‘I had never heard of autism before’

The experiences of East African immigrant parents of autistic children in the UK

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Rationale

- Research suggests that mothers born outside of Europe, who live in the UK have a significantly higher risk of having an autistic child compared to mothers who are born in the UK (Keen et al., 2010). East African immigrant communities in particular appear to have a higher prevalence of autism.
- Despite these stark findings, there are still significant gaps in knowledge and understanding as it is unclear how different cultures and belief systems influence the experiences and needs of children and families (Davenport et al., 2018). Autism is perceived differently in different cultures, thus there is a need to understand the role of culture on perspectives relating to an autism diagnosis (Papoudi et al., 2020).
- In 2019, people from Eritrea and Sudan were among the highest of nationalities that claimed asylum in the UK and they were the highest out of all of nationalities to be granted asylum (Home Office, 2020).
- Educational psychology (EP) involvement in relation to East African immigrant parents (EAIIP) has not been investigated previously. This is essential as the East African population is growing in the UK, thus professionals must be responsive to their needs.

Research Questions (RQ)s

1. How do East African immigrant parents living in the UK come to understand their child’s autism, both individually and in the context of wider family and community?

2. What are East African immigrant parents’ experiences of accessing support that is available to them in relation to their autistic child?

3. What are East African immigrant parents’ experiences of Educational Psychology involvement in relation to their autistic child?

Methodology

Design
A qualitative research design was used.

Participants
8 East African parents (3 Somali, 3 Eritrean parents, 1 Rwandan and 1 Sudanese parent) were recruited using purposive sampling from an inner London local authority. All parents had Educational Psychology involvement within the last 5 years and all of their children had Education, Health and Care plans.

Data Collection
Semi-structured interviews were conducted via Microsoft Teams. Interpreters were used for 3 of the interviews.

Analysis
The 6 phases of reflexive thematic analysis outlined by Braun and Clarke (2019) were followed to analyse the research findings. An intersectional lens was applied to privilege the unheard voices of the parents.

Results

RQ1: When most parents first noticed a developmental difference in their child, they had no prior awareness of what autism was and it was only by doing independent research that parents came to understand it. Wider families and communities often had no awareness of what autism was and with no word for autism in the Eritrean and Somali languages it was difficult to explain it to others.

RQ2: Parents accessed formal support in the form of DLA and a community inclusion service. However, all parents reported that they did not know what other support was available and/or how to access it. Many parents felt powerless and as a result, they tried to find professionals who could advocate on their behalf. Some of the parents joined autism support groups via social media and they found these extremely valuable as parents could share information, share their experiences, and learn from another one.

RQ3: Despite having prior EP involvement, most parents did not understand what the role of the EP was. Nevertheless, most parents reported that they found EP input valuable either because the EP helped them to understand the specific needs of their child and how to interact with them or because the EP upskilled staff who supported their child. The parents who did not find EP involvement helpful reported that they did not see any change in their child or the support that was received as a result of it. They felt that recommendations were made, however, these were not followed up.

Implications for practice

- The role of the EP should be made transparent
- Parents should be signposted to specific services
- Culturally sensitive resources should be made available, to enhance the understanding after receiving a diagnosis
- Professionals should aim to raise community awareness by working with community leaders (e.g. imams and priests) in order to promote knowledge and understanding, in an attempt to reduce stigma.

References