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NORWEGIAN PAKISTANI PARENTS' PERCEPTIONS OF CONGENITAL DISORDERS AMONG THEIR CHILDREN

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Abstract: This article addresses how Norwegian Pakistani parents, with children with congenital conditions; perceive the disorders that affect them. The parents have been to genetic counseling, which was offered as general or prenatal counseling by doctors.The purpose is to identify the parents' perceptions, and the aim is to show the co-existence of different perceptions, the dynamics and complexity of their perceptions, and the relevance it has for genetic counseling. With an ethnographic field-work approach (observation, participant observation and semi-structured in-depth-interviews) in two different studies among 41 couples, the researcher explored and identified the perceptions of the parents. The perceptions are categorised in seven categories by the researcher. The studies show that the couples' perceptions often differed significantly from that of the doctors, and identified that perceptions may change after genetic counseling, but not necessarily in a way that the doctors expected. Despite parents having prior perceptions of their children's disorders, these were not taken into consideration during counseling, implying a limitation in its value and effectiveness. This as opposed to gaining insight into what could contribute to more adjusted counselling and improves access to genetic information. Recommendations for further actions are outlined in the article.

Keywords: Genetic counseling, congenital disorders among children, parents' perceptions, Norwegian Pakistani families

INTRODUCTION

Why do those who give genetic counseling need to know how their patients perceive congenital conditions? One main task in genetic counseling is to offer non-directive counseling about managing genetic risk. It therefore matters clinically if the patients think about genetic risk in another way. From a perspective of medical genetics, patients may perceive genetic risk where there is none, or think there is no risk where it does exist. Based on my research among Norwegian Pakistani (NP) parents with children with such disorders, I will argue that knowledge about the parents' prior perceptions of the disorders should be addressed as a pre-requisite to help patients and their families in their management of risk, and in their wider coping process. Definitions of such counseling emphasize two-way communication and the education of patients (Clarke, 1998; Harper, 2010) and as one geneticist in my study said: *"My job is to make the situation more understandable for the family."*

Biomedicine can be seen as a system of cultural knowledge and practices (Good, 1994; Kleinman, 1980). Genetic counseling is an encounter between a medical genetic tradition of knowledge and a layman's perception, where the social construction of reality may be different. Patients' and doctors' perceptions may be based on very different knowledge systems (c.f. Kleimann's explanatory models (1980). How people understand and behave in a medical setting is influenced by their constructions of knowledge. The meaning of a disorder should therefore be understood within a cultural context. The perceptions of the specific event are not the same as cultural perceptions of diseases and treatments in general, but cultural perception

and practices are important as a contextual backdrop to understand how the patients' perceptions are shaped in a dynamic process. Patients may test different types of treatments for specific disorders, and the impact of such processes may be a different perception of the situation (Ingstad, 2007; Kleinman, 1980).

This article is a Norwegian based contribution to multi-disciplinary international research on the Pakistani Diaspora: about how parents from an immigrant population, who practice consanguineous marriages and therefore have an elevated risk for inherited conditions, perceive their children's disorders. The purpose is to identify the parents' perceptions, and the aim is to show the co-existence of different perceptions, the dynamics and complexity of their perceptions and the relevance these have for genetic counseling. The article is based on data from two studies of genetic counseling among NP families. The first was conducted to explore how genetic counseling takes place, the parents' access to information, and how parents manage the information (Sajjad, 2011b).This study identified that parents had prior perceptions of their children's conditions without this being a topic during the counseling. Both studies show that parents' perceptions often differed significantly from that of the doctors, as shown in studies among British Pakistanis, BP (Shaw & Hurst, 2008), public understanding of genetics (Condit, 2010; Meiser et al., 2001; Richards & Ponder, 1996), and for example among Norwegian families with disabled children (Ingstad & Sommerschild, 1984). Counseling in my first study was mainly provided in one-way communication, without accommodating the individual background of the parents, such as culture, level of knowledge, education and experiences. The analysis of the interaction shows that doctors were unaware of the families' prior perception of the reproductive problems and its relevance for geneticists to know about. No attempts were made to engage in two-way communication to understand the parents' grasp of the disorders better, to be able to aid the families in accurately understanding the medical information provided (Sajjad, 2011b).

The article also contextualises the NP families' frame of perceptions, and adds new knowledge for counselors to gain insight into delivering individually adjusted services in a cultural complex setting. Alison Shaw's (2009)studies among BP families was an inspiration in conducting the first Norwegian based study on such a topic(Sajjad, 2011b). The BP prior perception and knowledge was not assessed during genetic counseling (Shaw & Hurst, 2008). Genetic problems among BP and consanguineous parental marriages and risk factors are examined in studies performed in different subject fields (Atkin, Ahmad, & Anionwu, 1998; Bhopal, Petherick, Wright, & Small, 2014; Bundey & Alam, 1993; Corry, 2014; Darr, 1991; Modell & Darr, 2002; Sheridan et al., 2013). Studies also address questions of cross-cultural and cultural sensitive genetic services (Abad et al., 2014; Clarke & Parsons, 1997; Middleton, Robson, Burnell, & Ahmed, 2007), problems with culturally sensitive counseling (Kai et al., 2007; Shaw, 2009), and the need for counseling in an appropriate language (Darr, 1999). The importance of cultural knowledge is emphasized by Weil (2001) and Lewis (2002), together with the need for more research from the client perspective (Middleton et al., 2007).

Research among BP couples (Darr et al., 2013; Darr et al., 2015) shows that positive results are achieved with a family-centered approach(Modell & Darr, 2002)to genetic testing and counselling and indicates, along with others (Ahmed, Saleem, Modell, & Petrou, 2002; Shaw, 2011) "that families are prepared to pass on and use genetic information" (Darr et al., 2015, p. 77). A more unclear picture is also seen (Ajaz, Ali, & Randhawa, 2015). One conclusion of Darr et al.(2013, p. 55)states: "The need for effective communication of genetic information and support services is particularly pressing for families with children with a recessive disorder who are contemplating marriage within the extended family." They also state that such families not only need to be informed about their risk, but also to have an understanding of gene transmission and recessive

inheritance(Darr et al., 2013). Other UK based studies among BP families and other minorities have been conducted (Ahmad & Atkin, 1996; Fazil, Bywaters, Ali, Wallace, & Singh, 2002; Hatton, Akram, Robertson, Shah, & Emerson, 2003; Kaur-Bola & Randhawa, 2012), and some have focused on the parents' perception of the disorders (Bywaters, Ali, Fazil, Wallace, & Singh, 2003; Croot, Grant, Cooper, & Mathers, 2008).

In Norway, there has been little research on immigrants with disabilities (Berg, 2012; Fladstad & Berg, 2008; Kittelsaa, 2012).My studies (Sørheim and Sajjad is the same person) among NP families and young adults from different countries (Sørheim, 2000, 2004, 2006), include observations on health consultations as part of ethnographic studies. The research on genetic counseling (Sajjad, 2011a, 2011b, 2012)extends former insight with relevance to clinical genetics and reproductive health care. In Norway, genetic counseling is part of the provision of specialist health care and is offered by doctors specialised in clinical genetics, genetic counselors, or doctors during their specialisation.The NP population comprises 19 973 persons who have immigrated and 16727 who are the children of two immigrants and born in Norway.[1] Most NP are from rural Punjab, where migration began in the late 1960s and early 1970s (Brochmann & Kjeldstadli, 2008) as a chain migration: mainly from the districts of Gujarat and Jhelum, the same locations as immigrants in Denmark (Rytter, 2013).

Endogamous marriages within the caste and extended family is customary among Pakistanis, and 32-60 % are consanguine unions (T. Ahmed, Ali, & Aliaga, 1992; Jabeen & Malik, 2014; Sthanadar, Bittles, & Zahid, 2014). Such marriages are also common among other ethnic and religious groups elsewhere (Bittles, 2012), which includes the Pakistani Diaspora(Shaw, 2016; Shaw & Raz, 2015).

Parental consanguinity contributes to an elevated risk of certain reproductive problems such as stillbirth, infant deaths and genetic disorders (Bundey & Alam, 1993; Corry, 2014; Hamamy et al., 2011; Sheridan et al., 2013; Stoltenberg, 1998; Sørbye, Stoltenberg, Sundby, Daltveit, & Vangen, 2014).On average, all couples have a 2.5-3 % risk of having a child with a congenital malformation, and the risk increases to 5-6 % among first cousins(Harper, 2010; Stoltenberg, 1998) or more in parental unions among families who have been practicing complex endogamous marriages for generations. Studies in Norway show that when parents, across ethnic groups, are first cousins, the relative risk of infant death is about 2.4 times higher compared to the non-related population, the risk of congenital malformations is 2 times higher and the risk of still-birth about 1.6 times higher(Stoltenberg, 1998; Surén, Grjibovski, & Stoltenberg, 2007). When parents are related, the risk of carrying the same gene variant that causes an autosomal recessive disorder increases (Darr et al., 2013), and therefore also the risk of transferring such genes from unaffected parents to their children, who become affected when the gene is present on both alleles. The risk of having an affected child is 25 % in such a pregnancy, for related and unrelated parents. Consanguineous marriages contribute to redistributing recessive mutations for rare and more common diseases in the population. In consanguineous populations, family clusters are apparent for rare conditions (Corry, 2014) within extended family groups (S. Ahmed et al., 2002)in contrast to the ethnic Norwegian population, where such conditions are more randomly spread.

MATERIALS AND METHODS

Sample

The studies were approved by the Regional Committees for Medical and Health Research Ethics (REK) (11-2004 and 08-2014), and in accordance with Norwegian regulations, the first study was approved by the Norwegian Data Protection Authority (12-2004).Totally 41 couples participated. The first study consists of 35 couples who had received general or prenatal genetic

[1] www.ssb.no: September 2017

counseling from 19 different doctors during a period of 19 months during 2005-6.All persons identified as having a NP background were asked to participate. The second study consists of six couples who had been to general genetic counseling and were offered tests at the same hospital from July 2014 until January 2016. All NP consanguineous parents with children with congenital conditions of unknown cause, where a recessively inherited genetic condition was suspected, were asked to participate. Information was provided in Norwegian and/or Urdu.

The families had experienced miscarriages, infant deaths, congenital malfunctions, diseases, and rare disorders among their children. In the 41 families, 27 boys and 17 girls had ten different genetic diagnoses, and children were also in a diagnostic process .Four of the parents had a sibling with the same diseases. Four couples were unrelated. Most related couples were first cousins, and also related through complex kinship networks. 71of 82 parents were born in Pakistan and 80 were Muslims. 14 parents did not understand Norwegian, and two were illiterate. A majority had attended eight years at school, some a few years, and a very few had graduated from college or university.

Fieldwork and Data Collection

The starting point of the first study was observation of genetic counseling and through contact with the parents. I was introduced to different places in Oslo and neighbouring counties. The study was defined by the subject "access to genetic information", and by following the subject and persons I met people with different back grounds in Norway and Pakistan. Following people and a subject through a fieldwork process in time and place makes it possible to illuminate the research topic from different perspectives. The research was performed in accordance with Marcus' multi-cited ethnography(1995), and the methods used were observation, participant observation, semi-structured in-depth interviews, and informal conversations. For the second study, semi-structured in-depth interviews were conducted as conversations(Kvale, 1996)a few days after genetic counseling.Interviewtopic guides were used in both studies, and multiple interviews were conducted to gain additional information and insight. The interviews took place in the homes of the participants and lasted up to three hours. A challenge in the first study was that no parents with language problems accepted an interpreter due to the sensitive topic. Interviews in such families were therefore conducted in a combination of Norwegian, Urdu and English. During the second study a female translator was employed on one occasion to verify the accuracy of our conversation in Urdu/English. Notes were taken continuouslyby hand during observations and interviews, and transcribed on to a computer the same day. All names used in this study are fictitious to ensure the anonymity of the respondents.

Data Analysis

The data was analysed thematically. However, an analysis is an ongoing process where the anthropologist is observing, participating, interviewing, writing, systematising, reading and returning to the families for further interviews and then re-writing. The analysis is based on the identifications of the perceptions of the children's conditions, and categorised by me in seven types of perceptions. The orders of the categories are randomly set out. The longest section is inheritance, because it is part of the counseling and prone to misunderstandings. The analysis of the counseling sessions is relevant to the argument of this article because the flow of information was one way and parents' perceptions were not elicited. Therefore, two aspects of the first study: the counseling session and the parents' perceptions of the conditions, and one aspect of the second study: the parents' perceptions are combined in this article.

FINDINGS

The majority of the parents knew very little about biology, anatomy and physiology, including

procreation. The counseling was for most couples the first time they experienced inheritance (*werasat*) and disabilities among children as interrelated. The parents' prior perception of the disorders did not form part of the counselling. Parents' questions to the doctors about their own perceptions received responses like *"no"* or *"we don't think so"*, without further explanation.

Two cases are presented below to demonstrate the complexity and dynamics of the perceptions. The cases describe the perceptions of four parents during a period of about two years. Names and other identifiable information are changed to maintain their anonymity.

Case 1: Noor

Noor has a daughter with her first cousin. They had never taken their daughter out among NP because they blamed themselves for her condition, and were worried that other NP would think that they have done something wrong to get such a punishment from God. Noor felt relieved after counseling. She had blamed herself for the emotional stress and use of medication for this during her pregnancy. Noor's husband had been working away from home, and blamed himself for not being protective and supportive, and thought that God punished him for this. In addition, he thought that his wife had been exposed to black magic from a relative in Pakistan. From birth, they placed an amulet (*taveez*) on their daughter, for protection from both supernatural creatures (*jinns*) and black magic (*kaala jaddo*). After counseling both still blamed themselves, but the reason had changed. The doctor had said that their relatedness had caused the disorder. Therefore, they should not have married. When Noor talked about her perception of their future risk, she said it was 75 % if the condition was identified as inherited from both parents. Her husband did not remember, but also understood the risk to be high. According to the doctors, the risk of further children being affected was 25 %. After counseling they and his parents participated in a minor pilgrimage (*umrah*) to Saudi-Arabia, and washed away their sins, as he narrated. His family also expected that the doctor could identify the disorder as genetic, and subsequently Noor could take a prenatal test during a new pregnancy. Meanwhile, they used contraception. They understood that without genetic identification, the condition would not be identified through a prenatal test. After many months they received a letter from the hospital saying it was impossible to identify the exact gene responsible for their problem. They stopped using contraception, and he proclaimed that he would never again leave his wife. He gave his wife amulets, and when the next child was born healthy after prenatal tests, he was given amulets from day one.

CASE 2: SADIA

Sadia and her first cousin husband have a son with an undiagnosed congenital malformation. She came alone to the counselling.During her two pregnancies she had experienced difficult life situations. The first resulted in a miscarriage due to black magic, her female relatives told her, and she agreed. She also wondered if her depression had caused their son's condition, or the medicine she had used during the pregnancy without this being raised by her or the doctor as part of the counseling. After counseling she was confused, and continued to blame herself, also for not eating properly, as well as fearing she was suffering from a disease in her "belly". She said that the belly problem was caused by old germs (*jerasim*) in the meaning of left-over sperms. The concerns were aggravated by conversations with their families in both countries. Her husband returned from Pakistan with herbal remedies for the germs, and an amulet for her. Their son already had two. Sadia told her husband about the counseling, and that their relatedness had caused their son's condition. After discussing this with his parents, they rejected this explanation because Norwegians also have children with disabilities without being related. They also argued that they did not grow up together, and that he was the third born of his parents and Sadia was number two among her siblings. When he reflected on the situation, he also talked about

his wife's potential disease in the belly. Another day, he was concerned about his former alcohol drinking habits, and later on, he was concerned about the negative impact on his own and his son's health from the cold climate. They did not use contraception, and wanted all available prenatal tests to ensure that the next child would not have the same disorder, without understanding that such tests do not exist for unidentified conditions. Women are offered further tests as a safeguard against identifiable conditions.

These two cases indicate the complexity of the perceptions of the disorders, and the impact of family members' opinions on the perceptions of the parents. The parents often had quite different individual perceptions, which also changed. Also shown is the different impact of new knowledge in genetic counseling on their perceptions, reflections about kinship, and the misperception of the elevated risk and what genetic tests may show.

God's will

This perception refers to the fate (*kismat*) of a child given by God (Allah). According to the parents, the destiny is decided during the last period of a pregnancy, at the time of delivery, or shortly after birth. A child's destiny is understood to be influenced by parents' behaviors, and resembles previous observations(Sørheim, 2000). Their responsibility as parents was understood as an opportunity to search for information, new knowledge and treatment, and get as much insight as possible into their children's destiny. When God gives a disease to a child, most parents said it was a gift and a blessing to the parents or a punishment for violating taboos towards God, their families and their cultural norms and values. Drinking alcohol was one such taboo, as shown in the case of Sadia. Another example is the following:

The mother had acquired a good understanding of the information, which helped her to understand how their child got the inherited disease. According to her parents, their grandchild was a gift and a test. They did not gain insight from the genetic information, neither did the father. Her parents and husband arranged a trip to Pakistan for faith healing, and visited the graves of their relatives and holy graves (*darbars*). Despite this, during the next pregnancy both parents wanted prenatal tests and the mother was prepared to go through an abortion if the same disease was identified. Alone with me, she explained why their child got such a disease. As a teenager, she had a boyfriend. Now, she realised that she had broken a taboo according to the moral values of her parents and culture. Every day she prayed for forgiveness. When the next baby was born well, she felt absolved of her past.

Punishment for breaking taboos included blaming either one, or both parents, and making moral judgments on past behavior. Even if they did not see their situation as a punishment, many were conscious of such condemnation among other NP. A gift was not perceived to have the same moral burden as a punishment. To be protected and prevent new reproductive problems the parents had to live according to cultural and religious moral values. To perform the required Islamic rituals was seen as more important after such a child was born. However, families interpreted, practiced and adjusted to Islam in different ways. Families who could afford to go to Saudi-Arabia with the children had gone on a 10-day pilgrimage, and some went more than once. In all except one case, this was experienced as beneficial to the affected child. Performing rituals, the obligatory prayers and also the personal supplication prayer (*du'a*) during pilgrimage, gave parents a sense of relief. To perform prayers daily, the mothers more frequently than the fathers reported reading the Quran. To read and pray had not only a religious function, but kept them busy, which was also important in the management of grief and anxiety. Some of the fathers prayed regularly, some less frequently. Only two said that they never prayed at all. God's will was the perception shared by almost all, except for the fathers who never prayed.

Black Magic

Black magic (*kala jaddo*) is an act of evil intent, in these families understood to be used deliberately to harm the couple's reproductive capabilities or their children, as in the case of both Noor and Sadia. Black magic is considered to be a strong disturbing force, which contributes to disturbing God's plan. *Taveez* is a term used to describe both a protecting and healing amulet and something harmful. Some parents discovered harmful ones in their homes. Others did not have visible evidence, but assumed that one of them, or their child, had been exposed to evil drops through liquid or food, or harmful rituals. Envy by a relative, or other close persons, was believed to be the reason for being exposed, especially from someone who envied the couples' love for each other, as stated in the following example about a couple with a child with an autosomal recessive condition:

"We know that the curse is from our sister-in-law because she envies our love." The couple had discussed many options before they came to the conclusion that their sister-in-law's motive was her unhappy marriage to the husband's brother. If the husband's brother had loved his wife like the husband himself loves his wife, she would not have harmed their genes, the couple stated.

In other families the evidence came from spiritual experts. The parents were not considered to be at fault for the magic, but some blamed themselves for not being able to protect their family. It was considered important to take action to protect their children and themselves from further harmful exposure by using amulets with verses from the Quran, or prayers written on small pieces of paper. These amulets were understood to be empowered by God. Such amulets were visible on almost all children, located around their necks, or arms, in black leather, metallic lockets or small pouches, and under the clothing on other body parts. This practice also occurred in families despite parents saying that amulets are not accepted in Islam. The use of amulets could be initiated by grandparents without the consent of the parents. Other rituals included the drinking of blessed water, or verses from the Quran written in non-permanent ink, dipped in water and later consumed when the writing became illegible. The amulets were made by spiritual guides and religious healers (*pirs*) in both countries, or received from mosques in Norway. The spiritual guides also performed rituals designed to break spells. Fees ranged from £2500 in Norway, to less than £1in Pakistan. Women showed more concern about the use of protecting amulets and rituals than men, and more women were accused of performing black magic. Both highly educated and less educated parents held this perception, and few were skeptical of such an explanation in general.

Wrong Decisions

This perception is related to decisions and behaviors that they later decided were wrong. An example is Noor's husband working away from home. Other examples are not using nutritional supplements when they knew that their diet was not optimal, and side-effects from medicine (Noor and Sadia) which they should never have taken, because adults know that medicine also has such effects. Having a boyfriend, drinking alcohol, marrying both inside and outside the family were also such decisions. The proof was clear according to one couple, who, according to their opinion of kinship, were not related.

The couple had experienced miscarriages, infant death and congenital diseases for years, while none of their relatives had, although all were married to cousins. "We should rather have married a cousin," the husband declared. The doctor did not draw their family tree because they answered "no" when asked if they were related. However, during the fieldwork, I drew their family tree, which showed biological relations between them on their mothers' side. Leaving home unnecessarily during a pregnancy was also considered wrong.

"If I had not been shopping, I would not have been in the accident," a wife said. "If she had not been outside for pleasure, the baby would have been fine," her husband said. He continued to

blame himself for not looking after his wife so she would not have been exposed to any negative experience. He also continued to blame his wife for going out. Acceptance of wrong decisions was observed as a coping mechanism by parents, who felt that their situation could be viewed as a personal development, and would help them to manage during later pregnancies.

Emotions

This perception refers to a variety of emotional reactions, like worries and concerns during pregnancies and other stress-related reactions to current or earlier life experiences, as mentioned in the cases of Noor and Sadia.

One couple thought the reason for their child's disorder was due to their own emotionally painful experiences of violence in their childhood. Both had grown up with violence in their immediate and extended families and many of their relatives had also children with congenital disorders. When they, unsolicited, presented their explanation to the doctor, the doctor's response was only a negation before continuing to deliver her explanation. When drawing the family tree, none of the "victims" of the emotional experiences were identified.
Other parents said that their own children had been exposed to quarrels between them, or other family members, and wondered if this was the cause. After genetic counseling, the mothers' worries also increased due to information about many types of risks: they worried about the negative impact of their worries. The general attitude was that there is not much that can be done, except to try to minimize anxiety, quarrels and conflicts during future pregnancies.

Physiological Dysfunctions

Some of the parents thought that there was something wrong within their own body, or in that of their spouse, which had caused the disorder. Relatives also believed this and questions from within the families were related to "diseases" and "mutations" in the genes, "old eggs" or unidentified "infections" in the abdomen of the females.

Before counseling one father blamed himself for his child's genetic disorder, because he thought he suffered from physical dysfunctions due to "too little genes", which he did not know how to replenish. He did not tell the doctor that he blamed himself or about his miserable sex life. After the counseling, he went home and had sex with his wife for the first time in more than five years. Nine months later his wife gave birth to a healthy child. His prior perception had reduced their quality of life. However, he integrated the new knowledge in his own cultural and personal perception, as many parents did in one way or another.

The beneficial impact of the genetic counseling was evident in this family, and demonstrates the practical relevance of access to genetic information. If the cause of the reproductive problem was believed to be a disease, as in the case of Sadia, relatives said that women should use "medicine" before a new pregnancy. Medicine could mean biomedicine, homeopathic or *Unani* (Greek Arabic medicine). To prevent problems caused by "old eggs", a woman should not wait too long between pregnancies. Parents took the advice of the different non-biomedical practitioners during treatment. The mothers used different types of remedies, and also gave these to their children. Such treatment was not disclosed to doctors.

Climate

Previous studies have confirmed the belief among NP families(Sørheim, 2000) and BP families (Shaw, 2009) that a cold climate with absence of sweating has an effect on reproductive capacity and child health, as mentioned in the case of Sadia and her husband. The rationale is that the cold climate triggers a latent vulnerability to congenital disorders, which would not have occurred during warmer climatic conditions. This perception was less mentioned than all the others.

The disorders were proven in a family by the fact that no one else in the near or extended family, living in Pakistan, had experienced reproductive problems. However, all couples living outside Pakistan in cold climate zones had. In another family, the mother said that the cold climate was the reason behind the chromosomal abnormality. However, she also had integrated some perception of the genetic explanation.

Inheritance

During counseling, the doctors did not inform the parents that their questions about kinship were about biological relations between them. The way questions about kinship were asked implied a certain perception of the relation between biology and culture.

When a couple drew their family tree, the husband wrote his stepmother's name without mentioning that his biological mother had been replaced by another when he was small. The biological mother also had a congenital condition similar to that of her grandson. The father did not withhold information, but they did not understand that the doctor wanted to know about biological relatives.

A relative (*rishtedar*) was not understood as only a biological relative, but also as *affine*, which means related by marriage, also well-known according to a general perception of the concept in Urdu and Punjabi. The NP kinship-identity and descent were traced through the men's blood in their patrilineage,as found in previous studies among Pakistanis in Pakistan (Donnan, 1988) and in the UK (Shaw, 2000), and mentioned by others (Hamamy, 2012). However, the meaning of "blood relations" is not necessarily clear. During the studies, I asked the parents how much a child inherits from each of the parents, and most said "half- half". In the follow-up questions, they said that children inherit more biological material from the father, whose contribution is stronger than the mother's. The finding is confirmed by other studies (Shaw & Hurst, 2008). A mother can compensate for that through breastfeeding, or during the pregnancy, a belief also found in the UK (Shaw, 2009; Shaw & Hurst, 2008). Milk transfers the characteristics. In Pakistan and other Muslim countries people are restricted from marrying a milk sibling. Children who have received milk from the same woman are understood as siblings. Both blood and milk are understood to constitute kinship relations and transfer characteristics from adults to children. According to the data and observations from Pakistan, characteristics were also understood as being transferred from the person who was saying the Islamic call to pray (*azan*), with the Muslim creed, in the right ear of the newborn. In addition, characteristics were transferred from the person conducting the consecutive ritual (*ghutti*) in which something sweet is put on the newborn baby's tongue. As part of the interpretation of inheritance, couples were worried about the potential adverse consequence of having grown up geographically close to each other. This may have strengthened the kinship and elevated their risk of inherited conditions. As opposed to this, some parents questioned why they experienced genetic problems when they did not share the same environment before marriage, a question also raised by BP parents (Shaw, 2009). Furthermore, cousin-parents questioned if the risk declined for marriages between partners who were second andthird born among their siblings, shown in the case of Sadia. Inheritance from a common ancestor was assumed to be stronger in the firstborn. According to this interpretation, marriage to a spouse who was not first born was thought to reduce the risk of disorders.

After counseling, a perception of a condition as inherited was often associated with previous conditions within the extended family. An argument for rejecting the information was therefore that previous cases had not occurred. However, if the condition had been seen in the family, the cause may also be explained by exposure to emotions, climate or black magic.

A couple did not want to tell the father's younger brother that he and his (double) first cousin wife

also have a high risk of having a child with a recessive condition. The youngest brother's wife was also a first cousin to both. The couple was worried that relatives would think that such a condition was inherited from them, because it was identified in one of their children. Their thinking was that the transmission can happen by sharing food or drinking from the same glass, as family members commonly do. Education or social status did not necessarily determine the perception of how recessive genes can be transferred through biological inheritance.

An example is a couple with little formal schooling, who asked for a new consultation. They were concerned about how their extended family and *biradari* (patrilineal classificatory kinship group) could stop carriers from marrying and through changes in marriage practices make choices to prevent more children with the condition being born. Despite their adaptation of the genetic explanation and their initiative, they did not allow the specialist to inform their general practitioner about the identification of the recessive gene. Like many families with identified recessive conditions, they worried about their other children's chances of making a good marriage-relation (*rishta*) in the future if information about recessive genes, or carrier status, became known. This is also identified in other studies (Darr et al., 2013; Shaw, 2009). They would therefore withhold information about the identified condition and their knowledge about carrier status among relatives to any outside the kinship group.

As in Noor's case, most parents interpreted the genetic information in a way that their marital relationship resulted in the disabilities, as is confirmed by other studies (Darr, 1991; Darr et al., 2013; Darr et al., 2015; Shaw, 2009), even if no recessive disorders were identified. Parents and family members also argued against the genetic information of inheritance by stating that non-related Norwegian families also have children with inherited conditions, as shown in other studies (Ajaz et al., 2015; Shaw, 2009). Members of extended families had, to a large extent, resistance towards a genetic explanation. One reason may be because they did not get access to first-hand information, but were informed by the parents, who were struggling themselves to understand the genetic information.

Discussion

It was evident that parents placed value on the service and wanted to get access to the information which genetic counseling could provide. However, the research shows that the majority of parents had little knowledge of genetics prior to counseling and many misunderstood the information.One reason for changing perceptions depended on their ability to understand the information. Parents who did not understand much of the counseling were less influenced by it. If the couple who asked the geneticist if emotional reactions of violence had caused the disorder had not been met by only "no", their drawing of the family tree and affected relatives could have been quite different. Neither the geneticist nor the couple understood that their access to another understanding of the condition than that caused by emotions was limited by the doctor's rejecting their question. Inheritance was the category most likely to result in a clinical significant mis-understanding. It is well-known that kinship is constituted in different ways and also understood differently worldwide, (Carsten, 2004; Featherstone, 2006; Melhuus & Howell, 2007; Shaw, 2009; Wade, 2007). Also important to providers of genetic counseling is the unclear distinction between biological and social relatedness, and how inheritance is strengthened or weakened among siblings. In addition, it is important to know that there are also other factors outside of kinship-based marriages that have increased the occurrence of genetic conditions, (Bittles, 2012; Clarke & Parsons, 1997; Corry, 2014).

Lay perceptions of genetics and inheritance are different from those of the professionals (Condit, 2010; Meiser et al., 2001; Richards & Ponder, 1996). Therefore, NP parents are not much different from other users of genetic services. In the process of constructing an explanation,

almost all the parents and many family members asked themselves why it happened to them just now. God's will was a perception almost all were concerned about. Black magic was a challenge to God's power, understood as Satan's work, from which it is important to be protected. God's punishment for violating taboos limited the options for parents to talk openly about their situation among NP. It also functioned as a barrier for children to engage in social activities, also described by others (Croot et al., 2008). The punishment for violating taboos is based on moral judgment and parental response, like going to a pilgrimage, and is an act of absolution (Douglas, 1984).In Islam,everything has a God-given meaning. Life is made up of numbers of tests, where the meaning may be unclear. The meaning is also to be found in a wider context of folk religious practices and beliefs. It takes time to gain insight into the meaning, and some families were searching more than others. In contrast to other studies, which only categorisea punishment as a test (Croot et al., 2008; Kittelsaa, 2012), my studies show that a disorder given as a gift was also perceived as a test, as an earlier study also shows (Sørheim, 2000).The consequence of the test was understood to have an effect both in this life and the after-life. Their aims were to manage the tests and pass the examination to be rewarded in the next life. This belief is based on their interpretation of Islam as an integrated part of NP cultural beliefs. In another study the perception of the parents was categorized as cultural as opposed to a religious interpretation of the situation (Kaur-Bola & Randhawa, 2012). However, religion is always understood and practiced in a context of culture.

The religious aspects were important. Their experiences led most couples to become more dedicated to religious practice, although this applied more to the mothers than the fathers. Religion provided comfort and support to the families, confirming the findings of other studies(Ahmad & Atkin, 1996; Kittelsaa, 2012).Most parents reflected upon destiny, and it was up to them to explore God's plan. The findings of a previous study (Sørheim, 2000)show that healthcare providers interpreted the Pakistanis' beliefs as fatalistic. My studies show that destiny should be understood as a resource to manage the situation and not as a barrier to consulting biomedical healthcare providers, as also shown by By waters et al. (2003). The search for new knowledge was an important part of being a caring and responsible parent to a child, whose fate was decided, but not apparent. The parents were in an ongoing process to do everything to find out what to do, and to try it out. Therefore, their perceptions should not be interpreted as fatalistic, also supported by a study among BP parents (S. Ahmed et al., 2000). Parentsreflected on their experiences, which contributed to the construction of the narratives of the conditions (Kleinman, 1988). In some families genetic counseling challenged both their general perceptions of diseases as well as their perceptions of the disorder. Parents interpreted the genetic information and rationalised it in a way that made sense to them. This interpretation was dependent on the context of the couples and families, for instance prior perceptions and experiences, basic knowledge about the body and biology, education, language skills and family background.

The parents also sought information through conversations with relatives and friends, and some from the Internet, and included or excluded parts of it. Also traveling to Pakistan was part of the process of doing their best and slowly accepting the situation. In addition were gaining a second opinion from doctors, consulting religious healers and visiting holy graves. Some relatives aided interpretations of information, and consulted folk healers and experts, which shows the families' collective responsibilities. The conditions had to be treated in different ways according to their perception of the cause. Different forms of treatments and rituals are therefore complementary. To integrate a genetic diagnosis and follow up religious treatment is not a contradiction. Although patients will consult both medical and religious healers, their choice is embedded in their cognitive assessment(Sachs, 1987).

Shaw (2009)states that almost all the BP had considered "alternative" perceptions to the genetic condition, and her study identified many different types of explanations (Shaw & Hurst, 2008). As my studies also show, the perceptions are not instead of an explanation based on science. An extensive study among Norwegians also gives examples of parents with different perceptions of the conditions to those of doctors, and referred to magic as an explanation, in addition to biomedical explanation (Ingstad & Sommerschild, 1984). All parents in a BP study had "theological" perceptions (Croot et al., 2008). Such perceptions and biomedical perceptions are not mutually exclusive (Bywaters et al., 2003; Croot et al., 2008). However, according to Kittelsaa (2012),the use of theology to rationalise the cause of the condition is less significant than a medical explanation. This was incontrast to the findings in my studies. Kittelsaa explains that theological explanations are more connected to the meaning of the condition and the consequences for parents in everyday life(2012, p. 30). However, a separation of cause from meaning does not serve the purpose, because both are interwoven in the perceptions of the NP parents.

Questions of different forms of logic have been discussed since Evans-Pritchard and his study among the Azande people, where the lay perception explained events which could not be explained in other ways, as sorcery (Evans-Pritchard & Gillies, 1976). Such perceptions are logical and rational according to the Azande. Similar thoughts are found among the NP couples. Perceptions, like black magic and violating taboos, were integrated in a wider context, and as such these perceptions are rational, logic and therefore understandable. A jealous sister-in-law, who uses black magic to harm a couple's reproductive capabilities, is logical in this cultural context. In Pakistan, among Pakistanis in Denmark (Rytter, 2010) and among the NP, black magic is believed to be conducted by close family members. Accusations are most likely to be made within a family and among in-laws, or their social network. Even though many of the parents did not explain the disorders as such, it was an important perception irrespective of education and urban or rural background and widespread in families in general to fear. It should therefore not be assumed to be a "traditional understanding", which some researchers suggest(Kittelsaa, 2012), because "traditional" refers to a certain type of dichotomisation of phenomena as traditional opposed to "modern". Black magic is always a consequence of interpersonal conflicts, and notions of evil "forces" may be as real as notions of genes and chromosomes. Neither the Azande, nor the couples, reject biomedical knowledge, but this type of knowledge is not necessarily relevant when it comes to existential questions like, why me just now? Chris Goodey asks: "Genes exist, but how do we know? Because there is a technology that has told us"(1997, p. 206). When one perception gets priority, this is reflected in the choices of logic and rationality that shape their perception at that time. A lay perception is no more or less rational than a medical genetic explanation. A doctor's perception of diseases and actions is based on medical rationality, but the rationality of a lay person is in general different, because of different socialisation(Good, 1994). Biomedicine is one of many knowledge systems which are incomprehensible for a person who does not have access to the knowledge.

CONCLUSION, IMPLICATIONS AND RECOMMENDATIONS

There are different knowledge systems among NP families based on Islam, folk beliefs and biomedicine, without this necessarily being a problem. However, all the categories, except climate and a child perceived as a gift, contribute to parents' perceptions of guilt in one way or another. Such perceptions are therefore also relevant to clinical genetics in gaining insight into being able to give parents relief from guilt. The studies show that such relief may be an effect of counseling. Parents' own rationalisation helped the families to understand *why* their children were born with congenital conditions. Most couples integrated the genetic information with their own perceptions, and many understood it in

a way that was not how it was intended. Therefore, counseling had the potential to result in serious misperception. Despite misunderstandings, the new knowledge contributed to the perceptions of *how* their children were born with the disorders. After gaining access to new knowledge, their ability to rationalise it relied on a multitude of factors which did not reflect a general perception of the impact of education. For instance, both well-educated parents and less educated ones believed in black magic, the effect of climate and emotional stress or trauma on their reproduction. Furthermore, their different perceptions should be understood as co-existing with the power of God, and are also complementary to genetic perceptions. Their perceptions should also be understood as equally relevant, as supplementary to or overlapping the genetic explanations. Some perceptions did conflict and created tension among families. The lay perceptions could in certain circumstances take precedence over genetic information, and access to the genetic explanation could take precedence over prior perceptions. Therefore, the perceptions could compete. These studies show that couples' perceptions of diseases and disorders differ from those of the doctors, but it does not mean that culturally constructed perceptions are barriers to scientific perceptions(c.f.(Strathern, 1997)), and should not be used as an argument to not offering genetic counseling.

The research shows how perceptions are molded by individuals and families in an ongoing process, contributing to the complexity of their perceptions. In addition, the research contributes with empirical knowledge of how this unfolds, and shows that different forms of knowledge are integrated into their perceptions. Also shown is that every individual may have different sources of knowledge, which are not consistent with each other. This complexity in social life contrasts with a more bureaucratic and standardised way of understanding knowledge. Geneticists and parents may also think that they talk about the same things, but cannot be sure when talking about core issues in genetic counselling.Therefore, neither doctors nor researchers in this fieldshould assume that kinship is understood as based on biology (Featherstone, 2006), and should explore how kinship, inheritance and the transfer of characteristics to children are understood. Genetic counseling should be based on the individual's previous knowledge (Richards, 1997) and perceptions in order to aid the parents' access to the genetic knowledge. Understanding the genetic information correctly is especially important for families who have autosomal recessive inherited conditions and are practicing consanguineous marriages (Alwan & Modell, 2003; Darr et al., 2015; Shaw & Hurst, 2008) or endogamy. Where geneticists do not identify that parents have prior perceptions, the counseling may be of limited value. Gaining insight into the perceptions of the parents would enhance individual adjusted counseling and improve access to information. For instance, it may be useful for the families to understand that inherited conditions are not transmitted by sharing food or drinking from the same glass. Therefore, during the process of counseling there is a need for a mutual acknowledgement and perception of each other's perceptions. This does not mean taking the patients' perceptions as her/his own, or adjusting information according to their beliefs. It rather means improving the communication in a two-way-process of education, as emphasized in the theory of genetic counseling (Clarke, 1998; Harper,; Resta et al., 2006).To a large extent, genetic counseling as described theoretically was not offered to the NP families.

As an implication, structural shortfalls in genetic counseling services should be emphasised. Another implication 2010 of my article is the need to change counseling methods, and there is a need to implement already established and recommended counseling methods, as mentioned above. Such communication is essential to give all families access to genetic services in a culturally complex and diverse context. This is not only the individual counsellor's responsibility, but also the responsibility of those managing genetic services

and educational institutions. This should also be interesting for health policymakers. Projects should be designed to test different methods which incorporate the perceptions of the parents and family during a process where genetic counselling is one out of many clinical encounters for the family.An extended family-centred approach should be trialed to inform about the extended family risk, and to give the parents an opportunity to include important people in their networks to ensure that the genetic information is correctly understood among individuals across generations and gender. This could have a supportive effect on the parents' management and inform other decision-makers among relatives when it comes to marriage relations in the future, with clear preventive benefits to the healthcare system.These studies are especially important for countries where genetic counselling in a culturally diverse population is not yet an issue at the genetic clinics.

Study Limitations

This article is based on two ethnographic studies, which are in-depth-studies, and do not aim to address questions of *"how many*" say so, or *"how widespread"* the perceptions are.

Conflict of Interest

I declare that I has no conflict of interest.

Human Studies and Informed Consent

"All procedures followed were in accordance with the ethical standards of responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study."

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