
Professional Issues

Providing a Transcultural Genetic Counseling Service in the UK

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This paper uses a broad definition of culture to explore the practice of transcultural genetic counseling through three case studies. The first case involves a White genetic counselor seeing an Asian family, the second, an Asian genetic counselor seeing an Asian family and the third, a hearing genetic counselor seeing a culturally Deaf client. Boundaries, transference and countertransference reactions are considered within each transcultural encounter and the author of each case reflects in detail on their role in the client interaction and their impact on the transcultural dynamic. The cases are used to illustrate some cultural beliefs or characteristics that may challenge the genetic counselor's expectations. The value of identifying and interpreting these differences to facilitate useful clinical work is considered. The paper debates, where possible, whether it is helpful to culturally match genetic counselor and client.

KEY WORDS: transcultural; cross-cultural; genetic counseling; Asian; Deaf; supervision; countertransference; racism; consanguinity.

INTRODUCTION

Culture can be defined as the “shared history, practices, beliefs and values of a racial, regional or religious group of people” (D’Ardenne and Mahtani, 1999, p. 3). Transcultural genetic counseling aims to provide a service to and between people of different cultural backgrounds. However, it is not solely about race or language, but can be considered in terms of difference on many levels (Lewis, 2002; Wang, 2001; Weil, 2001; Krause, 1998).

The book “Culture, Kinship and Genes” following a conference in Cardiff, UK with the same

title (Clarke and Parsons, 1997) suggested that it is not enough to try and teach the genetics community about different cultures but it is also necessary to explore the ways in which we *experience* different cultures. It is also important to study the interaction between persons of the same broad culture as well as from different cultures (Lewis, 2001).

It is too self-comforting to think we can provide a transcultural genetic counseling service by only learning facts like we may be in the habit of learning genetics. We need to ensure that although we may be ‘culturally aware’ that this does not preclude recognition of intracultural variation (Lewis, 2002; Wang, 2001). It is also important to treat clients as individuals and resist the temptation to stereotype (Seeley, 2000); as well as to recognize that we will all have reasons to see ourselves separately from other groups of people. We should embark on the painful journey of identifying and acknowledging our own prejudices. This is necessary in order to equip us with a sensitive approach for working with individuals from any culture that we may encounter.

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As genetic counselors in Leeds, we have access to both one-to-one and group supervision with a psychotherapist external to the department (in accordance with the AGNC Supervision Working Group Report, 2007); this facility is paramount for enabling us to explore our values and beliefs within transcultural work. Our group sessions consist of genetic counselor and clinical geneticist teams. In writing this paper our intention was to share our experiences of working across cultural difference and explore how our own values and beliefs affected the genetic counseling process. We will present three cases, a White genetic counselor seeing an Asian family, an Asian genetic counselor seeing an Asian family and a hearing genetic counselor seeing a culturally Deaf client.

All three cases are written from the perspective of the genetic counselor. Obviously, any literature that alludes to practice recommendations must also include an evaluation of the counseling experience from the client's perspective. This paper can offer anecdotal experiences from one side only. However, the value of this should not be underestimated. The counselor's own values and input into transcultural counseling training have often been ignored, as the 'cultural' client has become the object of study (McRae and Johnson, 1991, cited in Wang, 2001, p. 211). The result of this is that "clients have been frequently misunderstood due to the counselor's own unfamiliarity of how his or her own racial-cultural affiliations have been influenced by discrimination and oppression" (Wang, 2001, p. 211). Therefore, this paper hopes to address the issues highlighted above by adding to the literature that explores the counselor's own beliefs and experiences within a transcultural setting.

BACKGROUND: GENETIC COUNSELING IN LEEDS

At the time of writing these cases all the authors were working as genetic counselors at The Yorkshire Regional Genetics Service, Leeds, UK. The center offered a genetic counseling service to the different cultural groups within our region, most specifically for the Northern Pakistani population, which is the largest subgroup. This center also had a major research and clinical program investigating genetic deafness. Thus, genetic counseling practice as well as research involved frequent interactions between hearing genetic counselors and geneticists and d/Deaf clients.

Practicalities of Seeing Asian Clients

The Asian transcultural genetic counseling service is provided by 5 genetic counselors, both male and female, in the appropriate languages (e.g. Panjabi, Urdu etc) as advocated by Modell and Anionwu (1996); Modell and Model (1992). This direct communication has helped in understanding the diverse needs of this group, so enabling us to provide accurate genetic information in a culturally informed and sensitive way. Since the introduction of a specialist service for Asian families involving culturally and linguistically matched genetic counselors the referral rates for Pakistani families increased over the years and seeking genetic counseling has become more acceptable within the community.

Traditionally, we have employed a very crude form of allocating all the referrals with Asian-sounding names either to the male or female Asian language speaking counselors, depending on the nature of the referral. They perform pre-clinic, home visits to all of these clients and depending on their assessment of language, psychosocial, and cultural factors they may or may not be present at the clinic appointment if the client is to see a clinical geneticist as well.

Up until 2004 it was usual for genetic counselors to do pre-clinic home visits to collect the pedigree and offer genetic counseling; in particular, for Muslim, Pakistani families who did not use English as their first language. The collection of a pedigree with multiple consanguineous relationships can be very complicated and time consuming. By using a home visit for collection of pedigree data, time is then freed up in the subsequent genetic counseling consultation in clinic. The home visit also often provides access to other relatives who may not have attended a clinic visit who are able to provide additional information. The home visit also allows the genetic counselor an opportunity to observe the family in their own home, which may help the counselor to further understand family dynamics.

Practicalities of Seeing Deaf Clients

At the time when this work was originally written, The Yorkshire Regional Genetics Service in Leeds was the main center for molecular and clinical genetic research into deafness in the UK. It therefore tended to be one of the main centers where d/Deaf clients were seen clinically for genetic counseling.

In addition to this there was the opportunity to participate in psychosocial genetic counseling research. When a clinical or research appointment was arranged to see a d/Deaf sign language user appropriate interpreters were booked for the consultation. Additional time was usually allowed for these consultations, to enable the interpreter to orientate themselves with the genetic terminology as well as to make space for accurate interpretation of terms for the client, together with extended time for questions. Within the psychosocial research program attitudes towards genetics and genetic testing were gathered via postal questionnaire as well as via a home visit. The genetic counselor who conducted this research also took part in one-to-one and group counseling supervision with her clinical colleagues.

Background to Cultural Deafness

Within this paper, 'Deaf' written with an uppercase 'D' refers to a deaf person who is culturally Deaf, i.e., uses sign language (e.g., British or a National Sign Language) as their first or preferred language and has a positive identity attached to being deaf. The term 'd/Deaf' refers to a collective group of deaf people to indicate those who identify with the Deaf community or hearing world. People who are culturally Deaf (written with a capital 'D') usually use sign language as their first language, often with little or no speech. Sign language is a unique language in its own right. It is not a literal translation of spoken language but uses concepts, facial expressions and hand placement as communication. People from the Deaf community are often very positive and proud to be Deaf and do not see themselves as disabled in any way (Lane, 2002). They enjoy that they are part of a community that shares a common history, values and language (Padden, 1980). In the UK there have been recent calls for the term 'Deaf community' to be replaced with 'Sign Community,' which refers to three key elements relevant to Deaf people—language, culture and community (Sign Matters, 2006).

The Sign Community in the UK has a strong cultural identity. The Sign Community does not want to be cured of their deafness, as being deaf is their identity, it is normal to them. They often compare themselves to an ethnic minority grouping; they have cultural differences and needs that may be different from mainstream, hearing society. This approach could be considered 'Pan-National' accord-

ing to Lewis's (2002, p. 206) adaptation of the Carter and Qureshi (1995) philosophy of multicultural counseling. Here, "there is a sense of a culture which is shared by the disabled that transcends Nation and thus acts in a way similar to racial group membership" (Lewis, 2002, p. 207). It should be noted that many Deaf people would reject the label 'disabled' (Padden, 1980).

CASE PRESENTATION OVERVIEW

Within these cases we highlight possible transference and countertransference processes that were unravelled in genetic counseling supervision (see AGNC Supervision Working Group Report, 2007 for a definition of supervision as used in the UK). Transference occurs when a client's behavior mirrors a dynamic that has been present in a previous encounter; countertransference is the genetic counselor's unconscious or conscious emotional response to the client (Weil, 2000).

We have used labels to describe our clients in these cases and are aware that some writers on transcultural counseling perceive that the labeling given generally to ethnicity is inherently racist:

Ethnicity and ethnic groups are . . . shifting and not static. They appear static because the gaze of the nation-state and the gaze of observers make them so . . . [there is] the tendency to totalise and essentialise and to be infatuated with those who are different to the point of assuming an orderliness about them which does not apply to oneself. This process is in itself racist, or at least it can be. The categories 'race' and 'ethnic' have themselves, both by racists and anti-racists, been based on an oversimplification." (Krause, 1998, p. 162)

This has highlighted for us our use of the terms 'White,' 'Asian' and 'Deaf' and while we had intended these labels to be useful descriptors that the reader would understand, we appreciate that these do suggest a level of stereotyping. We have deliberately chosen to leave these identifiers but challenge the reader to think carefully about what these mean for each individual.

Case 1: Accuracy or Assumption by Liza Burnell

This case describes the experiences of a White genetic counselor involved with an Asian family. The theme throughout this case relates to assumptions

about culture and whether there was cultural understanding between counselor and client. The case raises questions about the quality of service that a White counselor from the Dominant Culture (Davis, 1990), can offer to clients from a minority and different culture.

Accuracy or Assumption: Narrative

The proband, a woman of 26, was referred because she was concerned about her risks of developing cancer. Her mother had developed breast cancer at 42 and her grandmother had recently presented with an ovarian cancer, aged 56.

The client left a message on my answer-phone to reschedule the pre-clinic visit appointment and asked if her mother and two sisters could be present. Usually we encourage clients to attend alone or with their partners, though obviously other family members are more likely to be present when clients are seen at home. We aim to increase the client's autonomy by avoiding pressure on their decision-making from other at-risk relatives. However, in this case I hesitated. One of my prior assumptions about South Asian people had been their emphasis on the family and its close-knit nature. I thought it might still be important to give individuals separate consultations, but assumed this might be difficult to achieve. In the end, I explained this but left the choice to the client. When I arrived, the proband's mother and sisters were there.

The proband's mother, Shamina (pseudonym) greeted me at the door. Kindly, she offered her hand to me and I shook it. It was a different kind of handshake; one which I had observed between male members of the British Pakistani community in Bradford, UK, where I live. It was more gentle and less of a formality than our usual British handshake. I wondered if I should have grasped her hand between my two and pressed them, rather than just offering her one. Or, is this only appropriate between men? I wasn't sure. This incident highlighted my ignorance of the nuances of social etiquette and body language in this culture.

The family home appeared to be middle class and fairly westernized in both in its location and décor. The proband and her sisters were dressed in Western style clothing. Their mother, Shamina, was traditionally dressed in shalwar kameez, so I assumed she was originally from Pakistan. As we discussed the family history I learned that Shamina's parents had

migrated from Pakistan when she was very young. She had been brought up in England and her daughters were all born here. I assumed that they were Muslim and she mentioned the Mosque when making reference to how important her religion was to her at this time. I knew that female Muslims did not attend the Mosque, but I did assume she would have access to other forms of worship.

As I asked about the family history we approached the obviously painful subject of Shamina's mother, who was receiving palliative chemotherapy for a recently diagnosed ovarian cancer. It seemed she needed to talk about her feelings so I encouraged her to do so. I was able to demonstrate empathy (Rogers, 1961) and understanding and, like any other client when this process works, I think that she felt that I understood her. She told me that it had taken the doctors a long time and many investigations to decide on the diagnosis for her mother. Becoming more agitated, she described her feelings of frustration and anger about how the hospital staff had treated her. She had asked if they suspected cancer on number of occasions, but they had avoided answering her. She had felt patronized, as if, she said, they thought she would not be able to understand what they were saying. Finally, she was told in a very blunt, cold way, that the diagnosis was cancer, as she had suspected and that they could only offer her mother palliative treatment.

Shamina was clearly well educated and an intelligent woman who was more than able to understand the rationale for the various investigations her mother had undergone and the implications of the findings. There was obviously some discrepancy here. She repeatedly said 'why wouldn't they tell me what was happening?' 'why did they treat me like this? . . .' My hunch was that her experience, which seemed pronounced, was due to racism. Suddenly, I felt angry too. But I did not know if this was the answer in her mind. I did not want to let my own reaction get in the way and I was not immediately sure what to say. Then I asked her: 'Do you know, do you have any idea why you were treated in this way?' Sadly, she was unable to answer this.

By the end of the session I had paid more attention to Shamina than to her daughters. They all listened carefully but said very little and I was aware of a feeling of a need to include them. However, my assumption was that it would be usual for the mother, as the elder of the family, to take this position. I was aware of choosing to respect what I thought was the family's cultural norm.

I was also aware of the need to give each woman space to talk about their own feelings about their genetic risks so before leaving I gave everyone my number and offered them all separate clinic appointments. They were pleased to take up this offer. One of the sisters, who lived in her own home, smilingly stated 'that would be great because I do have a very different lifestyle to my mum and my sisters.' This contradicted my prior assumption that it might be difficult to separate them. I also offered for them to see a female genetic counselor in clinic and they each expressed a preference for this.

Accuracy or Assumption: Discussion

In preparation for this work I had to reflect on my experience and knowledge of other cultures and of people from different ethnic backgrounds. I had to acknowledge my own experience as a White person and part of the Dominant, institutionally racist society in which we live; it is an unavoidable part of the Self that we bring to the counseling relationship. I think that all counselors who intend to work transculturally need to do this. I recognized the 'knowns', i.e., assumptions that I was aware of, but wondered about the 'unknowns'; unconscious elements which, with my post-colonial heritage, I cannot have failed to have internalised in some form. Karbani *et al.* (1997) have described how such unconscious factors may impinge upon the genetic counseling process.

When talking to Shamina and her family, I felt some of my initial observations helped me to relate to her appropriately and I had a strong sense that she felt I understood her. Assuming that she and her daughters would want the option of seeing a female genetic counselor in clinic was helpful; hence it is likely that my gender was important for them too. In the end, each of my clients wanted to take the opportunity to discuss their individual needs in a separate appointment, so I was glad I had held on to the idea they might need this, despite my original, incorrect assumption that it might be difficult to separate them.

I realized that I had failed to involve the family members in our discussion as much as I might have done, due to my assumption that it was right to defer to Shamina, as the family elder. Qureshi (1997) has argued that genetic counseling can make use of the dynamics within British Pakistani families to facilitate communication. However, family dynamics are also idiosyncratic and, reflecting on this process with my counseling supervisor, I could see I was in danger

of stereotyping. As in all families the counselor needs to be skilled enough to make a fair assessment of the dynamics present at the time. A greater experience of the more subtle aspects and nuances of cultural behavior is likely to have helped me here.

At one point Shamina made reference to her Mosque, although I knew she would not actually visit it I assumed she would have access to psychological and moral support, with the difficulties surrounding her mother's illness, through her religious community, and emotional and practical support from the related social community. However, feedback from one of my Pakistani colleagues in group supervision showed me that I had overestimated the support she might receive. This assumption may have prevented me from identifying her needs more closely, and offering help where required.

Following the genetic counseling session I wondered about my reaction to Shamina's feelings about her treatment by the hospital staff caring for her mother. I have met White clients, who have been patronized in a similar way, so although I had wondered about racism on the part of the health workers, I was not sure if this assumption was correct. I thought my role was to help Shamina to her find her own answer, to increase my understanding about what this meant to her. In retrospect, maybe my assumption was correct. Perhaps, in reality, it was my own difficulty in naming the difference between us, or pointing out something very personal about Shamina, that prevented me from offering her this explanation. In my confusion I may have failed to empower her. I also wondered whether she might have felt more at ease in discussing this with a genetic counselor from the same cultural background.

I discussed my countertransference within supervision. I was aware my sudden, angry feelings around this issue could have been in counterpart to Shamina's, i.e., empathizing with her own angry feelings, or they could have been counteractive, in the sense of stirring up something in myself that wasn't resolved. We agreed that I could have made a tentative statement, such as: 'It sounds as though the staff made assumptions about your ability to understand them, I wonder if you felt they were being prejudiced or racist towards you?' This could have created the opportunity for her to say if she thought this really was the case.

This case illustrates how important it is for transcultural genetic counselors to have a level of cultural knowledge. More specifically I felt my experiences of living amongst the Pakistani Community

in Bradford for many years gave me the confidence to approach these clients in a way that was sensitive, even if I wasn't totally familiar with every social etiquette. Given Shamina's possible experience of racism from health service professionals in the past, the fact that she felt that I understood her is likely to have been very important and may have helped her. Any lack of complete cultural integration was far less relevant, more importantly I think I had enough cultural awareness to be mindful of difference rather than dismissive of it. I have obtained cultural knowledge both by lived experience, and through feedback from colleagues more generally involved in counseling Asian families. Such knowledge includes understanding family dynamics (including inter-generational hierarchies), socioeconomic diversity, marriage practices and social and religious customs. As a White counselor, I needed to be aware of how the racism undoubtedly experienced by clients from an ethnic minority group might affect the process between us.

Given the complexities of being of a different culture to the client, it was immensely important for me to explore what had happened with my supervisor on a one-to-one and group basis and in an incisive and supportive atmosphere. Supervision allowed me to sit with my own confusion, I had also learned a lesson about how I might be better able to respond when faced with this issue in the future. However, I found participating in one-to-one supervision the most helpful. Here, I have discussed and shared my own vulnerabilities surrounding racism and have been able to be honest about my prejudices, this is such a sensitive subject I would feel reluctant to share these with other colleagues in a group supervision setting. There is an opportunity to really question my own beliefs as well as 'practice' and role play different situations with the supervisor. The supervisor can also be used as a mirror for the consultation and as such we can swap roles and explore how it might feel to be on the receiving end of my prejudices. I find this painful and complicated work is vital for my own personal development and subsequently enables me to work more sensitively with clients.

In reality, it is obviously not possible to provide cultural matching between counselor and client for all situations. But where language is not an issue, I believe that genetic counselors that have developed and will to continue to develop, knowledge of different cultures and who receive regular supervision can provide an effective transcultural genetic counseling service.

Case 2: Closeness or Collusion by Mushtaq Ahmed

This second case is written by a male, Muslim genetic counselor from Pakistan, who describes his experiences of having the same cultural background as the client and how this can sometimes create a closeness which could facilitate a level of collusion with the client. This genetic counsellor has lived in Pakistan for 22 years and following this, in Leeds, UK for the last 17 years; he is very well integrated into the local Pakistani community in Leeds and Bradford.

Closeness or Collusion: Narrative

In this family, a two year old boy was diagnosed by the pediatric service outside the Yorkshire region with having an autosomal recessive disorder following which the family were referred to our centre for genetic counseling. The pediatrician involved was White and seemingly had conducted his consultation in spoken English, expecting the father of the child to understand what was being said and translate this for his wife, who didn't speak any English. The family was confused by the information they had been given, which was likely due to poor transcultural, communication skills on the part of the paediatrician.

This family was offered and accepted a home visit. When I arrived at the family's home, the father opened the door and took me into the front room of the house, where the mother of the boy also joined us. I introduced myself to the couple in English and while talking I looked more at the father than the mother, because culturally, if present, men or elder persons should be addressed. At the same time, I was aware of the mother, who was sitting quietly on one side of the room. From her silence, I realized that she may not speak English. On asking her in Panjabi about whether she could speak English, I found that she could not; she only spoke Hindku, a dialect of Panjabi. From the moment she started talking in Hindku, I knew the family's cultural background, as I share the same language and cultural background with them. In this case, I noticed a sigh of relief from the mother. She told me that she was hoping that I would be able to speak her language, and that she had not spoken directly to any health professional about her son.

I asked the couple how the diagnosis in their son came about. The father talked about his son's illness, how they went from one doctor to another. He said

that the cause of his son's condition was explained by their most recent doctor as 'the couple being first cousins.' The father did not say anything further. The mother said this explanation was very upsetting for them. She said, 'we think it is all from Allah, it is not in our control to have normal children.' She told me that the whole family was very upset and could not believe that family marriages could cause this illness as this had not occurred earlier in their family. The mother said, 'you understand this don't you? We always arrange marriages within the family.' The family was waiting for me to explain how first cousin marriages could cause illness. They perceived me to be 'one of them' and expected me to understand and affirm that there is nothing wrong with consanguinity.

The couple was right in that I understood the importance of cousin marriages in Pakistani families and the social benefits and emotional attachment due to such marriages. This made me feel close and empathic with the family. However, as I felt this I also tried to distance myself a little so that protective boundaries were in place.

I tried to establish what the couple understood about the inheritance pattern or recurrence risk of their child's illness. The father told me that they were not given any information about this. However, the mother said that the doctor told them that all their future children would also have the same illness. This showed that they did not have an understanding of the recurrence risk. Such a lack of clarification about a particular disorder in the family may have serious implications, not only on the family concerned but also on the whole community. Often the birth of a normal child in the same family or in the community disproves the professional advice that there is a risk of other children being affected.

My next step was to take the family history. I always find it easier to explain inheritance patterns, and the role of consanguinity, using the pedigree. While I was doing this, the paternal uncle of the boy and his wife came into the room. The father introduced me to his brother and explained that he was involved in the care of the child, so wanted to know what was going on. Both the uncle and his wife helped in providing information about the family during pedigree taking, but did not ask any questions and soon left.

After completing the family tree I gave them information about genetics and described autosomal recessive inheritance. I put more emphasis on the parents being carriers for the autosomal recessive condition, and their 1 in 4 risk of having affected chil-

dren rather than the fact that they were first cousins. Once the inheritance pattern is clearly explained, using the family tree, couples often do understand the implications of marriages among cousins or close relations, however, the significance of this is that it has been done using science rather than through the focus on the social custom of consanguinity.

After all my explanation, the mother again said 'but it is not in our control to decide whether to have normal or affected children. It is Allah who decides for us.' The mother's religious beliefs in relation to her son's illness may be a way of her taking the blame away from the parents. Muslims believe in God's divine plan. God controls illness, health, good and bad fortune, as well as life and death. Having such a belief often helps families to come to terms with problems in difficult times.

Closeness or Collusion: Discussion

Darr (1999) feels it is the responsibility of the counselor to ensure that accurate genetic counseling information is provided in an appropriate language that Pakistani families understand. Inaccessibility in the native language can have serious consequences for families (Anionwu, 1996), for example without accurate clinical information the tendency may be to blame women in this male dominated culture for the birth of an affected child.

In many of the Pakistani families referred to our department, at least one partner does not speak English. I have seen that being unable to speak English not only hinders communication with professionals, but between couples and within the family as well so leading to misinformation and misunderstanding. For example, in this case, because the mother did not speak any English, any information she had about her son's illness was always received through her husband. Furthermore, she had been unable to ask any questions directly, or to express her concerns. Even if she did have some level of English it is still likely that she would prefer to speak in her mother tongue, in order to easily articulate emotions.

There are times, when I see that using a Pakistani language in the counseling session falsely raises the family's expectations. I feel a sense of shared empathy and the client may feel it appropriate to probe into my personal life by asking other questions about my personal or family background. Although I sometimes feel this could put me in a

difficult position, this etiquette is culturally acceptable and a way of creating rapport with professionals. I therefore do not mind sharing information about whether I am married or have children and find that this can help clients to share their own information and concerns. However, sharing of too much personal information may create a closeness that might hinder the goal of counseling and interfere with the necessary neutrality of the counselor. Such closeness in genetic counseling may cause difficulties, especially when unwelcome or painful information needs to be communicated.

As a Muslim genetic counselor I respect and share the same beliefs with the Pakistani, Muslim families I see. However, I also understand that fatalistic beliefs, as found within Islam, may become a barrier for individuals to seek help, especially where knowledge of religion's stance on a subject is poor or clouded by cultural mysticisms. In order to provide whole information, the counselor should be aware of the religious stance on certain matters and how these may be clouded. For example, clients often express that termination of pregnancy is against Islam, but it is not if the condition is serious and termination of pregnancy is within 120 days of gestation.

Consanguineous marriage is a highly favored practice among Pakistanis and British Pakistanis (Darr, 1997). Explanations of consanguinity need to be handled with sensitivity; otherwise it may cause tension during counseling, particularly when explained in the presence of other family members. There are a number of reasons why other family members may be interested in the issue of consanguinity. Perhaps because of the threat to their socially beneficial system of marriages; because grandparents may want to justify that there is nothing wrong with consanguinity; or because uncles and aunts may want to know if their nieces or nephews would be suitable matches for their children. Families often give examples of other consanguineous couples in the community with no genetic abnormality in the family. Families need detailed explanation of why consanguinity may be of relevance to their situation, as it has been suggested that scant knowledge of genetics and genetic counseling may do more harm than good (Darr, 1997).

Given the sensitivity of the subject it would be ideal for the counselor to discuss consanguinity initially with the couple alone then to offer an extended or additional visit to discuss it with other family members. Families understand the implications of a particular disorder, if they are provided with

information in an appropriate manner. Sadly, it is common for families to be told that the condition occurs *because* parents are first cousins. The result of this is that it may reinforce misconceptions and mistrust of health professionals and services (Ahmed, unpublished work as described in Middleton *et al.*, 2005).

Pakistani families from my background often expect health professionals to be directive (Moazam, 2000) and seem to be unaware of the concept of client-centred counseling and non-directiveness. Therefore, during counseling I sometimes feel the pressure to be directive and the closeness and feeling of empathy can make me anxious and question my beliefs about directiveness. Such closeness may be disadvantageous in genetic counseling, preventing transfer of necessary information. Therefore, the counselor should make his or her role explicit at the onset and clarify that the emphasis will be on supporting and facilitating decision making, rather than giving advice on what action to take. In order to avoid leaving the client confused or abandoned it is important to pay specific attention to careful explanations so that informed decision making and full autonomy is still possible.

Overall, I believe cultural matching between counselor and counsellee facilitates understanding, enables the counselor to challenge any misconceptions and disbelief, in a way, which is culturally and religiously sensitive and acceptable.

Case 3: Difference or Disability by Anna Middleton

The third case involves a White, hearing genetic counselor who interviews a White, culturally Deaf client for research. This case shows that transcultural genetic counseling is not only pertinent to race and ethnicity as it considers the Deaf culture, a community of deaf people bound by a shared language, history and outlook on life. The difficulties associated with the communication between genetic counselor, Deaf client and the sign language interpreter are highlighted. The research study from which this case derives involved visiting participants at home to deliver a structured questionnaire via a sign language interpreter. The questions centered on feelings about new discoveries in genetics and attitudes towards the use of genetic testing in pregnancy, the findings of this study have been published elsewhere (Middleton *et al.*, 2001; Middleton, 2005).

Difference or Disability: Narrative

I knew before I met the Deaf participant that she was profoundly deaf and used sign language as her first language. I made the assumption that she may be culturally Deaf and so mentally prepared myself for the fact that she might have negative views about genetics.

When I arranged to visit her she informed me she wanted to use a sign language interpreter that she was familiar with and so organized this for herself. As I arrived at her house I found the interpreter had already been there all afternoon chatting, since they were friends. I felt before we even started the interview that I was very much an outsider. The woman was quite intimidating in her manner and appeared hostile and aggressive; she gave me little eye contact and did not offer any positive facial expressions. I asked her why she had agreed to take part in the research and she answered only because she wanted to make sure that someone put across the 'real' view about genetics.

Interestingly, the interpreter had the same manner; she appeared to empathize strongly with her friend and translated back to me in a curt manner with unfriendly eye contact and a defensive stance. Her spoken translation was clipped and at times she shouted. Indeed, she appeared to be accurately reflecting the tone and intonation of the Deaf woman perfectly. I asked her to clarify for my own understanding as to her feelings about genetics and she signed that she was angry and upset. I am able to converse in sign language to some extent and I recognized the signs she was using to display her strength of feeling. However, to my frustration the Deaf woman and the interpreter continually had internal conversations between themselves to the exclusion of me. I felt as if I was not part of the dialogue and I had to keep asking the interpreter to repeat what was being signed as I needed to clarify if the woman was responding to me or her friend.

Since both the woman and the interpreter had a confrontational manner I decided to chat generally to them before going through the research questionnaire in the hope that this might create a more relaxed atmosphere. I found myself wanting to overtly express an appreciation of her perspective. I found it very difficult to just accept her hostility and had to make an internal decision on how to handle this. My instinct was to try to disarm her by justifying my presence and letting her know I understood her point of view. If left unchecked, I felt it could be easy

to collude with her. However, I knew that this was not my role and the internal supervisor in my head (Casement, 1991) helped me to reflect on this.

I hoped that it would help her if I acknowledged her fears through writing them down for the research. She told me she was isolated by the Hearing World, which discriminated against her and she fought for equal rights within society. She felt very threatened and believed that genetic technology would be misused by hearing people to wipe out the larger d/Deaf community. She thought that if testing in pregnancy for deafness became routinely available that all people would abort deaf babies and this would mean that there would be fewer deaf people in society and therefore more discrimination (pre-natal testing for deafness is not routinely available nor is it technically possible for many forms of deafness). She said there needed to be many d/Deaf people around so that they could have a collective 'voice' to have an equal status in society with hearing people. We had a very interesting interview and I managed to document her strongly negative views.

Difference or Disability: Discussion

Through doing this research I conducted interviews with many different people who had varying degrees of hearing loss. This particular interview occurred relatively early on in my research career and I have worked for several years in this field since. In considering the various interactions I have had with Deaf people over the years, the anti-genetics stance is fairly typical. Although I would not claim that this particular case is representative of the views of all culturally Deaf people, I have certainly met many others who share similar views and also with the same intensity (Middleton *et al.*, 1998). People who are hard of hearing or who are non-culturally deaf, tend to have different views towards genetics, genetic testing and genetic counseling (Middleton *et al.*, 2001).

In looking at this case afterwards, it is possible to dissect some interesting points. Culturally (by being hearing and from the genetics community), I had a very different background to the Deaf woman; she did not allow us to develop a rapport, possibly because in her eyes the barriers between us seemed insurmountable. Interestingly, we were both White, female and middle class and yet this cultural match was totally irrelevant in this situation and appeared to offer no common ground. I had made assumptions before I even met this woman that she would have certain attitudes. As it turns out she fitted my

superficial stereotype, I consciously tried to resist this. I reflected on my thoughts about individualism and wondered whether her angry stance had made it easier for me to fall back on the stereotype rather than see through it. I also reflected on whether my keenness for political correctness held back my engagement, perhaps this was necessary for a research interaction as I was able to document what she wanted to tell me in a relatively detached (on the surface) manner, but this approach may not have been adequate if this had been a clinical encounter. This highlights the dichotomy for genetic counselors in a clinical setting versus a different role when they work as researchers. I considered the stereotype and whether I had a better awareness of the issues that might be relevant to her because I had consciously identified this, or maybe this meant I did not go far enough to try and understand her as an individual. This case has made me think about cultural judgments, their role and how writers on transcultural genetic counseling (e.g. Barlow-Stewart *et al.*, 2006) suggest it can only be successful when there is an acknowledgement of stereotypes.

The woman was angry and threatened. She directed these feelings at me, as if I represented all that was wrong with the world. It seemed that she was almost responding to a supposed 'racist' attack that I might deliver and was ready to fight back. In applying my counseling skills developed through clinical practice I considered the clear process of transference and countertransference in action. Within my own supervision I reflected on the feelings I had—I felt diminished and responsible for her pain, despite the fact that I knew logically it did not belong to me. The cultural difference between us was magnified via our interaction and I was aware that my own feelings of injustice could surface; inside I felt almost apologetic. I wondered whether, in retrospect, it might have been more helpful to label this within the interaction with this woman, perhaps saying 'I feel as if you are threatened by what you feel I represent' or 'I can see you are really angry, can you help me to understand why?' By aiming to distance myself a little from the intensity of feeling and labelling the woman's expressed emotion I wondered if this would go some way to diffusing the situation.

There is often an anti-medicine attitude from culturally Deaf people, particularly with regards to genetics (Middleton, 1998). Although, one should apply caution in stereotyping attitudes towards genetics based around Deaf cultural identity only (Guillemin and Gillam, 2006). There is sometimes a view of

suspicion and fear that genetic technology will be used in some way to destroy the Sign Community, with many examples throughout history to support this fear (see Schuchman, 2004; Middleton, 2006 for a brief overview).

The experience of working with this interpreter was not typical at all; it was most unusual to work with someone who continued to have internal chats between themselves and the client, although it happens more frequently when friends or relatives are used. If it had not been for these aside conversations I could have assumed that the interpreter's negative stance towards me was just a reflection of her client's, i.e., she was interpreting not only her words but also her demeanor and stance. However, since she did side-line my involvement by contributing to the discussion separately from me, this meant that she contributed to the dialogue and also the drama. She also played a part in the exchange of emotion, which created an even more complicated process of transference and countertransference in a three-way movement of emotional input.

The interpreter's own feelings of solidarity with her friend must have been complicated by the fact that she herself was hearing and inevitably in collusion with the Dominant Culture. Her actions may have been exaggerated in order to compensate for this. This highlights an important issue for interpreters and one that their training should enable them to reflect on for themselves. Using a friend or family member without specific training in interpreting may cloud this level of self awareness and reflection.

The bond between the interpreter and the woman heightened my sense of separation. It occurred to me that my lack of fluency in using sign language excluded me totally from the conversation they were having and I had a real sense of how Deaf people may feel when mixing with people using speech. It is possible that I was picking up this woman's own feelings of isolation or exclusion from the hearing world, via a process of countertransference. Through my own post-interview supervision I explored whether (if this had been a genetic counseling session rather than a research interview) I could have helpfully labeled this. Perhaps by saying 'from what you describe, it feels quite isolating' or 'I feel quite excluded from your conversations, can you help me understand why?'

I feel that my cultural difference did heighten the woman's sense of isolation, with the presence of the interpreter who gave her solidarity; there was an

expectation for her to express her anger openly. This may have been helpful to her and by the end of the session, I felt as if she was quite jubilant—as if she had ‘won’ in some way through educating me. It is not unexpected that the woman’s Deaf identity could have been accentuated due to the encouragement and support she received from the interpreter. Social categorization theory suggests that being a member of a group carries more weight in expressing a collective opinion than might have been expressed if alone (Turner and Oakes, 1989).

The value of this research is that it allowed access to interactions that may not often be available to the clinical service. Some members of the Sign Community in the UK may hold such strongly negative views about genetics that this prevents them from feeling able to access genetics services, even if on one level, they are interested. There are many misconceptions surrounding what genetic counseling is and what genetic counselors do. For those genetic counselors who are fortunate enough to meet culturally Deaf clients it is imperative that they are mindful of the historical context within which they practice. Deaf clients are often very familiar with the eugenic practices of the past which have impacted on the Sign community and may sometimes assume that modern day genetics services will oppress them in the same way. Having an awareness and sensitivity to this is vital for any genetic counselors working in this area (Middleton, 2006). However, as already mentioned previously, it is important not to become too caught up in the stereotypes of cultural Deafness. There are many people with varying levels and perspectives of hearing loss and deafness and for whom it is impossible to categorize as belonging to one community or another, such people find they can fit in to the Sign Community and Hearing World in different circumstances and function effectively in both (Corker, 1998). There are also many members of the Sign Community who are willing and excited to embrace genetic counseling.

One difference between the research and clinical setting is that within a genetic counseling session the focus is often on receiving information from the counselor (Kessler, 1997) rather than educating the counselor (quite forcibly in this case) with the client’s views. Perhaps if the genetic counselor delivered the genetic information in sign language or was culturally Deaf her/himself then this may have enabled the client to let their guard down. It may be that from this position that an exchange of information could then occur more naturally without the need for ‘winners’

or ‘losers.’ Alternatively, if the counselor and client were of the same cultural background this may have resulted in collusion between the two of them as they reinforced each other’s views about genetics.

I am not suggesting that cultural matching on every level has to occur, or that disabled clients can only effectively be counseled by disabled counselors. However, I wonder whether transcultural genetic counseling in the Deaf context is different to contexts that perhaps relate to ethnicity, religion or disability; since here there is the added issue relating to fear and suspicion about genetics. Therefore, for the genetic counseling context it might be more helpful for someone with the same Deaf cultural background to tackle genetics issues with Deaf clients. Where this is not possible it would be most helpful if the Deaf client is aware that the genetic counselor is familiar with their culture. This can be done by ensuring the counselor uses politically correct language, such as not referring to deafness as ‘abnormal’ or with negative connotations or talking in terms of a ‘risk’ of deafness in the family. Also, accepting that Deaf people may prefer to have deaf children and so discussing inheritance of deafness in terms of passing deafness on in a positive sense. The Deaf culture is strong and vibrant and keen to be recognized. It would be helpful for genetic counselors to have an awareness of this so that when they see Deaf clients they can counsel them effectively without inadvertently being culturally insensitive (Arnos, 1990; Israel *et al.*, 1992; Israel *et al.*, 1996). It is also vital to be aware of stereotyping, to acknowledge that this exists, to bring this to the conscious and to keep it check, so that the individual rather than the stereotype emerges.

This case highlights cultural difference in a context relating to what the hearing world might consider a disability. The description of culture encompasses so much more than simply ethnicity and race. Although all three people in the interaction described in this case (myself, interpreter and client) were White, however, the cultural similarity in this sense was overridden by other by other differences integrated within Deaf versus Hearing—it did not matter that on one level we may have been very culturally similar.

DISCUSSION OF THEMES

The three case studies raise some common themes to consider when working transculturally.

Cultural Matching

Each case considered the issue of matching counselor and client for cultural background. Daar (1997), Qureshi (1997) and others argue it is imperative to match counselor and client for language and possibly culture; conversely D'Ardenne and Mahtani (1999) challenge all counselors to "... develop their skills in response to clients' cultural needs." Many authors have accepted it may not always be possible to match client and counselor and have described ways in which genetic counselors can begin to develop skills in transcultural counseling (e.g., Wang, 1998; Weil, 2001; D'Ardenne and Mahtani, 1999).

It would be naïve to suggest that cultural matching between genetic counselor and client has to occur in every situation, this is neither feasible nor necessary. As we are all different culturally in one sense or another we should be able to work with any client if we can appreciate our differences (Lewis, 2002).

In our experience most Asian families may not express a preference for a particular genetic counselor but when asked would prefer a similar cultural and linguistic matching. We have had an Asian woman requesting a visit by a White counselor. Despite the fact that she intellectually knew confidentiality would be maintained it was overridden by her fears and fantasies that her closely guarded personal difficulties would become known about in her close knit community. She felt she could not see an Asian counselor as this person would represent the part of her culture that she could not forgive. This reluctance for cultural matching has been reported elsewhere (Bond, 2000, pp. 84–85).

We have also had isolated requests from White clients saying that they prefer *not* to see an Asian counselor. This immediately evokes a spine chilling sensation of racism. It is important not to react from a legacy arising from the practitioner's own race. This, for example, could be the White colonial guilt felt on varying levels from within the White British culture that most of the team in Leeds belong. Some agencies would see such requests as an opportunity to challenge potentially racist positions within their client population. Would there be a similar drive to do the same when an Asian person requests that they do not have a White counselor? Although these requests may feel immediately distasteful and unacceptable we do know that many of our clients are grappling with some of the most potent aspects of grief and loss that human beings ever have to face. This may cause people to regress as a quite normal part of the

process of recovery and exhibit attitudes under stress that would not be part of their usual lives.

We feel that where language barriers are minimal that cultural matching between counselor and client is not necessary as long as the counselor has a good self awareness and understanding of culture, boundaries and difference. However, where there are different language needs and there is the luxury of having access to genetic counselors who speak (or sign) non-native languages, cultural matching is helpful so that clients are able to express their thoughts in their mother tongue. Where it is not possible to linguistically match genetic counselor and client, quality, professional interpreting services should be employed.

Consanguinity

The issue of consanguinity can be very sensitive and deserves careful consideration. Case 2 demonstrated that cultural matching between counselor and client meant that the counselor was able to ask freely about cousin marriages without causing offence and without the need to tread carefully. This could be because the clients knew that their counselor was of the same cultural background, so assumed he understood their customs. Alternatively it could be because he was so familiar with this issue that he was able to time it in such a way that it seamlessly fitted into the session. Anecdotal experience from White genetic counselors in our group was that most of us feel uncomfortable asking about consanguinity. The experience, particularly from Case 2, helps us to appreciate that the issue of consanguinity should be tackled by explaining clearly why it is of importance, emphasizing confidentiality and never using it as a tool to blame or give reason why a child has been born with a disability—it is recessive genes that may offer an explanation (Darr, 1999).

Language and Translation Issues

The use of a trained, independent interpreter, as highlighted in Case 3, is paramount. Although conversation was a success in Case 1 between the White counselor and Asian client this may have been because the Asian client had good English skills. It is not possible to truly know how much is interpreted correctly when there are language barriers between counselor and client.

Problems inherent in the use of translations of written educational materials on genetics were described in a study by Shaw and Ahmed (2004). Client leaflets written in Urdu were back-translated into English and then evaluated for understanding and sense. In Urdu, there is a lack of genetic language—terms like recessive, gene, chromosome and DNA cannot be literally translated as these terms often do not make sense. Shaw and Ahmed (p. 330) found that text from the leaflets indicated ‘recessive’ translated into ‘subdued’ or ‘out of sight,’ ‘tests during pregnancy’ became ‘pregnancy tests’ and ‘genetic counselor’ became ‘expert in procreation.’ Similarly, in sign-language, the words ‘gene,’ ‘chromosome’ and ‘DNA’ have sometimes been denoted in British Sign Language with the same sign.

Shaw and Ahmed concluded that it is most appropriate in this case to retain the English word rather than attempt to offer a direct translation and then provide a descriptor from the local language. For sign language, the term could be fingerspelt (e.g., g-e-n-e) and then a contextual sentence can be signed that describes the concept. Once each term has then been defined the signer can either refer to the fingerspelt word or else indicate which shorthand sign they will use when referring to each concept. Thus, when interpretation/translation is occurring the interpreter must have a clear, basic understanding of genetics, in order to be able to describe the technical terms correctly in context as without this knowledge major inaccuracies could be relayed.

Both the counselor and family in Case 1 were able to communicate effectively in English. However, there may have been an underestimation of the other non-linguistic cultural differences between them. Roberts *et al.* (2004, 2005) present some relevant work from non-English speaking clients with their English speaking doctor in a primary care setting. Here, they highlight that if both doctor and client do not have a similar approach to the consultation, for example, through expectations of what the doctor can offer, shared understanding of how to explain and elicit symptoms and knowledge of how general practice consultations are ‘normally’ constructed (e.g. the client describes their symptoms and the doctor decides from this what to do), then the communication between doctor and client can become very confused. In this work, the authors found that the non-English speaking clients in this study were less ‘orderly’ in the manner in which they described their problems and appeared to have different cultural expectations of a doctor. This finding implies that

cultural difference was not just limited to linguistic difference; there was an impact of social knowledge and communicative style that influenced the consultation too. It is therefore not possible to truly know how much could have been missed in terms of non-verbal communication in Case 1 between the White genetic counselor and Asian family.

Cultural Directiveness

A client in a transcultural encounter may seek out directives from the counselor, and may not know how to respond to non-directiveness (Raz and Atar, 2003; Wang and Marsh, 1992). The client may even feel that the counselor is not skilled when advice is not forthcoming (D’Ardenne and Mahtani, 1999). The Asian genetic counselor in Case 2 experienced difficulty with maintaining non-directiveness, as the cultural expectation was that he would give advice and share his wisdom. He has managed to develop a style of counseling that offers some direction in relation to his own personal information, but when crucial and important family decisions needed to be made is able to explore the family perspective and help them to make informed and personal decisions. This tension between two cultures (the host, Asian culture and the culture of genetic counseling practice) has to be finely balanced.

Dealing with the Anticipation of Racism

Writers on transculturalism insist that consideration of racism is paramount to any discussions about race, ethnicity and healthcare (Culley, 2006). Personal experience of discrimination or racism can realistically lead to mistrust of the genetic counselor (Telfair and Nash, 1996) and so it is vital that trust is established early in the consultation. If the doctor or the counselor is from the Dominant Culture (Davis, 1990) and the client is from a minority culture the inequity in the power relationship between the two could get magnified as the same dynamic is repeated in the professional context as well as the cultural one. This power difference could expand where transference issues are strong.

As with the Deaf woman in Case 3, culturally different clients may bring their feelings of distrust, indignation and persecution to the counseling relationship and may act these out here. A genetic counselor skilled in transcultural work should

acknowledge their client's inner turmoil as well as the prejudiced environment within which their client lives. The genetic counselor can really only achieve this by having an awareness of their own place within the Dominant culture as well as an acknowledgement of their own fears and prejudices.

In counseling, racism is seen as the largest barrier to effective multicultural counseling.... racism is caused by ethnocentrism and feelings of superiority rather than lack of knowledge of cultural differences... Race-based genetic counselors would seek to understand their own racial socialization and how their beliefs and expectations concerning clients of different race may affect the counseling process."

(Lewis, 2002, p. 206)

Once the genetic counselor has explored their own 'racial socialization' she/he can then focus on helping their client accept, understand and cope with their feelings as well as re-claim their own power and confidence. Had this been a genetic counseling consultation rather than a research setting as described in Case 3, it may have been possible to focus on this.

Therapeutic counseling can be used as a tool for 'empowerment' (D'Ardenne and Mahtani, 1999)— "Transcultural counsellors have a special responsibility to examine the power differential in their therapeutic relationship and to make connections with the power imbalance in wider society" (D'Ardenne and Mahtani, 1999, pp. 91–92). This means that the counseling relationship can be used as a mirror of the imbalance the client experiences in everyday life.

Not all genetic counselors may have examined their own cultural prejudices and racist feelings, for those that are unaware of the necessity of this, problems can occur:

"... unacknowledged prejudice is reflected back unconsciously in the counseling relationship. When this occurs, the client no longer experiences unconditional positive regard, genuineness and empathic understanding in the transcultural genetic counseling, and may consequently withdraw. Worse than this, the unaware counselor only perceives the clients' withdrawal as non-compliance or resistance. This dissonance in the relationship results in both parties having their beliefs about the other's culture reinforced." (D'Ardenne and Mahtani, 1999, p. 93)

Therefore, in order to work effectively in a transcultural setting we have to take the painful and honest step of exploring our stereotypes (Barlow-Stewart *et al.*, 2006) as well as being open to our experience of racism from the side of the Dominant culture.

Cultural Identity

It is vital that genetic counselors have an awareness of their own cultural identity, history and 'world view' (Weil, 2001, p. 145; Wang, 1994, p. 269) if effective transcultural genetic counseling is to be achieved. Weil (2001) suggests that self-study guides might be helpful in such exploration; Wang (2001), Weil (2000), Greb (1998), Lago and Thompson (1996), Wang (1993, 1994) offer useful insight into this. Clients who have experienced a lifetime of racism and prejudice will understandably bring this as a part of them to the therapeutic relationship (D'Ardenne and Mahtani, 1999). The vast majority of genetic counselors in the US are White (James *et al.*, 1995), which is the same in the UK, and thus clients who have experienced racism will identify the counselor with White, (hearing) prejudiced society. This means that for issues that touch on prejudice, the genetic counselor will form part of the problem but also the solution (D'Ardenne and Mahtani, 1999).

Considerations for Genetic Counselors

The work of Lago and Thompson (1996) also offers a useful insight into the knowledge that could be gathered and summarises a set of ideas developed by Sue *et al.* (1992) and D'Ardenne and Mahtani (1999). The following quote aptly summarizes this:

"To become a transculturally skilled counselor, students will need to:

- have knowledge about the complex concepts of race, culture, ethnicity and how these relate to their own heritage and thus affect their perceptions of the world
- gain understanding of the historical and contemporary relations between their own culture and others
- understand how systems of racism and oppression operate
- attain specific knowledge about the client group/s they may work with, including family systems and community hierarchies
- understand how race, culture and ethnicity impacts upon people's development and informs and motivates their actions in society
- understands how the processes of the dominant group in society impacts upon minority group members
- consider the impact of language difference from clients and construct strategies to deal with this

– have knowledge about the cultural limits of counseling Lago and Thompson (1996, p. 139).

Transcultural genetic counseling approaches and techniques are in development. There is a very great need for more research in this area not only from the genetic counselor's perspective but also from the clients.' Encounters that cross culture are based on all sorts of assumptions about the process of what works and what does not, mostly (as with here) from the counselor's perspective. Knowledge can really only be expanded in this area with an independent assessment/evaluation of the client's experience of this work.

CONCLUSION

In conclusion, this paper has shown how the genetic counselors from The Yorkshire Regional Genetics Service, Leeds, UK have experienced different cultures via the process of transcultural genetic counseling. Honest and sincere accounting of how these interactions occurred have helped in learning about the most effective ways of practicing in this field. Good quality genetic counseling supervision has also been vital in understanding how to explore and therefore manage this appropriately.

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