

# [Consanguineous marriages and indigenous perceptions of congenital disease](https://assignbuster.com/consanguineous-marriages-and-indigenous-perceptions-of-congenital-disease/)

Objectives: Scientists consider cousin marriages one of the root causes of congenital dieses, but in Pakistan, especially in the rural areas, cousin- marriage trends remain stable. The present study was aimed at to investigating the gap between cosmopolitan knowledge of the congenital diseases due to cousin marriages and indigenous perceptions about the phenomenon. The study locates roots of the phenomenon in the traditional and structural set up of the Pakistani society.

Methods: In-depth interviews were conducted for this study. Annotation of the interview is given in the report by following the Grounded Theory Methods.

Results: People justify the practice of cousin marriages as fate and destiny. Cosmopolitan science is seems to be less priority among a remote community of Pakistan. A strong belief system dominates the people’s behaviour. Cousin marriages are perceived to be the best solution of the marriage. However, the symptoms of the genetic problems exist in the community.

Conclusion: Cosmopolitan knowledge lacks the relevance with the belief system. The study suggests a culture specific policy to handle the issue of the marriages and the genetic problem.

## 1. Introduction

Every person has two copies of similar genes including a recessive mutation cell. If one cell does not obtain proper commands to allow regular function. This can cause in genetic disorders. Similar genes form homozygosity (through autosomal gene) is found among cousin couples. This generates a number of disorders among the children of the couple. These problems come from the autosome (non-sex chromosome, of which every human being has a pair) and give birth congenital diseases: heart disease, thalassaemia and disability among the children of the cousins (1, 2, 3, 4). However, majority of the population in Pakistan arrange a marriage with possible nearest cousin (1, 4). The consanguineous marriages are stable and indicate dominant trends in Pakistan. This study deals with the issue of cousin marriages and the cultural-construct in the Pakistani society.

## 1. 1 Genetic problems of the cousin marriages

Scientists working on the genetic issues of inbreeding argued that autosomal recessive gene increases homozygosity and produce malformations which are a common cause of “ cardiovascular, central nervous system, urogenital, ophthalmic, gastrointestinal, skeletal, cutaneous, and also multiple malformations” (5 page 14). Similarly, Bundey and Alam found postneonatal mortality and childhood morbidity in the offspring of consanguineous Pakistani parents (6). Ahmed, et al (1) identified hemoglobinopathies as a major genetic problem among Pakistani cousin couples. The research- team studied 15 families carrying hemoglobin and eight control families without the history of a hemoglobin disorders. The scientists in this study found that the cousin couples carry -thalassemia and 0. 5 to 1 percent carry hemoglobin S or hemoglobin E. The infants of the cousin couples affected ratio is 1. 3 per 1000 live births, and according to the study infants present -thalassemia. The ratio of genetic disorders among the children of the control couple was lower than the cousin marriages couple. Bullock and Khalid (4) found increased risk of low intelligence, mental instability, sickle-cell anaemia and cystic fibrosis among the children of the cousin couples. Bittles (2) argued that various types of genetic disorders have been reported to be more common among consanguineous children. For example congenital disorders including neural tube and congenital heart defects were reported. According to Bittles “ Autosomal recessive hearing loss disorders and visual defects such as early-onset retinal dystrophies, primary congenital glaucoma and anophthalmos also are present at increased prevalence” (2 page 95) among the children of the consanguineous spouses. These inbreeding studies are conducted among the Pakistani ethnic diaspora communities living in the Western countries. However, there is a dearth of inbreeding studies within the Pakistani society.

There are two perspectives about the impact of genetic problems caused by cousin marriages among the scientists working on the inbred population. Genetic problems are likely to happen in between 4 to 10 % of cases among the cousin’s children and these researchers argue that the chances of these genetic disorders can increase within two or three generations of the cousin marriage (see 1, 3, 4, 7). Therefore, this perspective argued for legislation to ban cousin marriages in order to reduce the health problems.

However, second perspective (8, 9) argued that the chances of the genetic disorders are low and exaggerated. This perspective claimed that there are lower chances of the genetic disorders and that the media has stigmatized ethnic minority groups which alienated the community from mainstream Western society[1].

## Socio- Genetic Problems

## Genetic Problems

## Social Problems

Congenital malformations

Learning difficulties,

hearing impairment, infant mortality, morbidity, long term disability, increase birth prevalence, blindness

Cardiovascular disease

Asthma/ eczema

Single-gene disorders (neurological disorders)

Cerebral palsy

Down syndrome

Metabolic disorders

Spontaneous abortion or infertility

Cystic fibrosis

Urogenital

Ophthalmic

Gastrointestinal

Skeletal

Cutaneous

Hemoglobin

Thalassaemia

Fig 1 Genetic and social issues found in relevant literature

Hence, it is claimed (10) that the chances of a 4 % health risk are possible among the non-relative marriages. The chances of unrelated cousins are also high and there is nothing significant on cousin marriage offspring’s (11). Genetic effects appear in later age and are overtly emphasized on the basis of medical justification (9). Thus, it can be seen from the above debate on genetics that the problem exists and the main cause is the consanguineous marriages. This is accelerating debate among medical healers, geneticists and other health professionals within the Western countries about populations carrying genetic disorders and being stigmatized on medical grounds. However, this debate is nor prevalent within the countries where cousin marriages occur on a large scale.

## 1. 2 Cultural traditions of the cousin marriages

Consanguineous marriages constitute from 20 to 60 % of all marriages (9, 12). Worldwide 8. 5% of child births are from consanguineous couples (9, 12 ). Ten percent of worldwide congenital and genetic disorders are due to these marriages. In the Middle East and parts of Japan, and South Asia the marriages are dominant. Nevertheless, the majority ratio is in the Middle East (30 %) and in Pakistan (40 %) (1). Such marriages are under criticism in Europe and America; get on common in Asia, Africa and Middle East (4, 7).

A number of factors are listed in favour of cousin marriages; for instance property preservation within the similar social group, socio-cultural concerns of the cousins, blood ties maintenance, purification of family and association among the similar group (5). The marriages are a closed network of relatives, and they form socio-political alliances. The marriages are a source of social welfare and strong ties between the cousins that forms a kinship structure (12, 13). This pattern of marriage is customary in the Middle East and pre-dominantly in Muslim societies, especially Pakistan. There is growing argument and debate over the issues, caused by the genetics problems which are originating mainly through cousin marriages. The perceptions of genetic problems are over- emphasized in the developed nations (due to the technology, medical treatment available and awareness of the genetic issues) and with less serious concern in the developing countries which could not afford the technology and cost of medicine. Therefore, there is a need to know, how and where the problem lies and what impact it has on child health care.

## 1. 3 Cosmopolitanism and indigenous knowledge of cousin marriages

Cosmopolitanism is the notion that all human beings share a similar moral and scientific normative system (14, 15). The cosmopolitan knowledge is the common body of knowledge across the discipline and geographical boundaries. In this paper ‘ cosmopolitan knowledge’ I used as scientific debate on the cousin marriages. The term ‘ indigenous knowledge’ refers to ethnic and cultural perceptions of the people in a particular region which share origins and a common belief system. Cosmopolitan knowledge is a lesser debated issue among the common man in developing countries, like Pakistan, where cousin marriages prevail on a large scale. Does the cosmopolitan knowledge of congenital disorders undermine the indigenous perspectives of the belief system in the community of Kabirwala (Pakistan)? The study is aims to understand the genetic problems due to cousin marriages and the people’s perceptions of cousin marriages (daughter/ sister exchange for spouse selection) and the impact on congenital diseases. This is an effort to know how cosmopolitan knowledge differs with the indigenous perceptions of congenital diseases among the families who are living under a woman exchange system (among cousins) and how the system is affecting child health care and why health services are unable to handle the issue within the cultural context.

## 2. Research design

I was working on my research project “ exchange marriage system” in Kabirwala, a town in Pakistan. During the fieldwork, I found the blind and disabled persons whose parents were married on the basis of the exchange marriage.

Fig 2 Respondents level of the education[2]

I conducted interviews in a village of Kabirwala with the spouses’ who were married with cousins, their children to know the issue of genetic and their perceptions about the issue. The data was analyzed in line with Grounded Theory Method. This method develops the categories from the data (19, 20, 21). I developed the concepts and categories from the interviews. I interpreted and elaborated the data relevant to genetic problems for understanding the issue and categorized the data according to the themes. Relevant reports, articles were used to strengthen the findings of the primary data (16, 17, 18).

## 3. Results

I categories the results into below categories:

## 2. 1 Destiny and Luck: cousin marriages and congenital diseases

Mehboob[3]57 year old male is married with his cousin Rubia, 42 years. Rubia has nominal education. The couple have 11 children (3 sons and 8 daughters), and one child (Rakha in Fig 3) died one month after birth. Among the 11 children, two (Tahir and Najma) are blind and one child (Mehwi) has a hearing problem. The couple called it a matter of taqdeer (destiny) and argued that two children are blind due to their sin and one had died because “ us kay din poray ho gaye thay” (he has finished his life: means he has only this life given by God).

Fig 3 Family of Mehboob

When I asked, “ was this not a genetic problem?”, the respondents replied that it was ‘ God’s will’ and this was the reason for his son’s death. It is a matter of luck, destiny and genetics has minor role to play, explained the respondents.

## 2. 2 Religious authority and genetic problems

Aslam, a 57- year old man has different views about the genetic issues and he argues that genetic issues are not real ones, and that the Prophet’s daughter was married with Ali (the cousin of Prophet Muhammad). He explains: “ it is not possible that cousin marriage has problems and that the Prophet did not forbid it”. People believe that the religious interpretation is the real one, and it is Allah who gives and solves genetic problems.

The family has authority to arrange the marriages and enjoy in return obedience of the son/daughter. It encourages the elders to be conformist with the local traditions and follow the traditional norms to regulate cousin network. However, a 29-year, Kalsoom a female, argued that parents control the decision-making authority because they want to rule their offspring. She tells that religion has given authority to parents but they should use this authority in a careful manner. She explains that genetics has no link with cousin marriage. The respondent claimed it is God who does whatever HE wants. Nevertheless, Kabir, a 33- year male believes that cousin marriages are as a source of security, stability, strength and unity.

## 2. 3 Consanguineous marriages and formation of social capital

Cousin marriages determined the level of the kinship involvement in the Kabirwala community. Marriage with nearest relative is preferred. The relationship between in-laws extends beyond the couple. If a marriage is successful, it will be followed by others between the two families. Fig 4 indicates the few ratios of alternatives.

Fig 4 Marriage patterns

Cousin links, formed through marriages persist and are reinforced through the generations. The foremost source of the marriage proposal is within the lineage (22). It is found in this study (see Fig 5).

Fig 5 Marriage trends

The cousin marriages form a kind of social capital because the relatives are responsible to provide for a person in need. These cousins help, support and maintain the social security of a person in Pakistan.

## 2. 4 Public health problem: the gaps between knowledge and indigenous belief system

Akram, a 50- year male respondent elaborated his account and said, his children are more beautiful than his brothers because he was married with his cousin and his brother was married with someone other than cousins. He mentioned that it was due to his own genes that his (spouse) gave birth to beautiful children. However, Kalim a 30-year, male disagreed with the above argument and he said it was marriage of his cousins that has given a blind child. Akram is a single case so whose generalization is not possible. Some young and educated respondents have awareness about the cousin marriages and genetics problems. Rabia, 25 years, a single, female respondent mentioned that cousin marriages creates zahanat ki kami (less intellect), kamzori (physical-weakness), zahni bemari (abnormality), and apas main gharello jahgrey (domestic conflicts). Although there is evidence of blind and disabled children from cousin marriages. This appears to be with medical research on the subjects. There is nominal awareness among the people of the genetic issues. The community is not aware about role of the genetic disorders. If anybody in the community has knowledge they negate it due to the belief system.

## Cultural opportunities and constraints

## Opportunities

## Constraints

Purification of the family

Family conflict, less knowledge of congenital disorders, lack of research, lack of awareness, lack of medical treatment & infrastructure availability in the community of Kabirwala, lack of counseling opportunities, paternal authority, superstitions

Strengthen kinship ties

Availability of the spouses within family

Support for woman status

Better relations with in-laws

Old age care

Stable marriages

Property preservation

Preservation of land fragmentation

Less stigma

Loosening ties brings social problems

Political alliances

Fig 6 Comparison of opportunities and constraints

## 2. 5 Policy steps to handle the issue of consanguineous marriages

There is a dearth of the research in the community of Kabirwala with reference to the cousin marriages and the probability of genetic diseases. The scientists working in the field of inbreeding have an opportunity to study the community which has a chain of cross-cousin marriages from generations. The inbreeding scientists may be able to find some significant results about the chain of genetic diseases; the following policy steps are suggested.

1) Genetic problems are considered an important issue among the scientists and less concern among the people as the present study shows. The people in the community of Kabirwala believe that disease is a matter of destiny and luck. They do not know that there is a possibility of positive relationship between the genetic disorders and the marriages. It is possible to provide education to the people. It would be helpful to add the issue to the school syllabus.

2) The local imam (religious preacher) could spread awareness of the issue in their Friday-sermons. The imam is a person who may effectively convince the people, because the majority of the people could not read and write. The people believe the religious teachings. These illiterate people could be influenced through the cultural specific ways and means. This is an easy way for the health professional to convince the local imam about the possible inherited diseases so that he is a catalyst of social change. Short run measures are also possible to sensitize the people through media and stage-drama. However, these measure are likely not sustainable because the media is either restricted or without due credibility to spread such kind of information.

3) Counselling services create awareness if they can be delivered to the remote communities like Kabirwala. However, there is no counselling service available in the community of Kabirwala yet.

4) Legislation is a last step to ban the cousin marriages. But the ban on cousin marriage will be counter productive in this cultural context where breaking the law is considered as ‘ fashion’ and ‘ symbol of superiority’. Non-conformity indicates a high social status in this community.

## 3. Discussion and conclusion

Cosmopolitan knowledge has diagnosed two distinctive problems among the Pakistani cousin marriage couples, hemoglobin and thalassaemia. However, the hemoglobin is the main genetic trouble among Pakistani ethnic people (1, 4, 23, 25, 26). Human biological diseases are crucial one and need proper attention from health professionals and policy makers within the cultural and religious setting’. A significant factor of cousin marriage is protection of property, to avoid land fragmentation and to maintain the close family ties and reassurance of the bride (5 page 13). This is similar to work by Shaw (24) which argues that social environment and religious belief has affected the prenatal diagnosis.

Cousin marriages are stable and have a low divorce rate among first cousins (10) and have a strong socio-economic impact on the traditional family system in Pakistan. These traditional marriages are cousin, caste and endogamy marriages. The marriages form a single fabric, and if violated can harm marriage patterns with serious ‘ moral-decay’ consequently emerging (5, 25, 26). Thus, the present debate has a strong affect on the exchange marriages, which are overwhelmingly cousin marriages and has a negative affect on the public health. In my data, despite of the fact that respondents have education they have less knowledge about this issue. The community is lacking lively debate on the problem. Genetically disorders, visible from the health conditions, are likely to happen among the community.

## Cosmopolitan perspective

## Indigenous perspective

Physical incapacity

Exaggerated issue, stigmatized issue, qismat (luck) and taqdeer (destiny), child beauty, children are integrated

Mental incapacity

Harmful

Chronic disorder

Fatwa (an authoritative ruling on a point of Islamic law)

Fig 7 Cosmopolitan and indigenous perspective

Contrary, indigenous belief and attitudes have pointed to a few concerns: less awareness of the genetic issues, knowledge and facilities availability. The people in the community of Kabirwala believe that genetics problems have a negative relationship with the cousin marriages. This is the issue of a Western society and has less validity in Pakistani society. It is matter of destiny and luck and not a medical concern. Kabir explains: does western medicine ever stop a person to dying? This indicates apathy towards the genetic phenomenon where has less validity in the community. Therefore, the study found the evidence that cosmopolitan knowledge has no relevance with the indigenous belief system based on the above data.

Culture centred techniques to cope with these problems reduce chances of cousin marriages. For example, if a local imam/ molvi or the school syllabus stresses these. There are chances to reduce the possibility of the cousin marriages in coming generations. However, this is the turning point to convince the community to tackle and handle the issue with proper strategy. This is an open choice for the public and the health professional able where with proper facilitation and information can attract the public effectively. A failure to tackle the issue in a culturally specific manner could betray the health professional.

The current study found that community knowledge, belief and indigenous practices are the main causes responsible for the prevalence of cousin marriages in Kabirwala. These factors are also the stumbling-blocks in making the indigenous knowledge compatible with the cosmopolitan knowledge. Therefore, there are few concerns among the Kabirwala community about the genetic problems which way occur. They feel protected by their system of beliefs. Notion of luck and destiny is dominant in indigenous knowledge.