Cultural Views of Autism Among Somali Immigrants in Minnesota: a qualitative study

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Introduction

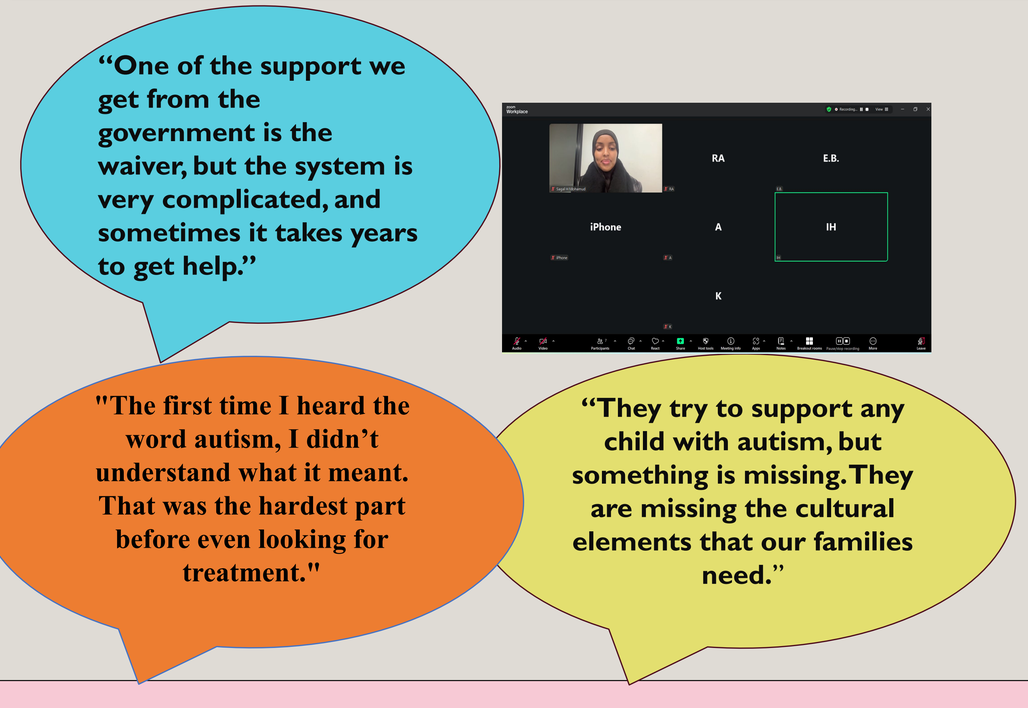
- Autism spectrum disorder (ASD) is a complex neurodevelopmental disability affecting one in 31 children under 8 years in the United States.[1]
- ASD affects children across diverse racial and ethnic groups, yet Somali families often experience unique challenges when seeking diagnosis, treatment, and community support.
- In Minnesota, where there is a large Somali population, ASD is frequently misunderstood and discussed through cultural, religious, and social lenses. Many families report stigma, misinformation, and isolation, which can delay diagnosis, and treatment and increase stress on caregivers.
- If screening, assessment, and treatment for Somali children is to be effective, it needs to be culturally responsive. It is widely known that Somali children with ASD experience severe challenges. Much less is known about the cultural meaning of ASD phenomenon in this demographic group.

Aims

1) Assess differing experiences of Somali Parents of children with ASD and
2) Explore cultural meaning of ASD phenomenon, differences in symptom manifestation, experiences and challenges with diagnosis and treatment practices.

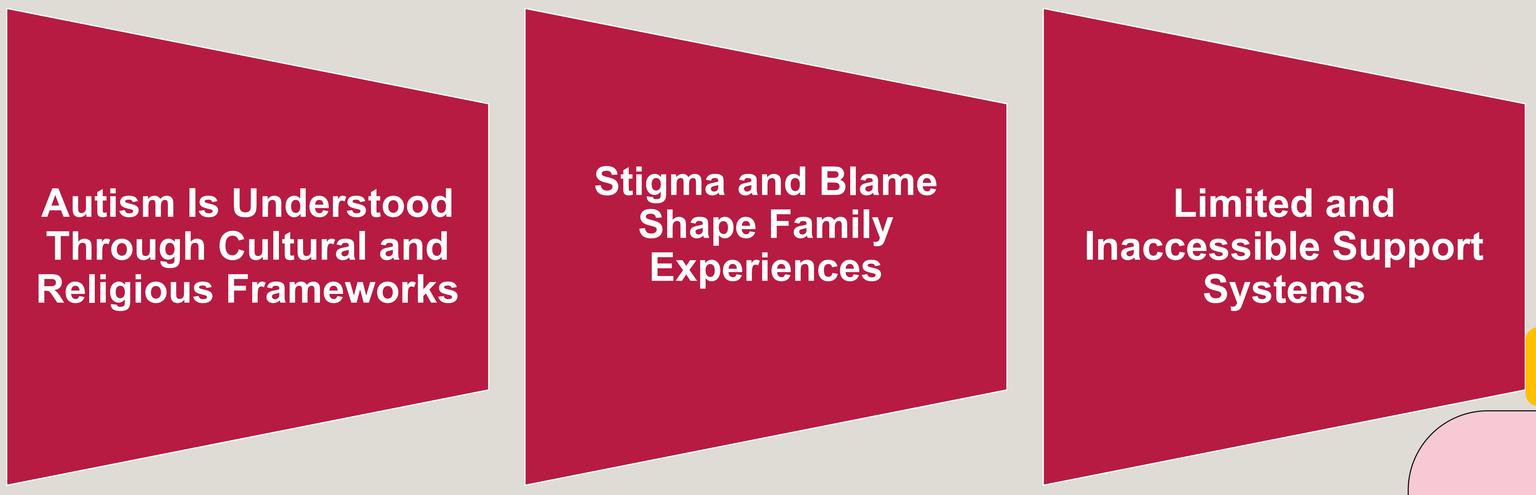
Methods

- Focus group discussions were conducted with Somali parents of children with ASD in Minnesota.
- A total of 15 parents participated in focus group discussions.
- Discussions were done online and semi-structured around a topic guide co-created from literature review and community knowledge.
- Discussions were video-recorded, transcribed verbatim and analyzed.
- Transcripts were analyzed thematically using the Framework approach.



Results

- The experience differed from the Western countries as many Parents described feeling judged, blamed, or pitied by others in the community. In some cases, families felt pressure to hide their child's diagnosis due to fear of shame or judgement from others.
- Autism was often described as an unfamiliar concept within the Somali community, especially when parents first encountered the diagnosis
- Autism was frequently explained through cultural or religious frameworks, such as being "the will of God,"
- Many participants stated that there is no clear Somali word for autism, which makes understanding and communication difficult.
- Increased advocacy and awareness efforts were noted to be slowly changing community perceptions, though stigma remains strong.



Conclusions

- Autism within the Somali community is often understood through cultural and religious frameworks, especially at the time of diagnosis.
- Stigma and blame toward parents remain common and contribute to isolation, delayed diagnosis, and reluctance to seek services.
- Families emphasized that autism presents differently in each child, reinforcing that there is no single experience or treatment that fits all.
- Access to diagnosis and treatment is challenged by language barriers, lack of culturally competent services, and complex support systems.
- Improving autism outcomes for Somali families requires culturally responsive education, community-based awareness, and services that center family experiences and voices.

References

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