sdgs.v12i8.3887

8. Khuri FI. Parallel Cousin Marriage Reconsidered: A Middle Eastern Practice That Nullifies the Effects of Marriage on the Intensity of Family Relationships. Man. 1970;5(4):597–618. doi:10.2307/2799105

9. Korotayev A. Parallel-Cousin (FBD) Marriage, Islamization, and Arabization. Ethnology. 2000;39(4):395–407. doi:10.2307/3774053

10. Hussain R. Consanguinity: Cultural, Religious and Social Aspects. In: Kumar D, editor. Genetic Disorders of the Indian Subcontinent [Internet]. Dordrecht: Springer Netherlands; 2004 [cited 2026 Mar 1]. p. 125–35. Available from: http://link.springer.com/10.1007/978-1-4020-2231-9_6 doi:10.1007/978-1-4020-2231-9_6

11. Edlund L. Cousin Marriage Is Not Choice: Muslim Marriage and Underdevelopment. AEA Papers and Proceedings. 2018;108:353–7.

12. Teeuw ME, Loukili G, Bartels EA, ten Kate LP, Cornel MC, Henneman L. Consanguineous marriage and reproductive risk: attitudes and understanding of ethnic groups practising consanguinity in Western society. Eur J Hum Genet. 2014 Apr;22(4):452–7. doi:10.1038/ejhg.2013.167

13. Meyer SB, Rotolo B, Majowicz S, Amoako J, Crouch M, Hopwood P, et al. Perceptions of COVID-19 related risks by platform-based couriers: An analysis of user comment threads on Reddit. Work. 2023;75(4):1113–25. doi:10.3233/WOR-220244 PubMed PMID: 36776089.

14. Rotolo B, Bin Noon G, Chen HH, Butt ZA. Public Attitudes Towards Vaccine Passports in Alberta During the "Pandemic of the Unvaccinated": A Qualitative Analysis of Reddit Posts. Int J Public Health. 2023 Dec 22;68:1606514. doi:10.3389/ijph.2023.1606514

15. Alquayb A. The discourse surrounding Saudi women's attire on Reddit: a critical discourse analysis. Proceedings of the Linguistic Society of America. 2025 May 7;10(1):5908–5908. doi:10.3765/plsa.v10i1.5908

16. Gee JP. An Introduction to Discourse Analysis: Theory and Method. 5th ed. London: Routledge; 2025. 290 p. doi:10.4324/9781003535935

17. PRAW 7.7.1 documentation [Internet]. [cited 2026 Jan 7]. Available from: https://praw.readthedocs.io/en/stable/

18. Zola IK. Whither medicine—Three views. Social Science & Medicine (1967). 1970 Dec 1;4(6):687–90. doi:10.1016/0037-7856(70)90110-1

19. Akrami SM, Osati Z. IS CONSANGUINEOUS MARRIAGE RELIGIOUSLY ENCOURAGED? ISLAMIC AND IRANIAN CONSIDERATIONS. Journal of Biosocial Science. 2007 Mar;39(2):313–6. doi:10.1017/S0021932006001684

20. Khan U. Kissing Cousins: Racism, Homophobia and Compulsory Able-Bodiedness in the Controversy Over Inter-Cousin Marriage. JINDAL GLOBAL LAW REVIEW [Internet]. 2013 [cited 2026 Mar 25];4(2). Available from: https://completejusticepodcast.s3.ap-south-1.amazonaws.com/Ummni+Khan+-+Kissing+Cousins+-+Rasicim%2C+Homophobia+and+Compulsory+Able-bodiedness+in+the+Controversy+over+Inter-Cousin+Marriage.pdf

21. Hamamy H. Consanguineous marriages. J Community Genet. 2012 July 1;3(3):185–92.

22. Modell B, Darr A. Genetic counselling and customary consanguineous marriage. Nat Rev Genet. 2002 Mar;3(3):225–9. doi:10.1038/nrg754

23. Vignoles VL, Owe E, Becker M, Smith PB, Easterbrook MJ, Brown R, et al. Beyond the 'east–west' dichotomy: Global variation in cultural models of selfhood. Journal of Experimental Psychology: General. 2016;145(8):966–1000. doi:10.1037/xge0000175

24. Edis T. Modern Science and Conservative Islam: An Uneasy Relationship. Sci & Educ. 2009 Jun 1;18(6):885–903. doi:10.1007/s11191-008-9165-3

25. Clarke AJ, Wallgren-Pettersson C. Ethics in genetic counselling. J Community Genet. 2019 Jan 1;10(1):3–33. doi:10.1007/s12687-018-0371-7

26. Subramanian S. The Abundance of Harmful Rare Homozygous Variants in Children of Consanguineous Parents. Biology (Basel). 2025 Mar 19;14(3):310. doi:10.3390/biology14030310 PubMed PMID: 40136566; PubMed Central PMCID: PMC11940780.

27. Aromataris E, Riitano D. Systematic Reviews: Constructing a Search Strategy and Searching for Evidence. AJN The American Journal of Nursing. 2014 May;114(5):49. doi:10.1097/01.NAJ.0000446779.99522.f6

Chapter 5. General Discussion

Paper 1, the scoping review of perspectives on genetic counselling for cousin marriage, found key gaps: (1) The majority of studies in the space were in the Middle East and North Africa (MENA) region, leaving a gap in terms of obtaining perspectives in non-MENA regions; (2) Quantitative methodologies were dominant across studies, leaving a gap in terms of the insights that qualitative research can afford investigation in this research area (e.g., more specifically, for instance, while a survey can show that a certain percentage of people may find religion to be a reason for rejection of genetic counselling, qualitative studies can show the underlying reasoning behind why that is the case); (3) Finally, a gap in the incorporation of theory was found, in that the vast majority of studies did not apply theory either in terms of analysis or as an explanatory framework for findings. Paper 2, the qualitative study of perspectives on cousin marriage and genetic counselling for cousin marriage within Muslim-focused subreddits, addressed these gaps: Paper 2 employed a qualitative methodology, used social media to capture potentially global perspectives (as well as in the consideration that this is a sensitive topic that may be difficult to discuss in interviews or focus groups), and incorporated social theory in the explanation and discussion of findings. In this sense, there is a synthesis between both papers in that one paper identifies gaps in research and the second paper attempts to address them. The overall work demonstrates that while studies on cousin marriage and genetic counselling exist, there is still work to do in terms of diversifying locations of study, methodologies, and theoretical bases of future studies. Perspectives surrounding cousin marriage may also include derisions of scientific concerns for genetic risk to offspring, in addition to stigmatising statements that can alienate those within cousin marriages. Both the scoping review and the qualitative study affirmed that

religion is a factor in people's perspectives on genetic counselling for consanguinity – this was a clear similarity between both papers. The qualitative study built on the perspectives from the scoping review by showing new insights, specifically regarding the ways in which people talk about cousin marriage and genetic testing for it – for instance, the qualitative study uncovered that people view an East-West dichotomy when it comes to cousin marriage, an aspect that did not emerge from the review. A tension that emerged, however, was that while the scoping review showed that people lacked awareness of genetic counselling, a substantial portion of the data in the qualitative study showed clear awareness of the practice, though with the caveat of there being rejection of the science behind genetic counselling. Next steps could include conducting deeper investigations into the way people balance perceptions of science and religion, particularly within the context of people who may deride science, as well as ways in which to address stigma against those in cousin marriages. In addition, more work could be done to address the gaps found by the scoping review, such as by conducting more qualitative work in a wider variety of locations.

There are several more specific implications from this thesis that could lead to tremendous impact on the research landscape for cousin marriages: For instance, highlighting the geographical concentration of studies identified in the scoping review could prompt researchers globally to conduct local research on how their respective Muslim communities view genetic counselling for consanguinity. While the second paper of this thesis opted for using social media as the site for qualitative data, other researchers may conduct interviews for potentially richer and more guided information. The insights gathered from the second paper have the potential to inform genetic counselling practice, as well as future research surrounding cousin marriage views. When

considering the varied nature of people's views, the qualitative study could contribute to changing the practical landscape of genetic counselling by highlighting language and statements used by people with regards to religion, understanding of science, cultural dichotomies, stigma etc. to fine-tune the ways in which genetic counsellors engage with Muslims. Practice guidelines have been developed for genetic counselling in the past (57), and the paper's findings can potentially contribute to said guidelines by ensuring sensitivity to religion and culture are maintained. Understanding people's views and beliefs with regards to cousin marriages can help genetic counsellors balance said sensitivity with provision of an educated choice to cousin couples with regards to offspring, and the quotes captured by the second paper of this thesis delineate diverse public discourse surrounding cousin marriage that can be used to inform the counselling process. In addition, there have also been calls for genetic counselling to be more understanding of the cultural significance of cousin marriages (58), and this thesis' second paper provides a baseline from which to understand Muslim discourse regarding cousin marriages and associated genetic counselling. Implications are not limited to practice, however; given the finding of stigma potentially being felt by those who practice cousin marriages, there could be future research on best intervention practices for mitigating the backlash Muslims may receive for entering cousin marriages, as any stigma may impact the desire to seek genetic testing or medical assistance for potential offspring. In this sense, there are even implications in legal research that could be pursued, centrally in ensuring respect of cultural practice while also upholding child safety by mandating genetic testing for cousin marriages, for instance. A law in the UK was proposed to outright ban cousin marriage but was struck down due to not considering people's cultural sensitivities with the topic (59). Given that the second paper of this thesis is a social media-based

study, future studies could look into perspectives on cousin marriages and genetic counselling situated among Muslims within specific countries across the globe, particularly ones that are not Muslim-majority. Hence, this research has wide-reaching implications across multiple fields of research and practice.

Chapter 6. Conclusion

This thesis was a two-pronged investigation into both the research surrounding perspectives on genetic counselling for consanguinity and Reddit-based perspectives on cousin marriages and genetic counselling. The first paper was a scoping review while the second paper was a qualitative study. Both used search strategies and iteratively created search strategies to gather information, with the first paper sourcing from journal databases while the second paper sourced from Reddit. The findings across this thesis aim to help inform future discussions, research, and initiatives regarding cousin marriages and genetic counselling.

References

1. Simpson JL, Rechitsky S, Kuliev A. Before the beginning: the genetic risk of a couple aiming to conceive. Fertility and Sterility. 2019 Oct 1;112(4):622–30. doi:10.1016/j.fertnstert.2019.08.002

2. Bener A, Mohammad RR. Global distribution of consanguinity and their impact on complex diseases: Genetic disorders from an endogamous population. Egyptian Journal of Medical Human Genetics. 2017 Oct 1;18(4):315–20. doi:10.1016/j.ejmhg.2017.01.002

3. Hamamy H. Consanguineous marriages. J Community Genet. 2012 Jul 1;3(3):185–92. doi:10.1007/s12687-011-0072-y

4. Al-Eisawi Z, Jacoub K, Alsukker A. A large-scale study exploring understanding of the national premarital screening program among Jordanians: Is an at-risk marriage a valid option for Jordanians? Public Underst Sci. 2021 Apr 1;30(3):319–30. doi:10.1177/0963662520968468

5. Hussain R. COMMUNITY PERCEPTIONS OF REASONS FOR PREFERENCE FOR CONSANGUINEOUS MARRIAGES IN PAKISTAN. Journal of Biosocial Science. 1999 Oct;31(4):449–61. doi:10.1017/S0021932099004496

6. Gingrich A. The prophet's smile and other puzzles. Studying Arab tribes and comparing close marriages. Social Anthropology. 1995;3(2):147–70. doi:10.1111/j.1469-8676.1995.tb00299.x

7. Dorsten LE, Hotchkiss L, King TM. The effect of inbreeding on early childhood mortality: Twelve generations of an amish settlement. Demography. 1999;36(2):263–71. doi:10.2307/2648113

8. Kundu S, Jana A. Consanguineous marriage and associated diseases among their children and grandchildren in India: evidence from large-scale data. Journal of Biosocial Science. 2024 Jul;56(4):796–808. doi:10.1017/S0021932024000178

9. Popescu G, Rusu C, Maștaleru A, Oancea A, Cumpăt CM, Luca MC, et al. Social and Demographic Determinants of Consanguineous Marriage: Insights from a Literature Review. Genealogy. 2025 Jul 3;9(3). doi:10.3390/genealogy9030069

10. Cohen T, Vardi-Saliternik R, Friedlander Y. Consanguinity, intracommunity and intercommunity marriages in a population sample of Israeli Jews. Annals of Human Biology. 2004 Jan 1;31(1):38–48. doi:10.1080/0301446032000159255 PubMed PMID: 14742164.

11. Leach ER. The Structural Implications of Matrilateral Cross-Cousin Marriage. The Journal of the Royal Anthropological Institute of Great Britain and Ireland. 1951;81(1/2):23–55. doi:10.2307/2844015

12. Murphy RF, Kasdan L. The Structure of Parallel Cousin Marriage. American Anthropologist. 1959;61(1):17–29.

13. Tapper R, Tapper N. Marriage, Honour and Responsibility: Islamic and Local Models in the Mediterranean and the Middle East. Cambridge Anthropology. 1992;16(2):3–21.

14. Denic S, Nagelkerke N, Agarwal MM. Choice of kin in consanguineous marriages: Effects of altruism and ecological factors. Annals of Human Biology. 2010 Nov 1;37(6):738–53. doi:10.3109/03014460903575354

15. Power EA, Ready E. Cooperation beyond consanguinity: post-marital residence, delineations of kin and social support among South Indian Tamils. Philos Trans R Soc Lond B Biol Sci. 2019 Jul 15;374(1780):20180070. doi:10.1098/rstb.2018.0070

16. Eggan F. The Maya Kinship System and Cross-Cousin Marriage. American Anthropologist. 1934;36(2):188–202.

17. Bras H, Van Poppel F, Mandemakers K. Relatives as spouses: Preferences and opportunities for kin marriage in a Western society. American Journal of Human Biology. 2009;21(6):793–804. doi:10.1002/ajhb.20896

18. Darlington CD. Cousin marriage and population structure. Eugen Rev. 1961 Oct;53(3):139–44. PubMed PMID: 21260832; PubMed Central PMCID: PMC2972853.

19. Kilshaw S, Al Raisi T, Alshaban F. Arranging marriage; negotiating risk: genetics and society in Qatar. Anthropology & Medicine. 2015 May 4;22(2):98–113. doi:10.1080/13648470.2014.976542 PubMed PMID: 25609185.

20. Mobarak AM, Chaudhry T, Brown J, Zelenska T, Khan MN, Chaudry S, et al. ESTIMATING THE HEALTH AND SOCIOECONOMIC EFFECTS OF COUSIN MARRIAGE IN SOUTH ASIA. Journal of Biosocial Science. 2019 May;51(3):418–35. doi:10.1017/S0021932018000275

21. Reilly B. Revisiting Consanguineous Marriage in the Greater Middle East: Milk, Blood, and Bedouins. American Anthropologist. 2013;115(3):374–87. doi:10.1111/aman.12023

22. Islam MM. THE PRACTICE OF CONSANGUINEOUS MARRIAGE IN OMAN: PREVALENCE, TRENDS AND DETERMINANTS. Journal of Biosocial Science. 2012 Sep;44(5):571–94. doi:10.1017/S0021932012000016

23. Islam MM. Effects of consanguineous marriage on reproductive behaviour, adverse pregnancy outcomes and offspring mortality in Oman. Annals of Human Biology. 2013 May 1;40(3):243–55. doi:10.3109/03014460.2012.760649 PubMed PMID: 23384045.

24. Kaplan S, Pinar G, Kaplan B, Aslantekin F, Karabulut E, Ayar B, et al. THE PREVALENCE OF CONSANGUINEOUS MARRIAGES AND AFFECTING FACTORS IN TURKEY: A NATIONAL SURVEY. Journal of Biosocial Science. 2016 Sep;48(5):616–30. doi:10.1017/S0021932016000055

25. Akrami SM, Osati Z. IS CONSANGUINEOUS MARRIAGE RELIGIOUSLY ENCOURAGED? ISLAMIC AND IRANIAN CONSIDERATIONS. Journal of Biosocial Science. 2007 Mar;39(2):313–6. doi:10.1017/S0021932006001684

26. Al-Arrayed S, Hamamy H. THE CHANGING PROFILE OF CONSANGUINITY RATES IN BAHRAIN, 1990–2009. Journal of Biosocial Science. 2012 May;44(3):313–9. doi:10.1017/S0021932011000666

27. Nouri N, Nouri N, Tirgar S, Soleimani E, Yazdani V, Zahedi F, et al. Consanguineous marriages in the genetic counseling centers of Isfahan and the ethical issues of clinical consultations.

Journal of Medical Ethics and History of Medicine [Internet]. 2017 Dec 10 [cited 2026 Feb 22]. Available from: https://jmehm.tums.ac.ir/index.php/jmehm/article/view/289

28. Shenk MK, Naz S, Chaudhry T. Intensive Kinship, Development, and Demography: Why Pakistan has the Highest Rates of Cousin Marriage in the World. Population and Development Review. 2024;50(4):1045–90. doi:10.1111/padr.12678

29. Hoben AD, Buunk AP, Fisher ML. Factors influencing the allowance of cousin marriages in the standard cross cultural sample. Evolutionary Behavioral Sciences. 2016;10(2):98–108. doi:10.1037/ebs0000034

30. Agha N. Kinship in rural Pakistan: Consanguineous marriages and their implications for women. Women's Studies International Forum. 2016 Jan 1;54:1–10. doi:10.1016/j.wsif.2015.10.005

31. Khuri FI. Parallel Cousin Marriage Reconsidered: A Middle Eastern Practice That Nullifies the Effects of Marriage on the Intensity of Family Relationships. Man. 1970;5(4):597–618. doi:10.2307/2799105

32. Charsley K. Risk, trust, gender and transnational cousin marriage among British Pakistanis. Ethnic and Racial Studies. 2007 Nov 1;30(6):1117–31. doi:10.1080/01419870701599549

33. Shaw A. Drivers of Cousin Marriage among British Pakistanis. Human Heredity. 2014;77(1/4):26–36.

34. Ghanim M, Mosleh R, Hamdan A, Amer J, Alqub M, Jarrar Y, et al. Assessment of Perceptions and Predictors Towards Consanguinity: A Cross-Sectional Study from Palestine. Journal of Multidisciplinary Healthcare. 2023 Dec 31;16:3443–53. doi:10.2147/JMDH.S433506 PubMed PMID: 38024133.

35. Kalam MA, Pal S. Consanguineous Marriage in Global Perspective: Anthropological Roots, Genetic Risks, Contemporary Relevance, and the Way Forward. Nature Anthropology. 2025 Dec;4(1):10023. doi:10.70322/natanthropol.2025.10023

36. Bener A, Abdulrazzaq YM, Al-Gazali LI, Micallef R, Al-Khayat AI, Gaber T. Consanguinity and Associated Socio-Demographic Factors in the United Arab Emirates. Human Heredity. 1996;46(5):256–64.

37. Warsy AS, Al-Jaser MH, Albdass A, Al-Daihan S, Alanazi M. Is consanguinity prevalence decreasing in Saudis?: a study in two generations. Afr Health Sci. 2014 Jun;14(2):314–21. doi:10.4314/ahs.v14i2.5 PubMed PMID: 25320579; PubMed Central PMCID: PMC4196414.

38. Ben-Omran T, Al Ghanim K, Yavarna T, El Akoum M, Samara M, Chandra P, et al. Effects of consanguinity in a cohort of subjects with certain genetic disorders in Qatar. Molecular Genetics & Genomic Medicine. 2020;8(1):e1051. doi:10.1002/mgg3.1051

39. Jaber L, Halpern GJ, Shohat M. The Impact of Consanguinity Worldwide. Community Genetics. 1998;1(1):12–7.

40. Olubunmi O, Neves K, Badreldeen A, Konje JC. A review of the reproductive consequences of consanguinity. European Journal of Obstetrics & Gynecology and Reproductive Biology. 2019 Jan 1;232:87–96. doi:10.1016/j.ejogrb.2018.10.042

41. Shawky RM, Elsayed SM, Zaki ME, El-Din SMN, Kamal FM. Consanguinity and its relevance to clinical genetics. Egyptian Journal of Medical Human Genetics [Internet]. 2013 Apr 17 [cited 2026 Feb 22];14(2). Available from: https://www.ajol.info/index.php/ejhg/article/view/87408

42. Tadmouri GO, Nair P, Obeid T, Al Ali MT, Al Khaja N, Hamamy HA. Consanguinity and reproductive health among Arabs. Reprod Health. 2009 Oct 8;6(1):17. doi:10.1186/1742-4755-6-17

43. Anwar S, Mourosi JT, Arafat Y, Hosen MJ. Genetic and reproductive consequences of consanguineous marriage in Bangladesh. PLOS ONE. 2020 Nov 30;15(11):e0241610. doi:10.1371/journal.pone.0241610

44. Anwar WA, Khyatti M, Hemminki K. Consanguinity and genetic diseases in North Africa and immigrants to Europe. Eur J Public Health. 2014 Aug 1;24(suppl_1):57–63. doi:10.1093/eurpub/cku104

45. Hajjaji M, Khadmaoui A, El Bakkali M. The practice of consanguineous marriage and the risk of diabetes among offspring in the province of Tetouan (Morocco). Arab Gulf Journal of Scientific Research. 2023 Feb 27;42(1):30–43. doi:10.1108/AGJSR-08-2022-0134

46. Bhinder MA, Sadia H, Mahmood N, Qasim M, Hussain Z, Rashid MM, et al. Consanguinity: A blessing or menace at population level? Annals of Human Genetics. 2019;83(4):214–9. doi:10.1111/ahg.12308

47. Bittles AH, Black ML. The impact of consanguinity on neonatal and infant health. Early Human Development. 2010 Nov 1;Selected Proceedings of the Neonatal Update 201086(11):737–41. doi:10.1016/j.earlhumdev.2010.08.003

48. Ehlayel M, Bener A, Laban MA. Effects of family history and consanguinity in primary immunodeficiency diseases in children in Qatar. Open Journal of Immunology. 2013 Jun 5;3(2):47–53. doi:10.4236/oji.2013.32008

49. Khayat AM, Alshareef BG, Alharbi SF, AlZahrani MM, Alshangity BA, Tashkandi NF. Consanguineous Marriage and Its Association With Genetic Disorders in Saudi Arabia: A Review. Cureus. 2024;16(2):e53888. doi:10.7759/cureus.53888 PubMed PMID: 38465157; PubMed Central PMCID: PMC10924896.

50. Bennett RL, Motulsky AG, Bittles A, Hudgins L, Uhrich S, Doyle DL, et al. Genetic Counseling and Screening of Consanguineous Couples and Their Offspring: Recommendations of the National Society of Genetic Counselors. Journal of Genetic Counseling. 2002;11(2):97–119. doi:10.1023/A:1014593404915

51. El Shanti H, Chouchane L, Badii R, Gallouzi IE, Gasparini P. Genetic testing and genomic analysis: a debate on ethical, social and legal issues in the Arab world with a focus on Qatar. J Transl Med. 2015 Nov 14;13(1):358. doi:10.1186/s12967-015-0720-9

52. Darr A, Small N, Ahmad WIU, Atkin K, Corry P, Benson J, et al. Examining the family-centred approach to genetic testing and counselling among UK Pakistanis: a community perspective. J Community Genet. 2013 Jan 1;4(1):49–57. doi:10.1007/s12687-012-0117-x

53. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. International Journal of Social Research Methodology. 2005 Feb 1;8(1):19–32. doi:10.1080/1364557032000119616

54. Rotolo B, Bin Noon G, Chen HH, Butt ZA. Public Attitudes Towards Vaccine Passports in Alberta During the "Pandemic of the Unvaccinated": A Qualitative Analysis of Reddit Posts. Int J Public Health. 2023 Dec 22;68:1606514. doi:10.3389/ijph.2023.1606514

55. Meyer SB, Rotolo B, Majowicz S, Amoako J, Crouch M, Hopwood P, et al. Perceptions of COVID-19 related risks by platform-based couriers: An analysis of user comment threads on Reddit. Work. 2023;75(4):1113–25. doi:10.3233/WOR-220244 PubMed PMID: 36776089.

56. Lustig A, Brookes G. Corpus-Based Discourse Analysis of a Reddit Community of Users of Crystal Methamphetamine: Mixed Methods Study. JMIR Infodemiology. 2023 Sep 29;3(1):e48189. doi:10.2196/48189

57. Skirton H, Patch C, Voelckel MA. Using a community of practice to develop standards of practice and education for genetic counsellors in Europe. J Community Genet. 2010 Dec 1;1(4):169–73. doi:10.1007/s12687-010-0024-y

58. Modell B, Darr A. Genetic counselling and customary consanguineous marriage. Nat Rev Genet. 2002 Mar;3(3):225–9. doi:10.1038/nrg754

59. Glover-Thomas N. Consanguineous Marriage: Law and Public Health. Health Care Anal. 2025 Dec 1;33(4):321–36. doi:10.1007/s10728-025-00541-2

Appendices

Appendix for Paper 1

Search Strategies:

Web of Science:

ALL=("genetic counselling" OR "genetic counseling") AND ALL=("first-cousin" OR consanguin* OR "consanguineous relationship" OR "consanguineous marriage" OR "cousin marriage" OR "close-kin marriage" OR "close kin marriage" OR "consanguineous couple" OR "consanguineous couples" OR "premarital counseling" OR "premarital counselling" OR "pre-marital counseling" OR "pre-marital counselling" OR "preconception counseling" OR "preconception counselling" OR "pre-conception counseling" OR "pre-conception counselling" OR "premarital screening" OR "pre-marital screen" OR intermarr* OR inbreeding OR inbred OR inbred OR preconception OR premarital OR "pre-conception" OR "pre-marital" OR "reproductive behavior" OR "reproductive behaviour") AND ALL=(attitude* OR experience* OR perception* OR perceive* OR belief* OR view* OR trust* OR confiden* OR aware* OR decision* OR knowledge* OR perspective* OR awareness OR mistrust OR distrust OR stigma OR taboo OR ethics OR "ethical issues" OR "social issues" OR "cultural issues" OR "culture")

- Searched performed on 2025-02-18 by first author
- Retrieved 503 results

Scopus:

(TITLE-ABS-KEY ("genetic counselling" OR "genetic counseling") AND TITLE-ABS-KEY ("first-cousin" OR consanguin* OR "consanguineous relationship" OR "consanguineous marriage" OR "cousin marriage" OR "close-kin marriage" OR "close kin marriage" OR "consanguineous couple" OR "consanguineous couples" OR "premarital counseling" OR "premarital counselling" OR "pre-marital counseling" OR "pre-marital counselling" OR "preconception counseling" OR "preconception counselling" OR "pre-conception counseling" OR "pre-conception counselling" OR "premarital screening" OR "pre-marital screen" OR intermarr* OR inbreeding OR inbred OR inbreed OR preconception OR premarital OR "pre-conception" OR "pre-marital" OR "reproductive behavior" OR "reproductive behaviour") AND TITLE-ABS-KEY (attitude* OR experience* OR perception* OR perceive* OR belief* OR view* OR trust* OR confiden* OR aware* OR decision* OR knowledge* OR perspective* OR awareness OR mistrust OR distrust OR stigma OR taboo OR ethics OR "ethical issues" OR "social issues" OR "cultural issues" OR "culture"))

- Searched performed on 2025-02-18 by first author
- Retrieved 934 results

PsycINFO:

Any Field: "genetic counselling" *OR* **Any Field**: "genetic counseling" *AND* **Any Field**: "first-cousin" *OR* **Any Field**: consanguin* *OR* **Any Field**: "consanguineous relationship" *OR* **Any Field**: "consanguineous marriage" *OR* **Any Field**: "cousin marriage" *OR* **Any Field**: "close-kin marriage" *OR* **Any Field**: "close kin marriage" *OR* **Any Field**: "consanguineous couple" *OR* **Any**

Field: "consanguineous couples" *OR* **Any Field**: "premarital counseling" *OR* **Any Field**: "premarital counselling" *OR* **Any Field**: "pre-marital counseling" *OR* **Any Field**: "pre-marital counselling" *OR* **Any Field**: "preconception counseling" *OR* **Any Field**: "preconception counselling" *OR* **Any Field**: "pre-conception counseling" *OR* **Any Field**: "pre-conception counselling" *OR* **Any Field**: "premarital screening" *OR* **Any Field**: "pre-marital screen" *OR* **Any Field**: intermarr* *OR* **Any Field**: inbreeding *OR* **Any Field**: inbred *OR* **Any Field**: inbreed *OR* **Any Field**: preconception *OR* **Any Field**: premarital *OR* **Any Field**: "pre-conception" *OR* **Any Field**: "pre-marital" *OR* **Any Field**: "reproductive behavior" *OR* **Any Field**: "reproductive behaviour" *AND* **Any Field**: attitude* *OR* **Any Field**: experience* *OR* **Any Field**: perception* *OR* **Any Field**: perceive* *OR* **Any Field**: belief* *OR* **Any Field**: view* *OR* **Any Field**: trust* *OR* **Any Field**: confiden* *OR* **Any Field**: aware* *OR* **Any Field**: decision* *OR* **Any Field**: knowledge* *OR* **Any Field**: perspective* *OR* **Any Field**: awareness *OR* **Any Field**: mistrust *OR* **Any Field**: distrust *OR* **Any Field**: stigma *OR* **Any Field**: taboo *OR* **Any Field**: ethics *OR* **Any Field**: "ethical issues" *OR* **Any Field**: "social issues" *OR* **Any Field**: "cultural issues" *OR* **Any Field**: "culture"

- Searched performed on 2025-02-18 by first author
- Retrieved 106 results

PubMed:

("genetic counselling"[All Fields] OR "genetic counseling"[All Fields]) AND ("first-cousin"[All Fields] OR "consanguin*"[All Fields] OR "consanguineous relationship"[All Fields] OR

"consanguineous marriage"[All Fields] OR "cousin marriage"[All Fields] OR "consanguineous couple"[All Fields] OR "consanguineous couples"[All Fields] OR "premarital counseling"[All Fields] OR "premarital counselling"[All Fields] OR "pre-marital counseling"[All Fields] OR "pre-marital counselling"[All Fields] OR "preconception counseling"[All Fields] OR "preconception counselling"[All Fields] OR "pre-conception counseling"[All Fields] OR "pre-conception counselling"[All Fields] OR "premarital screening"[All Fields] OR "intermarr*"[All Fields] OR ("inbreeder"[All Fields] OR "inbreeders"[All Fields] OR "inbreeding"[MeSH Terms] OR "inbreeding"[All Fields]) OR ("inbred"[All Fields] OR "inbreds"[All Fields]) OR ("inbred"[All Fields] OR "inbreds"[All Fields]) OR ("preconception"[All Fields] OR "preconceptional"[All Fields] OR "preconceptions"[All Fields]) OR ("premarital"[All Fields] OR "premaritally"[All Fields]) OR "pre-conception"[All Fields] OR "pre-marital"[All Fields] OR "reproductive behavior"[All Fields] OR "reproductive behaviour"[All Fields]) AND ("attitude*"[All Fields] OR "experience*"[All Fields] OR "perception*"[All Fields] OR "perceive*"[All Fields] OR "belief*"[All Fields] OR "view*"[All Fields] OR "trust*"[All Fields] OR "confiden*"[All Fields] OR "aware*"[All Fields] OR "decision*"[All Fields] OR "knowledge*"[All Fields] OR "perspective*"[All Fields] OR ("awareness"[MeSH Terms] OR "awareness"[All Fields] OR "aware"[All Fields] OR "awarenesses"[All Fields]) OR ("mistrust"[All Fields] OR "mistrusted"[All Fields] OR "mistrustful"[All Fields] OR "mistrusting"[All Fields]) OR ("distrust"[All Fields] OR "distrusted"[All Fields] OR "distrustful"[All Fields] OR "distrusting"[All Fields] OR "distrusts"[All Fields]) OR ("social stigma"[MeSH Terms] OR ("social"[All Fields] AND "stigma"[All Fields]) OR "social stigma"[All Fields] OR "stigma"[All Fields] OR "stigmas"[All Fields] OR "stigma s"[All Fields]) OR ("taboo"[MeSH Terms] OR "taboo"[All Fields] OR "taboos"[All Fields]) OR ("ethic s"[All Fields]

OR "ethical"[All Fields] OR "ethicality"[All Fields] OR "ethically"[All Fields] OR "ethics"[MeSH Terms] OR "ethics"[All Fields] OR "ethic"[All Fields] OR "ethics"[MeSH Subheading]) OR "ethical issues"[All Fields] OR "social issues"[All Fields] OR "cultural issues"[All Fields] OR "culture"[All Fields])

- Searched performed on 2025-02-19 by first author
- Retrieved 645 results

Final results count after removal of duplicates:

1311

Data extraction – Appendix for Paper 1

Year	Authors	Study Location	Consanguinity Type	Study Design	Findings	Theories
2021	Aga et al	Saudi Arabia	First-cousin	Quantitative	Majority of participants had positive outlook on use of counselling process	N/A
2015	Ahram et al	Jordan	First-cousin	Quantitative	Education is an important factor in decision-making	N/A
2024	Al Eissa et al	Saudi Arabia	First, second	Quantitative	Family history increases likelihood of awareness of counselling	N/A

2008	Al Sulaiman et al	Saudi Arabia	N/A	Quantitative	Most participants had positive attitudes related to genetic counselling	N/A
2006	Al Sulaiman & Hewison	Saudi Arabia	First-cousin, second-cousin	Quantitative	Education is an important factor in decision-making	N/A
2021	Al Zeedi & Al Abri	Oman	First-cousins, second-cousins	Quantitative	Most had positive outlook on use of counselling process	N/A
2023	Alawad et al	Saudi Arabia	N/A	Quantitative	Gender is not an important factor in	N/A

					decision-making	
2021	Al-Eisawi et al	Jordan	First-cousin	Quantitative	Education, religion, and gender are important factors in decision-making	N/A
2005	Al-Gazali	UAE	First-cousin, second cousin, double cousin	Mixed-methods	Religion is an important factor in decision-making	N/A
2019	Alhowiti & Shaqran	Saudi Arabia	First-cousin	Quantitative	Most participants possessed knowledge; gender	N/A

					determined knowledge	
2023	Alizary, A. et al	Saudi Arabia	First, second, double	Quantitative	Religion is an important factor in decision-making	N/A
2022	Alkalbani, A et al	Oman	First and second cousin	Quantitative	Religion is an important factor in decision-making; Gender is not	N/A
2002	Al-Khaldi et al	Saudi Arabia	N/A	Quantitative	Religion is an important factor in decision-making	N/A
2019	Al-Kindi, et al	Oman	First and second cousin	Quantitative	Religion is an important	N/A

					factor in decision-making	
2001	Alkuraya & Kilani	Saudi Arabia	N/A	Quantitative	Religion is an important factor in decision-making	N/A
2022	Almannaei et al	Bahrain	N/A	Quantitative	Most medical students stated that they would go against genetic counselling advice, most non-medical students said opposite	N/A
2022	Almasmoum et al	Saudi Arabia	First and second cousin	Quantitative	Gender is an important factor in	N/A

					decision-making	
2023	AlOtaiby et al	Saudi Arabia	N/A	Quantitative	Participants had positive perspectives towards the counselling process	N/A
2019	Al-Qattan et al	Saudi Arabia	First cousin	Quantitative	Less than half had positive outlook on process and less than half were aware of it	N/A
2022	Al-Shafai et al	Qatar	First and second cousin	Mixed-methods	Gender is an important factor in decision-making	N/A

2021	Al-Shroby et al	Saudi Arabia	First-cousin	Quantitative	Education is an important factor in decision-making	N/A
2021	Altaany et al	Jordan	N/A	Quantitative	Education is an important factor in decision-making	N/A
2024	Alwhaibi et al	Saudi Arabia	First-cousin	Quantitative	Education is an important factor in decision-making	N/A
2020	Asadollahi et al	Iran	First and second cousin	Quantitative	Less than half were aware of genetic counselling	N/A

2019	Bener et al	Qatar	First and second cousin	Quantitative	Education is an important factor in decision-making	N/A
2020	Cohen-Kfir et al	Israel	N/A	Qualitative	Most participants had negative outlook towards genetic counselling	N/A
2018	Eissa et al	Saudi Arabia	N/A	Quantitative	Most participants showed positive outlook towards genetic counselling	N/A
2021	El Sabeh et al	Lebanon	First and second cousin	Quantitative	Only a third of participants had tested, and only a third did	N/A

					it for medical reasons rather than only mandatory	
2025	Ghanim et al	Palestine	N/A	Quantitative	Education is an important factor in decision-making	N/A
2019	Hashemi-Soteh et al	Iran	N/A	Quantitative	Education is an important factor in decision-making	N/A
2023	Hassan, A.H.	Saudi Arabia	First cousin	Quantitative	Education and religion are important factors in decision-making	N/A

2013	Ibrahim et al	Saudi Arabia	First-cousin	Quantitative	Religion is an important factor in decision-making	N/A
2000	Jaber et al	Israel	First-cousin and other consanguineous types	Quantitative	Poor awareness	N/A
2019	Josephi-Taylor et al	Australia	First and second cousin	Qualitative	Religion is an important factor in decision-making	N/A
2016	Nikzadian et al	Iran	N/A	Quantitative	Lack of knowledge and awareness	N/A
2003	Raz et al	Israel	First cousin	Mixed-methods	Education is an important factor in	Health belief model

					decision-making	
2015	Sharkia et al	Israel	First and second cousin	Quantitative	Religion is an important factor in decision-making	N/A
1995	Shiloh et al	Israel	First and second cousin	Mixed-methods	Counselling doesn't always lead to change in decision	N/A
2014	Teeuw et al	Multiple countries	First-cousin	Quantitative	Positive outlook on genetic counselling	N/A
2019	Thain et al	Canada	First and second cousin	Qualitative	Widespread knowledge among consanguineous couples	N/A

2023	van der Hout et al	Multiple countries	First, second, double cousin	Qualitative	Religion is an important factor in decision-making	N/A
1999	Zahed et al	Lebanon	First-cousin	Quantitative	Poor awareness; Religion is an important factor in decision-making	N/A
2022	Zaien et al	Saudi Arabia	N/A	Quantitative	Positive outlook on genetic counselling	N/A
2021	Zaien et al	Saudi Arabia	First-cousins	Quantitative	Insufficient knowledge	N/A

Appendix for Paper 2

Extra explanation of methodology. Paper 2 is structured for submission to a journal – this acts as extra information potentially relevant to the thesis:

Genetic counselling-related terms were removed due to redundancy and scraper restrictions. To elaborate on the redundancy, we need to go back to the initial aim of this study: to look at people's views on cousin marriages and genetic counselling within the context of cousin marriages. Given that the search string used already focuses on cousin marriages, any genetic counselling-relevant views would have been captured as well since any genetic counselling perspectives should be within the context of cousin marriages. Hence, adding a string for genetic counselling in addition to the cousin marriage search string would have looked like the following:

'(cousin AND (marry OR marries OR nikah OR nikkah OR marriage)) OR ((cousin AND (marry OR marries OR nikah OR nikkah OR marriage)) AND (gene or prenatal or 'pre-natal' or preconception or 'pre-conception' or premarital or 'pre-marital')'

The initial cousin marriage string (prior to the 'OR') would have captured all the information that the second search string searches for either way due to the cousin marriage string being in both strings, thus making the inclusion of genetic testing terminology in the string redundant. The limitations of the scraper, on the other hand, are mainly character-based, in that there is a character limit, and a longer search string such as delineated above would have likely hit that limit.

It is also important to note that the word 'married' was excluded due to limitations with doing a Boolean search query, namely in that the Reddit search is limited in the number of wordings it

can process. It was determined through an iterative testing process of searching with different numbers of keywords that beyond the fifth word in the parentheses of the Boolean search, the Reddit search simply did not return results. As a result, single terms were selected for searchers, as informed by the literature. For example, ‘married’ was chosen rather ‘marry’ or ‘marries’ because across the initial search, it was noted that people spoke about cousin marriages in the present tense or noun form, either identifying a currently occurring cousin marriage or discussing cousin marriages in general while mentioning past cousin marriages. While something like ‘marri’ could have been used, this would have prompted the scraper to look specifically for the word ‘marri’ and not words like ‘marriage’ or ‘marrying.’ Hence, due to the testing process and the limitations of the scraper, the five aforementioned words were used for scraping.

Attempted search strings prior to Boolean search string:

```
ORIGINAL_KEYWORDS = [
    'cousin', 'genetic counselling', 'genetic',
    'gene', 'nikkah',
    'genetic counseling', 'marry', 'marries', 'nikah',
    'marriage', 'premarital', 'prenatal', 'preconception', 'pre-marital', 'pre-natal', 'pre-conception',
    'premarital counseling', 'pre-marital counseling', 'premarital test, 'pre-marital test', 'premarital screen',
'pre-marital screen', 'prenatal counseling', 'pre-natal counseling',
```

'prenatal counselling', 'pre-natal counselling', 'prenatal test', 'pre-natal test', 'prenatal screen', 'pre-natal screen',

'preconception counseling', 'pre-conception counseling', 'preconception counselling', 'pre-conception counselling',

'preconception screen', 'pre-conception screen', 'preconception test, 'pre-conception test'

]

GENETICS_KEYWORDS = [

'muslim', 'islamic', 'muslims', 'islam', 'cousin', 'counselling', 'nikkah',

'counseling', 'marry', 'marries', 'nikah',

'prenatal', 'marriage', 'premarital', 'prenatal', 'preconception', 'pre-marital', 'pre-natal', 'pre-conception',

'premarital counseling', 'pre-marital counseling', 'premarital test, 'pre-marital test', 'premarital screen', 'pre-marital screen', 'prenatal counseling', 'pre-natal counseling',

'prenatal counselling', 'pre-natal counselling', 'prenatal test', 'pre-natal test', 'prenatal screen', 'pre-natal screen',

'preconception counseling', 'pre-conception counseling', 'preconception counselling', 'pre-conception counselling',

'preconception screen', 'pre-conception screen', 'preconception test, 'pre-conception test'

]

NIKAH_MARRIAGE_KEYWORDS = [

'cousin', 'genetic counselling', 'genetic',

'gene',

'genetic counseling',

'premarital', 'prenatal', 'preconception', 'pre-marital', 'pre-natal', 'pre-conception',

'premarital counseling', 'pre-marital counseling', 'premarital test, 'pre-marital test', 'premarital screen', 'pre-marital screen', 'prenatal counseling', 'pre-natal counseling',

'prenatal counselling', 'pre-natal counselling', 'prenatal test', 'pre-natal test', 'prenatal screen', 'pre-natal screen',

'preconception counseling', 'pre-conception counseling', 'preconception counselling', 'pre-conception counselling',

'preconception screen', 'pre-conception screen', 'preconception test, 'pre-conception test']