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Impact of cultural perceptions on diagnosis of autism

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Abstract

There is very little existing research about the perceptions and understanding of the Autism Spectrum Disorders (ASD) in families from different ethnic communities, and how they view difficulties in social behaviour, one of the defining characteristics of the disorder. This phenomenological research was set out to discover if there are any differences in the value given to different social behaviours amongst parents of children with ASD from four ethnic backgrounds (White British, South Asian, Afro-Caribbean and Somali), living in the UK. Semi-structured interviews were conducted with all the sixty three parents and thematic analysis was used for data analysis. Findings show that there are some differences between parents from the four ethnic backgrounds, and also between fathers and mothers from the same ethnic background in the value associated with the core difficulties in social behaviour. This preliminary study highlights issues to consider when providing appropriate interventions, setting up relevant educational goals for children with ASD, and offering support to their families.

Introduction

There is an increasing realisation that the prevalence rates of autism spectrum disorders (ASD) vary based on ethnicity (Goodman and Richards,1995; Croen et al., 2002; Mandell et al., 2009). Due to limited research on the subject, it is difficult to pin-point the reasons for these varying prevalence rates. It could be that the difference is because of some biological or genetic differences within the various communities or an outcome of the diagnostic criteria and procedures used. Unlike some other disabilities, ASD is primarily diagnosed on the basis of observed behaviour based on Wing's (1988) triad of impairments. However, Charman and Stone (2006) argue it is the social impairments that most characterise the disorder. Social development, in turn, is most affected by cultural factors and accepted social norms are subject to considerable cultural variation (Dyches et al., 2005). It is possible therefore, that there are differences in how a disability is perceived on the basis of the social and cultural milieu of which it is a part (Fletcher and Navarrete, 2003). In spite of this, there is very little research on how people from different cultural backgrounds interpret social behaviours associated with ASD. In this exploratory project, parents from four different cultural backgrounds in the UK were interviewed to discover how they interpreted the same set of social behaviours, all linked to an autism spectrum diagnosis

One of the main functions of social competencies is to enable individuals to function fully in their particular social situation. The very fact that it is supposed to help an individual to adapt to a particular social situation suggests there are different sets of socially acceptable behaviours for different circumstances. This means that a value or behaviour that is adaptive for socialisation under one set of societal conditions becomes maladaptive

(Woodhead, 1995) or leads to misunderstanding (Burton, Kagan, & Clements, 1995) under another. LaFranca and Mayo (1976), for example, found that there are ethnic and gender differences in the amount of eye contact given. They give the example that while listening, Black males gave the least eye contact and White females gave the most. Similar findings have been established from research in Asian American cultures (Wilder et al., 2004; Liu, 2005). However, lack of eye contact is considered as one of the symptoms of the disorder when found in individuals with ASD.

Kim, Kim and Rue (1997) found that it was common and accepted for Koreans to use elaborate language and indirect expressions in their communication. In communities where an indirect style of communication is expected, using a direct style would be considered rude or inappropriate. For this reason, some African communities use the third person for commentaries rather than the first person (Jamin, 1994). Yet, in Western cultures, using indirect language or referring to oneself in the third person, are also associated with communication patterns displayed by people with ASD.

Expanding on the idea of a cultural basis for observed behaviour, Wilder et al., (2004) add that a number of behaviours such as tantrums, aggression, lack of normal attachment to family members, poor social-interaction and communication skills, and lack of emotional expression, all have their roots in cultural differences and expectations. They provide the example of Asian-American children who may avoid eye contact with adults, and respond to the teacher's questions by being silent, out of respect for the adults. According to them these behaviours could be interpreted by the school staff who are unaware of their cultural relevance, as difficulties in the areas of social skills and communication, and hence treated as possible symptoms of ASD. These differences of opinion about social-communication behaviour are particularly important in a condition such as ASD, where one of the main areas of difficulty is social interaction.

The main aim of this research was to investigate the cultural influence on the understanding of what constitutes appropriate social behaviour by parents of children with ASD, belonging to four different ethnic backgrounds, living in the United Kingdom. The four groups involved in the study were White British, Somali, South Asian (India, Pakistan, and Bangladesh), and Afro-Caribbean (countries such as Nigeria, Ghana, Guyana, Congo and Sierra Leonia).

The main research questions were as follows;
1. Are there cultural differences in the importance given to the different social behaviours found in ASD?

2. Which of the identified social behaviours do these parents consider as important skills to be taught to their children?

Methodology
A qualitative approach was used for both stages of the research, as I deemed this to be more appropriate for my research questions, allowing the study of complex situations in their everyday context. This approach can also facilitate understanding of the knowledge and

practices of the participants (Flick, 2002). Grieg and Taylor (1999) state that *"Qualitative research enables the voice of the participant to be heard."* (P-46) This was crucial for this research, since the focus was to reveal the knowledge and understanding of the parents about social behaviour and to provide them with an opportunity to express their views.

Concerning the dilemma involved in doing research where cultural factors are involved Mink (1997) comments;
"Cultural nuances may be missed if only quantitative methods are employed, and these important nuances may also be overlooked if the investigators are not culturally sensitive." *(*P- 94)

Within the interpretive approaches, one paradigm that takes the view that people may differ in their concerns on the basis of culture, language and their own situations, is the phenomenological approach (Leonard, 1994). Its aim is to understand how the world is experienced by people within particular contexts at a given time. It does not try to explain the causes, but provides a description of the lived experiences (Willig, 2005).

I have used the interpretive phenomenological approach as the paradigm for this research. I felt that this would be an appropriate paradigm to answer the research questions, since this approach focuses on examining and understanding the situation through the eyes of the participants (Anderson & Burns, 1989; Cohen et al., 2000). Looking at a phenomenon through the eyes of different participants would provide different perspectives on the same situation. Langdridge (2007) asserts that this ability to see the phenomenon from different viewpoints is necessary to understand its essence. As the main emphasis of the research is to gather information about the understanding of the parents regarding ASD, social behaviour, and the importance given to various social skills in different communities, understanding the situation through the parents' and the professionals' eyes was a necessary aspect of the research. As suggested by Easterby-Smith, Thorpe, and Lowe (1994) small sample sizes were maintained to get the required in-depth information.

The interview is considered an important method to use when the objective is to understand the individual's perceptions (King, 1994) and the way people develop their understanding of the world (Hosie, 1986). Others mention that interviews could often be the only means of gathering information that cannot be observed, such as attitudes, beliefs, and values (Anderson & Burns, 1989; Bryman, 2001). Since this was the kind of information that this stage of the research was gathering I felt interviews were an appropriate tool. Many phenomenologists have also recommended using interviews as the best means of data collection (Van Manen, 1990; Benner, 1994; Langdridge, 2007).

Purposive sampling was used to collect participants from different ethnic communities, living in an inner city in the UK. The sample that emerged was the result of various recruitment approaches (see Table 1).

Table 1 Sample size

Ethnicity	White	Afro-Caribbean	South Asian	Somali

	British			
Fathers	9	3	5	0
Mothers	20	13	7	6
Total	29	16	12	6

Semi-structured interviews were used for data collection because of their flexibility. This was an important element as the research included parents whose understanding of English was varied. Providing explanations, and simplifying the language, was essential to gather the required data from these parents. The interview guide was developed from the outcomes of an initial focus group, a literature review of other research in the field, and a study of some of the screening and diagnostic tools used in the field of ASD. To capture some of the variations between ethnic groups referred to by Diniz (1999) and to measure acculturation, I used an adapted version of the acculturation scale developed by Burnam et al., (1987).

Four common diagnostic and screening tools were selected to identify the common social behaviours associated with ASD. The tools used were: The Childhood Autism Rating Scale (Schopler, Reichler, & Renner, 2002), Asperger Syndrome Diagnostic Scale (Myles, Bock, & Simpson, 2001), Autism Diagnostic Interview-Revised (Rutter, Le Couteur, & Lord, 2005), and Autism Diagnostic Observation Schedule (Lord et al., 2003). After comparing the behaviours that occurred in all these tools, six social behaviours were identified to be included in the interview guide. As these are used for diagnostic purposes, these can be classified as the behaviours that professionals generally consider as the prime areas of social difficulty for people with ASD. The participants were requested to rate these six behaviours on the basis of the importance they assigned to each of them. Along with these, an open question was included requesting the interviewees to add two more behaviours that they consider as important, which were not covered in the list. It was expected that these questions would provide opportunities to compare the importance given to these social behaviours by different ethnic groups. The prepared interview schedule was used after making the required amendments following the piloting stage.

Results and discussion

All the parents were asked to rate the six social behaviours in the order of their importance. Some parents did not rate some behaviours as they did not consider them as important, while others rated more than one at the same level as they considered all of them to be equally important. The first three ratings for each of the behaviours were totalled to get the aggregate percentages shown in Table 2. Once the parents prioritised the behaviours they were asked to provide reasons for the importance they gave to these behaviours.

Table 2 Social behaviours to be taught

- Using eye contact to communicate with adults and peers
Somali (83%), Afro-Caribbean (67%), South Asian (50%), White British (32%)

- Using a range of facial expressions to express emotions
Afro-Caribbean (53%), Somali (50%), White British (20%), South Asian (16%)

- Using gestures (including pointing)
Somali (67%), White British (43%), South Asian (41%), Afro-Caribbean (39%)

- Interacting with adults and people in authority- initiating, conversations, requesting, commenting
Somali (83%), South Asian (74%), White British (72%), Afro-Caribbean (39%)

- Respecting personal space
South Asian (67%), White British (54%), Afro-Caribbean (46%), Somali (16%)

- Following social rules, cues and boundaries for different situations
White British (93%), South Asian (75%), Somali (67%), Afro-Caribbean (60%)

Some parents from all the groups agreed that the identified six behaviours should be taught to children with ASD. Where there were similarities in the importance attributed to particular behaviours, broadly speaking these were shared between the Afro-Caribbean and Somali groups, and between the South Asian and White British groups. The difference in percentages for the six behaviours suggests that there could be cultural differences in the importance given to these behaviours.

Cultural differences:

The reasons most parents gave for teaching a particular behaviour were similar: to help their children to interact with others, to enable them to integrate into society, and a hope that learning these skills would help them to have a better future. Within this broad agreement, patterns of difference emerged based on culture and gender. For example, while White British parents felt facial expressions had limited importance in communication, parents from the other three groups felt that by learning this, their child would develop an understanding of others' emotions. As this South Asian mother states;

> *"Using facial expressions is second important to me. That will make him learn and be aware of others' emotions. I think the difference between humans and animals is that we are aware of others' emotions."*

Likewise, more fathers than mothers considered this to be a difficult skill to teach. This gender-based difference in the importance given to the skills was particularly evident in teaching to respect personal space, where a greater number of fathers than mothers considered this an essential skill to teach their children. Similar cultural and gender

differences have been found by previous researchers (LaFranca & Mayo, 1976; Sue & Sue, 1990) with regard to eye contact and personal space. Not many of the parents in this study specifically pointed towards cultural differences, but as seen in the above example, the fact that facial expressions have been considered to be more important by families from two ethnic groups compared to the other two, could indicate that there is a cultural bias in the selection of these skills. Similar differences in the important associated can be seen for the other skills as well.

Parents from minority ethnic communities felt that certain behaviours that are considered as inappropriate in their own culture were essential to learn because their child has ASD or to be able to live in the UK. For example, a Somali mother rated 'using gestures' as important for her son even though it is considered inappropriate in her own community. Similarly, this South Asian father uses his son's disability as the reason for selecting eye contact to be taught.

> *"Because I think it is a condition, Asperger's, where eye contact is important so I think, I am not going to go into that except for mentioning, I think eye contact is a cultural thing as well, but I am ignoring that cultural part of it. I am sticking to that that person has a disability and for him it is important to have eye contact so cultural issues shouldn't be there now."*

Another South Asian father also selected eye contact because it is important in Western society, as he explains,

> *"Even some socially active persons can sometimes feel like ...especially people coming from Bangladesh, because it has been taught that, if you look at the adult when you are speaking to them, you just think they are rude, too confident…. But in this country, people do not trust you if you do not look at them. They think the reverse in that case, that you could be lying. In our country it is politeness and in this country, in this culture, it could be lying, because you are not even looking at someone so that means you are probably not telling the truth. You are probably feeling embarrassed to look at the person's eyes."*

It could be that parents coming from some minority ethnic communities may be less confident in specifying their preferences because of their minority status in the society. Another possible reason for this difference could be as Parette, Chuang and Huer (2004) suggest, that acculturation within Western society influenced the way parents valued a set of skills.

<u>Influence of acculturation within British society:</u>

While it is generally understood that acculturation consists in accepting the norms of the majority culture, I feel it also includes developing the confidence to assert one's own culture. Both these strands were seen in the context of selecting skills such as eye contact, where some parents selected it because they thought it was an important skill to learn to live in the UK, while a third generation Caribbean mother thought it would be culturally inappropriate to teach it to her son.

The level of confidence can also be seen when groups as a whole are compared to each other. It was mainly the South Asian and the White British parents who said that some of the behaviours were inappropriate or unimportant to teach. In comparison, none of the Somali parents said this. This, to a certain extent, reflects the length of time that the different communities have lived in the UK. It was mainly the Afro-Caribbean and the South Asian parents in this study who have lived in the UK for longest, while most of the Somali parents were new immigrants. A similar pattern was followed when parents were asked if they would like to add any other skills to the list, it was mainly the White British and the South Asian groups that suggested additional skills.

Berry (1980) describes acculturation as a multi-linear phenomenon. The different emerging stages of acculturation were evident in the contradictory views that were held by some of the parents. For example, some Somali parents said that using gestures was an important skill to learn for non-verbal children with ASD. When they were asked later if learning any of the skills would cause problems in the social integration of their child within their community, some of these mothers also accepted that pointing was not considered appropriate by some members of their community, and therefore they would have to explain to them why their child was being encouraged to learn this.

However, all the differences noticed in this study cannot be solely attributed to a cultural basis. In addition to the influence of the gender of the parents, the age of the child, the severity of his/her ASD, and the training attended by the parents also seem to affect the importance they associate with the various social behaviours.

Conclusion

This study was developed to explore parental attitudes towards social behaviours, and the value given to teaching some of these to their children with ASD, on the basis of their cultural background. The evidence gathered in this research indicates that the importance given to the 'deficit' social behaviours associated with ASD is not universal and is influenced by a number of factors including culture. The difference in the importance attached to the social behaviours needs to be considered when explaining the diagnosis of ASD to the parents as they may not consider the lack of certain skills as a disability. It is also possible that these differences impact when and whether parents seek a diagnosis for their child's condition.

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