OpenLearn podcast
Cousin Marriages and Genetics: Understanding Inherited Health Risks

Dr Anood Sohail, Sadia Haqnawaz and Naznin Akter:

DR. ANOOD SOHAIL: Hello, and thank you so much for joining us today. I'm Dr. Anood Sohail. I'm a lecturer in precision medicine at the Open University.

I am also a member of The GRACE Project that is working hard in tackling under representation in genetic research. I also have genetic counselling experience in Pakistan. And I'm also a visiting fellow at Oxford Centre for Islamic Studies.

In today's podcast, we will be talking about a topic that sits at the intersection of genetics, culture, family tradition, and personal experiences, and that is consanguinity. So, consanguinity refers to a union between two individuals that share a common grandparent, most commonly a marriage between first or second cousins.

So, before we talk about cousin marriages, I just want to remind everybody that cousin marriage isn't just common in the Muslim or the South Asian community. For example, in Ancient Egypt, royal families often married within close groups, including cousins, to preserve power.

Similarly, in European aristocracy, especially among royal families like the Habsburgs or Queen Victoria's family, cousin marriage was pretty common in order to retain wealth and form political alliances within a limited circle.

In parts of South Asia, Africa, and even early Chinese societies, cousin marriage was accepted or even preferred because it strengthened family unity, ensured compatibility between spouses, and kept property within the extended family. So, it's all about money, possibly. [CHUCKLES]

So, I'm joined here by two lovely ladies-- Sadia Haqnawaz and Naznin Akter. Thank you so much for coming.

SADIA HAQNAWAZ: Mm-hmm.

NAZNIN AKTER: Thank you.

DR. ANOOD SOHAIL: So, we are going to talk a bit about cousin marriages, and also the risks that are related to cousin marriages. For example, from a genetic perspective, cousin marriage can carry increased risk because close relatives are more likely to share genes inherited from a common ancestor.

So, speaking of cousin marriage and their implications, Sadia, because you're married to your first cousin, do you want to unwrap that for us?

SADIA HAQNAWAZ: So, I am married to a first cousin. Not by choice. It was a forced marriage. I was married to a cousin on my mom's side of the family back in Pakistan. And we lost a baby to a genetic condition. We do have four healthy boys.

This condition runs in my family, so my sister lost five babies to the same genetic condition. And she's married to a cousin on my dad's side of the family. So, we both are married to first cousins, and both have lost our babies to this genetic condition.

We had the whole family tested because my parents are first cousins also. And we found that they both carried this faulty gene called ARPKD, which is Autosomal Recessive Polycystic Kidney Disease.

They have had seven healthy children. And with this condition, it's usually a 1 in 4 chance of having a baby affected by the condition, so they're quite lucky in that sense.

But I always question that luck because, yes, they have had seven healthy children, but then those children who have gone on to marry cousins have then gone on to lose babies to this genetic condition. So, they've lost six grandchildren to this condition, so it's not really lucky.

DR. ANOOD SOHAIL: No, it's not. Uh-uh. Yeah. No, that's really unfortunate. And wow, what an experience you've had.

SADIA HAQNAWAZ: But that's-- yeah, that's to show how it's inherited and to understand the statistics. I'm not very good with statistics and looking at numbers, but when I share the story of my family, it gives you a picture of how that inheritance pattern works.

DR. ANOOD SOHAIL: Yeah.

SADIA HAQNAWAZ: The one sister has a lot of losses. The other one, just the one.

DR. ANOOD SOHAIL: Yeah, yeah.

SADIA HAQNAWAZ: But when you look at it from a grandparents' kind of perspective, they've lost a lot as well, so--

DR. ANOOD SOHAIL: Yeah, yeah, yeah.

SADIA HAQNAWAZ: Yes.

DR. ANOOD SOHAIL: I read an article in the BBC, which said that 55% of British Pakistanis are married to their first cousins. So, you can imagine that you're not the only one. There must be so many. And thank you so much for coming and talking about it. I'm sure people will find it relevant to them.

So, Naznin, you are not married to your cousin, and you are married to your husband.

NAZNIN AKTER: Mm-hmm.

DR. ANOOD SOHAIL: You both met in Bangladesh.

NAZNIN AKTER: Yeah.

DR. ANOOD SOHAIL: Do you want to talk about that?

NAZNIN AKTER: So, I grew up in a family where marriage among cousins wasn't considered as a suitable option. My mother used to tell us that your cousins are an extension of the family. And in our society, you know a lot about your cousin and your relatives.

And it might often create complications in the future, so in my family and in my relatives' family, we tend to find suitable relationship outside the family. Way, way outside the family.

So, my two-- both siblings, actually-- got married outside the families. And all my other cousins actually married outside the families and they have healthy children. I met my husband at the university, and we also are blessed with a healthy son.

DR. ANOOD SOHAIL: Yeah, exactly. And this is within the religious norms.

NAZNIN AKTER: Yes.

DR. ANOOD SOHAIL: It's not like you've done anything wrong; your families were against it. It was all happy and-- So speaking of genetic conditions mentioned that you all got tested.

SADIA HAQNAWAZ: Yeah.

DR. ANOOD SOHAIL: How was that experience? Did you seek a genetic counsellor. Do you want to—

SADIA HAQNAWAZ: So, this happened to my sister first before it happened to me. And I used to think it was a problem with the genes, but with her genes and her husband's genes rather than the wider family.

So, when it happened to us, I think it made the whole family of sit up and take notice that, OK, now it's happened to another daughter. Surely, this is beyond just the couple. It's a family issue.

So, we had the whole family tested, and we know now who carries the gene and who doesn't carry the gene. Myself and my older sisters, we're married to cousins. But the younger ones are not, and they've had their own choices. And I feel like this test and the results had something to do with that. It gave everyone knowledge. Everyone saw the risks that you know of baby loss.

But it's not just baby loss. If you have a condition, it could be, I mean, a whole lifelong change.

Looking after a child, a sick child, constant visits, visits to hospital. So, it made people think about what's worth it? Is this heartache really worth it? I think it opened a lot of people's eyes, and I think it's really important knowledge to have that. Knowledge is power, and people can make informed decisions and choices, yeah.

DR. ANOOD SOHAIL: Something that I do wonder-- because I've grown up studying about genetics and that's my career. But for you two, did you study about genetics? Did your family know about inheritance? How much knowledge did you have? And after your unfortunate situation, how did you gain that knowledge, and was there some resistance from your parents or anybody around you?

SADIA HAQNAWAZ: Yeah. I think me personally, growing up, the only thing I was aware of genetics-wise, was cystic fibrosis. And that's because we were taught that in school. That's all I knew. So, when it happened to my sister and then when it happened to myself, we did go on the internet. We did a lot of research. We tried to educate the family.

And as a family, we kind of talk openly about this. I know it's such a taboo topic, but I feel like we need to start talking about these taboo topics and it might help someone. But I think what's really sad and upsetting is that, even after it happened to our family, there's still close relatives who've got their children married to first cousins.

So, it's almost like, do they believe that information? Are they leaving it up to God? What is it about this science that they don't understand? Or is it trust with people in authority? It makes me question why do people not believe this information when our family is like a living example of when things go wrong in cousin marriage.

DR. ANOOD SOHAIL: Going back to you. You've grown up in Bangladesh.

NAZNIN AKTER: Yes.

DR. ANOOD SOHAIL: And I've spent a couple of years. I haven't grown up in Pakistan, but I've spent a couple of years in Pakistan. How do you think, when it comes to progress, are people more open to medicine, advancements and medicines or any interventions that are available?

Because I feel that for me, when I do genetic counselling or discuss genetics with people back home, despite the fact that some people don't even know how to read or write, they still know there is something that's being passed on.

And I remember one of the ladies, she had about eight miscarriages and she was just desperate. She and her husband were desperate to find out the reason. And they knew that something was-- it was because of the family, but they just didn't know how to deal with it, so they were desperate for advice.

I have met with resistance here when I speak about genetics with people, because they feel that maybe it's outside our cultural norms or religious norms. Do you want to talk about the Bangladeshi community back home?

NAZNIN AKTER: Mm-hmm. Mm-hmm.

DR. ANOOD SOHAIL: How progressive are they in comparison to here?

NAZNIN AKTER: I can tell about my parents that they are-- I'm quite sure they are not aware about the repercussion of having cousin marriages and the children with genetic disorders. But it's not a cultural practice, so we actually haven't experienced such.

But it is also very common in our families and in my relatives' families to think about healthy, educated partner with compatibility. So, I think in one way they are aware about the health part.

Not particularly on the genetics part of it, but they would want their children-- whether for men or women-- they would want their next generation to be healthy and obviously happy in their lives. So yeah.

DR. ANOOD SOHAIL: Yeah. Yeah. Growing up in the Middle East, I've noticed that Arabs are more proactive, so they will take the necessary measures. There is a lot of genetic counselling and genetic testing that, even if they don't marry their cousins, they will get themselves tested.

But I find it quite disappointing when I speak to people, and people think that it's a Western thing. And how do you think, growing up here-- where do you think the change needs to come? And is it the genetic counsellors or the researchers that are the cause of this lack of awareness, or is it the people? Where is the problem?

SADIA HAQNAWAZ: Personally, I think it's about raising awareness from those people who have lived experience. So, I've got lived experience of things going wrong with cousin marriages.

And I'm talking openly about this taboo topic and hoping someone hears it and takes that information on board.

And I think it's to win people's trust so they can do that, to have more open and honest discussions about these kind of things. We do have genetic counsellors. I had a genetics counsellor from my background. They can speak to people in their own languages so that they understand.

And I think it's small steps to build that trust. But I think it's important within families as well to talk openly about genetics. So, I've talked about it openly with my family. My son experienced some mental health challenges during his second year of university, and he knew that his parents were first cousins.

And he went on the internet and did some research and found an article about mental health challenges in children whose parents are first cousins, and there's an increased risk. And that kind of validated his experience and his feelings. And armed with that knowledge, he went to his university and got some support because of it.

So that's an example of positive things that can happen when you talk openly about these taboo topics, and making sure people have information and access to information so they can make informed choices. I do talk about cousin marriages at schools and sixth form and colleges, just so that people have that information, they know what to do.

You can self-refer, for example, in Birmingham to genetic services. You can speak to your GP. If there is a chance that you're marrying a cousin, you can get things like IVF with PGT testing.

There's so much available now.

And it's so important to make informed choices, because what you're dealing with at the other end of the scale is either baby loss or having a baby with a life-long, life-limiting condition, which actually uproots and is challenging for the whole family, not just for the parents. So, saving some heartache, I'd say.

DR. ANOOD SOHAIL: Yeah, absolutely. And it is an obligation on us to take care of our health and our bodies, even from a religious perspective. So, I don't understand why anybody would go for something that is ultimately going to lead to heartache and health issues in your children. It's just unfair and it's cruel.

Speaking of religious values and cultural values, I think that we need to emphasise that there are a lot of things which are in our culture that are not necessarily religious. And I think that's where the gap needs to—

NAZNIN AKTER: Yes.

DR. ANOOD SOHAIL: It's just that's where things need to be addressed more. And, like you said about discussing, it is important to discuss these taboo topics because it is important to create awareness.

And speaking of-- again, back to the religious aspect. So, we all know that we are supposed to take care of our health. I did try to look for some references to the Prophet SAW saying that cousin marriages shouldn't be practiced. I don't know why some people say that. I haven't found any authenticity to it.

But I did find that Umar Ibn al-Khattab, may Allah be pleased with him, said to a family that was experiencing a lot of health issues that they have become frail and they should marry outside the family. And Imam Shafi'i also said that whenever people of a household do not allow their women to marry men outside of their line, there will be unhealthy children.

So there nobody talks about these things, so these things need to be-- people need to be aware of these sayings. And it's important to get tested because, when you go to a genetic counsellor or you go to a GP, they will guide you to the right sources. And people can get their family history taken; they can get tested. There are carrier screening tests that are taking place.

And these are very helpful to have a healthy family. I know somebody back home who's a clinician now. She has haemophilia. She was born and diagnosed with haemophilia. This was decades ago, and her parents decided that they will make sure that she marries outside the family.

She got married to her husband. They had one daughter. She almost died giving birth because of the blood loss. And then once she had her daughter, they made sure that they married her outside the family, or she married outside the family. And they've handled it. They've taken the necessary steps.

And in Pakistan also, she's been running a clinic where, if anybody has haemophilia running in the family and a woman is pregnant, she will get her fetus tested. And if it's positive, then they go for termination. But when you talk about things like this here, it is really hard to even start a conversation sometimes with people. So, is there anything that you would like to add?

SADIA HAQNAWAZ: I think it is a taboo topic, but our religion says you have to take responsibility. And I hear that a lot when I talk to people about terminations, for example. That's just one option, is you taking responsibility.

And it just makes me wonder if we have to start talking about this, because look at how technology is advancing. My children, even their grandchildren, will be in a time where there's so much more access to genetic testing where they have to make those decisions. Yes, maybe much earlier on.

But they need to know that, it's about responsibility. It's about taking that ownership of your health and your family's health and that it's OK to do that. So, we need to carry on talking about this so that the younger generation are armed with that knowledge as well.

DR. ANOOD SOHAIL: Yeah.

NAZNIN AKTER: Hmm.

DR. ANOOD SOHAIL: And people should have the freedom and choice to choose their partners. Nobody should be forcing anybody, whether it's parents or whether your friends or your relatives or individuals. Nobody should be.

And thank you so much for coming and sharing your experience and thank you so much for telling us that there are other ways as well, to get married and leading a happy, healthy life.

SADIA HAQNAWAZ: You never know what kind of challenges you're going to be faced. Like I always think, imagine my son comes to me and says, I want to marry my cousin. Would I say no? I would, but how much can you control your children? I can't lock him up. I can't control his life.

DR. ANOOD SOHAIL: Absolutely, yeah.

SADIA HAQNAWAZ: So what would I do in that situation? I would make sure that he has access to information, genetic testing, what kind of options you have, PGT testing. Just make sure you're tested. Make sure you know what you're dealing with, and you can make those informed decisions. I don't think it's about controlling people. It's about informing them and arming them with knowledge.

DR. ANOOD SOHAIL: So that they can make informed decisions. We're not discouraging people from marrying their cousins. We're just creating awareness so that people make informed decisions. That's basically the crux of all of this.

SADIA HAQNAWAZ: Yeah.

DR. ANOOD SOHAIL: Thank you so much for joining us, and I hope this discussion was useful. And we are sincerely hoping that this discussion allows or encourages other people to have a wider discussion amongst themselves within their families. And don't forget to comment below and please be respectful and I hope that everybody leads a happy and healthy life.