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Perceptions of and access to occupational therapy services among the Somali community in the UK: cultural barriers and systemic challenges

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Abstract

Background There is a notable lack of research exploring the perspectives of occupational therapy service users, particularly within ethnically diverse communities. Existing evidence highlights significant disparities in service utilisation among different ethnic groups. Developing a nuanced understanding of which populations are most at risk, alongside the specific barriers they face in accessing and engaging with occupational therapy services, is essential for achieving equity. This study focuses on the Somali community in England, an underrepresented group that experiences marked social and economic disadvantage. The aim is to explore perceptions of occupational therapy within this community, and to understand how cultural beliefs, lived experience, and systemic factors shape access and engagement.

Method Six storytelling circles were conducted to provide participants with a space to share authentic experiences related to occupational therapy. Participants were recruited through purposive and snowball sampling methods, with recruitment materials co-developed in Somali and English to ensure cultural and linguistic relevance. The story circles were facilitated in both English and Somali. Reflexive thematic analysis was used to analyse the data.

Results Three themes emerged from the data (1) Navigating the health care system and occupational therapy (2) Worth the Wait? The Human Cost of Delayed Occupational Therapy (3) Disclosure and trust.

Conclusion Story telling proved to be an effective, culturally sensitive method for capturing nuanced community voices. This study sheds light on the underexplored perspectives of Somali community members. It underscores the urgent need to reimagine occupational therapy service delivery through a lens of equity, cultural humility, and social justice. Occupational therapy services must invest in sustained community-led outreach initiatives that embed lived experience into service transformation. Without such change, the Somali community will continue to be underserved by occupational therapists.

Clinical trial number Not applicable.

Keywords Occupational therapy, Diversity, Somali community, Cultural relevance, Cultural barriers

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Background

In the United Kingdom (UK), demand for occupational therapy services exceeds the available capacity to provide timely care, with many individuals presenting with complex needs [1]. Significant disparities also exist in both the quality of and access to these services [2]. Access to occupational therapy is often of lower quality in socially disadvantaged areas, despite the higher healthcare needs within these communities [3]. An admittedly outdated but still important UK audit revealed significant variations in the utilisation of occupational therapy services across ethnic groups, with Asian clients experiencing disproportionately longer wait times for housing modifications [4]. Although this type of quantitative data remains limited, qualitative evidence suggests that these delays may be compounded by a lack of cultural understanding of the needs of South Asian older adults, thereby perpetuating occupational injustice and widening existing health inequalities [5]. Access is further impeded by complex referral systems and limited public and professional awareness of the role and expertise of occupational therapists [6].

To date, there remains a notable lack of research not only on service users' perceptions of occupational therapy, but also on the views of diverse communities. This gap is important, as inequalities are shaped by broader structural factors. These include sustained underfunding, that increases organisational pressures; and wider social and economic inequalities, that influence service quality and access across population groups [7].

While existing evidence does not suggest that occupational therapy practice itself is inherently racist, occupational therapy literature highlights how organisational systems, historical professional norms, and structural inequities can shape unequal experiences and outcomes. Within occupational therapy, emerging evidence indicates that the experiences of exclusion reported by minoritised practitioners are linked to barriers to career progression, and to discrimination within educational and professional settings [8–11].

International occupational therapy professional bodies have acknowledged the need to strengthen equity, diversity, and anti-oppressive practices within occupational therapy [12–16]. Whilst such commitments are positive, it has been argued that embracing cultural humility requires engaging with multiple philosophical orientations that reflect diverse worldviews [17], alongside ongoing critical reflection on how whiteness and Western-centric assumptions may influence practice [9]. In one recent example, Dumont et al. [18] adapted Ayres Sensory Integration to better meet the needs of Black American autistic communities, identifying barriers such as transportation and the geographic location of clinics that prevented equitable access to services. Their work highlights the need for alternative delivery models, alongside enhanced cultural humility training and stronger advocacy to raise service quality and practitioner awareness of the importance of culturally responsive practice.

In relation to occupational therapy's theoretical constructs and practice, Iwama et al.[19] argue that existing frameworks often fail to resonate with people from collectivist cultures, where interdependence, relational harmony, and social roles take precedence over individual autonomy. They critique the profession's tendency to universalise Western values and argue that, within collectivist contexts, interdependence is not a limitation but rather a normative and valued way of being. Supporting the relevance of collectivist values, a study conducted in Singapore [20] found that service users perceived activities as more meaningful when they could: (1) relate them to past social experiences (e.g. school or festive celebrations), (2) connect them to family members (e.g. creating items for loved ones or engaging in activities alongside relatives), (3) learn new skills, and (4) produce a tangible end product.

The term occupational justice has long been cited as a means of promoting fairness in the profession and eliminating barriers to equality, recognising that meaningful occupations for individuals and communities are essential for human health [21]. Kronenberg and Pollard [22] expand on this by introducing the concept of occupational apartheid, which refers to the systemic inequalities that restrict participation in occupations based on factors such as class, age, or race, as well as those created through social policies or organisational norms. The challenge, however, lies in how these concepts are implemented in professional practice, rather than remaining purely as theoretical ideas to be debated in academic circles without being meaningfully actioned.

It is here that Freirean approaches [23] are particularly valuable, as they emphasise dialogical, participatory, and emancipatory practices that foster critical consciousness, which is a foundation for collective action and social change, rather than mere critical thinking. A scoping review by Farias et al. (2022) [24] suggests that many occupational therapists demonstrate only a limited understanding of Freire's categories and theoretical contributions. By contrast, Social Occupational Therapy in Brazil provides a compelling example of Freire's ideas in practice, particularly through territory-based approaches in which occupational therapists work directly within marginalised communities. In doing so, they position themselves at the social margins, making their practice visible and responsive to the lived realities of those they serve [25]. Adopting territory-based, anti-oppressive, and culturally responsive approaches could help the profession move beyond theory and address occupational injustices in practice.

This study focuses on the Somali community, motivated by both the scarcity of research involving this group and the high levels of social and economic deprivation they experience [26, 27]. It is important to acknowledge that cultural identities are not homogenous and that preferences may vary considerably within any cultural group. To assess the appropriateness of occupational therapy practice for the Somali community, it is first necessary to understand how this community perceives occupational therapy. The aim of this study is therefore to investigate the Somali community's perceptions of occupational therapy.

Methods

We sought to adopt a research methodology that was not biased toward developed Western contexts. Consequently, we chose not to employ focus groups, as they are not inherently equity-centered and may inhibit certain voices from being heard [28], constrain the expression of divergent perspectives [29], and limit individuals' willingness to share personal experiences [30]. Instead, storytelling was selected as a community-focused methodology, grounded in the recognition that all communities possess stories. Storytelling fosters an equitable, collective experience that can enhance community solidarity, resolve conflicts, improve social integration, and support processes of truth and reconciliation. It also positions the researcher within participants' environments, enabling a deeper, more nuanced understanding of the data [31].

Although rarely used in occupational therapy or allied health research, story circles have been successfully implemented by UNESCO (United Nations Educational, Scientific and Cultural Organization) in five countries, including Thailand, Tunisia, Zimbabwe, Costa Rica, and Austria [32]. We adopted the approach proposed by Parks [33], who conceptualises storytelling as the analysis of narratives through the lens of 'small stories'. Our particular interest lay in these small stories, which are typically event-focused and socially situated [34]. The aim was to elicit accounts of specific events and lived experiences from participants' own perspectives, rather than to produce 'polished' or rehearsed narratives [35].

Research team and reflexivity

Our research team included four occupational therapists (X1, X2, X3, X4), a research assistant (X5), and a group of co-researchers from the Somali community. X1, X2, and X3 are occupational therapists who identify as women. X1, the project lead, is a mixed-ethnicity occupational therapist based in the United Kingdom. X2 is a South Asian senior mental health practitioner and research fellow in Brent, where this research was primarily based. X3 is a white clinical academic living in South Africa. X4 identifies as white British. Our research assistant, X5, is male and a member of the Somali community. While all core research team members speak English, X5 was the only member who also spoke Somali.

Our co-researchers included members of the Somali Advice and Forum of Information (SAAFI), a community-based organisation founded by British Somali mothers in Brent with refugee backgrounds, and aimed at supporting positive integration. X1, X2, X5, and the SAAFI members were involved in data collection, while X3 assisted the team with data analysis and interpretation. The research team was further supported by a Steering Committee consisting of local and national healthcare leaders, as well as Somali community members.

We had a well-established partnership with the Somali community prior to beginning this research. In 2020, X5 wrote a letter to a national newspaper highlighting the plight of the Somali community in Brent, which was experiencing the highest COVID-19 death toll in the United Kingdom at the time. This letter served as a call to action for X1, motivating efforts to improve fair access to occupational therapy.

In 2022, we conducted four Conversation Cafés as preliminary co-production work. To ensure the authenticity and relevance of this initial engagement, we prioritised building relationships with Somali community leaders. We also engaged in ongoing reflection on our own positionalities as researchers, clinicians, and individuals. Our relationship with participants in the current study was thus built upon previous engagement with the Somali community. Participants were informed about the purpose of the study, and we sought to maintain transparency regarding our own assumptions and potential biases throughout the data collection process among researchers of diverse heritages.

Participant recruitment and selection

We purposively sampled individuals who identified as members of the Somali community, had experience receiving occupational therapy, and were currently acting as a carer or parent of someone in need of occupational therapy. Table one outlines participant recruitment, session attendance, and gender distribution across the story telling circle sessions. Quota and snowball sampling techniques were employed, facilitated through Somali community connectors and SAAFI (a co-applicant), using outreach at community events and through faith and Somali community leaders. All recruitment and consent materials were made available in both English and Somali. Regarding sample size, we were guided by evidence suggesting that groups of 6–8 participants allow for richer storytelling and encourage active listening [36, 37].

However, we became aware that, despite the co-production of materials, certain terms such as 'occupational therapy' did not translate well into Somali. In response, we co-created a new recruitment poster that relied on visual representations rather than terminology that lacked cultural or linguistic familiarity. Recruitment awareness increased notably when Somali community members shared positive experiences of attending the sessions, highlighting snowball sampling as an effective recruitment strategy for this group. Table 1 outlines participant recruitment, session attendance, and gender distribution across the six storytelling circle sessions.

To maximise inclusivity, participants were offered the choice to attend sessions based on their preferences, whether in male-only, female-only, mixed-gender groups, Somali-speaking, English-speaking, or mixed-language settings, and whether conducted online or face-to-face. For researchers working within community contexts, it is important to consider "event-driven time." By this, we refer to the need for flexibility in session start times, as many participants expected the story circle to begin once everyone had arrived, rather than at a fixed time. Many participants also brought family members, including children and friends, which further shaped the dynamics of the sessions.

Table 1 Participant recruitment, session attendance, and gender distribution across six storytelling circle sessions

Session	Mode	Attended	Did Not Attend	Type of Session	Gender of Participants
1	Online	7	5	English& with interpreter assistance	2 males and 5 females
2	In person	3	7	English& with interpreter assistance	1 male and 6 females
3	In person	7	5	English& with interpreter assistance	1 male and 2 females
4	In person	1	5	English& with interpreter assistance	1 female
5	Online	4	4	English& with interpreter assistance	4 females
6	In person	14	6	Somali	14 females
Total		36	32	A total of 36 participants attended (4 males and 32 females).	

Setting

The storytelling circles were conducted in June and September 2024 in the London Borough of Brent. During this period, Brent experienced considerable civil unrest, including race-related riots occurring across the UK. Considering safety concerns, participants were given the option to join sessions online. However, many expressed a strong preference for face-to-face engagement. As a result, most sessions were held in local community centres, with one session online. The gender distribution of participants was predominantly female, which aligns with cultural norms in the Somali community, where women are often regarded as the primary decision-makers within the household [38].

Ethical clearance for this study was obtained from London South Bank University ethics committee. Verbal and written consent to participate in the study was obtained from all participants.

Data collection

Each storytelling circle lasted no longer than 90 min. One session was conducted exclusively in Somali, while the remaining five were facilitated in both English and Somali. Participants were encouraged to speak in the language they felt most comfortable using. To support this, the circles were facilitated by bilingual co-researchers, using discussion prompts and questions co-developed with the Somali community. These prompts were informed by guidance from the Health Foundation and Involve [39] whichprovide best practice guidelines for storytelling-based research (see Appendix 1).

All storytelling sessions were audio recorded. The recordings were transcribed, and the transcripts were reviewed for accuracy. Translations into English were carried out by four bilingual team members. As the study was grounded in the belief that each participant's story is valuable, data saturation was not sought. Rather, the findings reflect the diverse experiences shared by those who took part. Transcripts were not returned to participants for review, in recognition of varying literacy levels within the participant group.

Data analysis

We used thematic analysis to examine the stories shared during the circles [40]. All members of the research team began by familiarising themselves with the data through repeated reading of the transcripts and listening to the audio recordings. Each transcript was then independently coded, with three coders reviewing the consistency of their coding. Similar codes were grouped into categories, which were subsequently developed into overarching themes. Themes were generated by identifying shared ideas or concepts that underpinned participants' narratives [40]. The coding tree and resulting themes were

Table 2 Summary of themes from the storytelling circles

Theme	Codes	Narrative Summary
Navigating the health care system and occupational therapy	Lack of awareness of occupational therapy System barriers Communication School disparities in relation to resources in schools Self-management Peer support	Participants often lacked initial knowledge of occupational therapy (OT). Mainstream schools were often ill-equipped to support children with SEN (Special Education Needs). Referral systems and communication with services was unclear. Families were left to self-manage, so relied on peer networks, and delivering therapy at home.
Worth the Wait? The Human Cost of Delayed and Inaccessible Occupational Therapy	Long wait times. Not meeting expectations Developmental setbacks Emotional toll on families Lost opportunities for recovery Good occupational therapy service once accessed, but often too late	There were very long waits for occupational therapy. Parents feared missing the "window" for effective intervention, which took an emotional toll on families. Participants recognised the value of occupational therapy despite systemic barriers, and acknowledged benefits when therapy was delivered well.
Disclosure and trust	Lack of trust in services Cultural norms and beliefs Community expectations	Cultural stigma around mental health and trust of professionals' prevented access to mental health services. Cultural stigma was based on individual beliefs and cultural norms, as well as community expectations.

derived inductively from the data. The analysis was supported using Atlas.ti qualitative analysis software and are outlined in Table 2.

Ensuring quality in narrative research

Indicators of quality in narrative research include ethical sensitivity, critical reflexivity, and the reporting of negative cases [41]. Ethical sensitivity was central to our approach, ensuring that our personal values and interests did not conflict with the aims of the research. From the outset, we prioritised accessibility and inclusivity for all Somali participants, regardless of language proficiency or literacy levels. All study materials were translated and verified in collaboration with members of the Somali community. Sessions were held in trusted local community spaces regularly used by Somali residents. To create safe and inclusive environments, we offered separate storytelling workshops for individuals identifying as male or female, as well as language-specific groups with interpreters present in all circles.

In terms of critical reflexivity, the research team, remained conscious of potential biases throughout the study. We were guided by the lived experiences and knowledge systems of our co-researchers. Additionally, we engaged with the Somali community and local health connectors to deepen our awareness of positionality, power dynamics, privilege, and social context. Team members were encouraged to reflect after each session and share insights into their experiences. In our data analysis, we included negative cases and drew attention to individual stories that diverged from the broader themes, recognising their value and complexity.

Results

Navigating the health care system and occupational therapy

Navigating the health care system was often difficult. One participant stated:

> *Over the last five to ten years, the number of children with SEN has been increasing, but they are not getting the support they need. Families are not aware of where to find support or how to support their children. Even some mums are new to the system—they don't know and have no prior experience with children with SEN. (ST2 HH)*

Participants shared in their narratives how they had to actively advocate for access to occupational therapy. One participant described making multiple visits to a local health center before eventually receiving support:

> *My son sees an occupational therapist. It was quite a long process. He had to go to the centre several times, and they asked him tick-box questions. Then I challenged them, and they put him through to the workshops. After the workshops, he's now seeing an occupational therapist occasionally, which is great. (ST 5 AH)*

Schools were identified as another potential setting where Somali children could access occupational therapy; however, participants highlighted challenges with accessing such services in mainstream schools. One participant noted:

> *The support the school is offering is very limited because our school is not a special needs school. The staff, teaching assistants, and teachers are not*

> *trained for this, and managing 30 children in the same class makes it very difficult to pay attention on one child. It's not fair on them. (ST 4 HH)*

Another participant spoke about her difficulty accessing occupational therapy at a health centre, following a school SENCO (Special Educational Needs Coordinator) referral. Juggling life with other priorities was also an important part of her story.

> *It is difficult. I asked them for a letter to help with transport because I have another child, and I need to go to work. My daughter sometimes can't walk in the morning because her legs hurt. The SENCO refused to write a letter to support her in getting transport. The school referred her to an occupational therapist in Wembley, but the hospital is quite far from where we live, and that sometimes makes us late. It would be better if it were closer because it's hard for my daughter to walk. They are helping her, but she needs more support. They need to improve their service. (ST 3 S)*

In response, some parents sought placement in special schools to access occupational therapy services.

> *She attends a mainstream school, but now I have applied for her to be placed in a special needs school. She does not receive OT support at her school. (ST 3 S)*

This proved to be an effective strategy for some participants.

> *So, things are better because they've got OT in the school. He has an Education Health and Care (EHC) Plan. They come into the class and help him with how to hold a pen. (ST1 ZZ)*

For two other participants, poor communication between different agencies reflected a sense of powerlessness and a lack of involvement in decision-making and action:

> *They kept directing me back and forth between them. They didn't inform me when they were installing the rail. They were the ones who made the decision and the design. (ST4 SH)*

> *The shower has not been adapted to meet his needs. We have not yet had a visit or met with anyone. I didn't inform them about my own needs because I'm more focused on my son's. The housing association is supportive of the adaptations, but they said it's the council's responsibility, not theirs. (ST5 FH)*

In response to the difficulties accessing services, some parents described developing their own strategies. One participant spoke about online resources, noting that she had independently researched support options and interventions to assist her child.

> *I had to do my own research on how to help my son and what the OT will do... For example, for Down syndrome you go to the website, or you go to YouTube and then you just see how you can help your child play such as with play dough. There are so many places you can learn from. I put Down syndrome into Google. We are connected. (ST1 ZZ)*

Other participants highlighted the importance of peer support in managing the challenges of everyday life while navigating occupational therapy services. They explained that friendships initially established through casual social interactions, subsequently evolved into strong networks of reciprocal assistance. For instance, participants reported accompanying one another to appointments, shopping, or exercising at the gym (ST6 FA; ST6 SF; ST6 S). One participant spoke about the specific value of women supporting one another within these informal networks.

> *Support only from trusted friends... the group you formed has become a support network and is women supporting women... Since we don't always know what is happening in their homes, we need to have a place where parents can disclose their situation and receive the help and support, they need to address their needs. (ST3 HH)*

By contrast, formal parent support meetings were perceived less favorably.

> *We are tired, just tired. We just talk. We meet with other parents, not only Somali. There's a lot of coffee morning meetings—but not much action. (ST 1 ZZ)*

Human cost of delayed occupational therapy

When participants were contacted by an occupational therapist, they were often told they would "have to wait" (ST4 AH). Another participant explained:

> *They sent us a letter stating that it would approximately take one to two years to receive support. Now that one to two years have passed, when I email them, they tell me to keep waiting (ST5 DR).*

It was evident that occupational therapy timelines often failed to meet participants' expectations (ST4 AH). One participant shared:

> *I was expecting to receive help more quickly because the house we live in is not suitable for us. Therefore, I was expecting the occupational therapist to assess my house and determine how it is not suitable for us. (ST5 ND)*

The consequences of delayed access to occupational therapy were significant. For participants with children, concerns frequently centered on developmental delays, with parents expressing fear that missed opportunities for early intervention could compromise their child's ability to achieve independence.

> *He is six and not going to wait for me. I need the service now. He needs occupational therapy now. He does not need it when he is 12 years old… It is too late. When you need support and you do not get it, it is too late to catch up. There's nothing you can do then. (ST2 HH)*

Other stories highlighted how delays in accessing occupational therapy compromised independence. For example, one participant described a progressive loss of functional ability in food-related activities following an injury, illustrating how unmet needs during recovery can reduce quality of life.

> *I had an accident at work, and I hit the ground with my elbow. As result, I cannot lift anything with my hand. I live on takeouts because I'm unable to cook. I use my right hand for everything (ST 3 AK).*

For another participant, there was evidence of further deterioration during the waiting period, with their physical function declining.

> *I think if she had more occupational therapy—because her hand is getting shorter and shorter. She can't use it much. She can't use the bathroom or shower on her own and must call me for help with everything. I think that getting more occupational therapy would be helpful for her. (ST3 S)*

> *I was hoping he would have more hours, build a good relationship, and that we would see an OT regularly. I was very desperate …I used to think, 'Oh my God, if he doesn't have OT sessions, he won't make progress.' But now I'm used to it. I was so upset. (ST1 ZZ)*

After the assessments were completed, participants often described experiences of inaction or prolonged uncertainty regarding follow-up support:

> *The accommodation in Brent was not suitable. And when I asked for an assessment, I was told an OT would come… someone would come. We waited for two years. A person came and said, 'I'm the only occupational therapist in Brent, that's why you can't have it.' They did an assessment and made some recommendations that were never carried out. (ST1 ZZ)*

In some instances, occupational therapy cases were closed without any intervention due to the family residing in temporary and or rented accommodation.

> *A few occupational therapists did visit properties, but clients reported that they were unable to provide help because the families were living in temporary accommodation. (ST5 AH)*

> *The problem is the toilet. I've been waiting now about four months, and then they sent me this letter, and still, they want an interview. I am waiting. I need it now because it is more difficult. My landlord referred me to Brent. Then they interviewed me twice and asked me about my situation. I thought the process would be quick. It is taking a long time." (ST4 DK)*

> *His wheelchair cannot fit inside the house, so he has to crawl on the floor to move from the bathroom to the living room and then to the kitchen. There is no way he can be pushed in his wheelchair, and no adaptations can be made because the house is temporary accommodation. As a result, the case was closed. He still needs support but cannot receive the help he requires due to their living situation. (ST2 ND)*

Despite these challenges, some participants also acknowledged improvements with individual practitioners:

> *To enter through the front door, I must lift her out of her wheelchair to enter the house. This is the challenge I am facing. Previously, we did not receive good support from an occupational therapist, but now our current occupational therapist is very helpful. (ST5 SM)*

Several stories highlighted the value and positive impact of occupational therapy interventions.

> *I have a nine-year-old child with special educational needs. We were referred to this service and used it for about six weeks. They arranged sessions outside of school at a community centre, each lasting*

> *around half an hour. They taught him helpful things, how to play, how to balance his body by asking him to stand on one leg and jump around, and how to use large balloons by placing his chest on them. He wasn't familiar with these kinds of games. They supported him with all these play activities. (ST4, S)*

At the same time, participants highlighted concerns about the rationing of occupational therapy.

> *They were good, but the power is not in their hands. They just do what they have been told to do it. If your child has got an appointment, they will see him and when they finished will see the next person. (ST 3 HH)*

> *My child receives therapy once a month or every two months. She is currently unwell, with issues affecting one side of her body, including her leg and arm. However, I would like her to see the occupational therapist more frequently. (ST3 S)*

> *They gave me just a little bit of technique on how I could help him. It is a very, very good service but it is not a lot. They are not giving me enough support. (ST3 J)*

Early discharge from services, before rehabilitation had enabled the person to reach their full potential, was also a problem.

> *It was very, very good service and I liked it, but they discharged me. The technique she gave me I am still using it, you know when he is putting on his shoes, his clothes. It was very, very helpful. (ST3 HH)*

> *I've seen this service offer just a few sessions—maybe four or five—and then they discharge. I feel that my son still needs help because of the limited mobility in his hands. I am still helping him to get dressed, eat… Even tasks like coloring and holding a pencil are difficult for him. (ST3, J)*

Disclosure and trust

Mental health challenges were another consequence of long waiting times and inadequate support, which participants often expressed indirectly. One participant shared feelings of being overwhelmed and emotionally exhausted:

If you are already overwhelmed by the condition of your children—especially if one or two of them have special educational needs… you are struggling to get the necessary support. The difficulty in finding adequate help can lead us to feel miserable, and it can feel like each day is a black day for you, which is not good. (ST3 HH)

A range of barriers to mental health disclosure and accessing support were evident in the narratives. In Story Circle 3, participants expressed concerns about disclosing mental health issues due to fears of child protection scrutiny from services, particularly around parenting capacity. This reflects a deep mistrust of support services, underpinned by a fear of having your vulnerable child removed.

Cultural norms and beliefs about mental health were a second barrier which influenced participants' willingness to discuss mental health challenges or admit to struggling. As one participant explained.

> *Most of the time we hide [mental health], and they do not talk about it. Often, they hide it and don't discuss it openly. Like infection, cold and flu, it's an illness, and we should not be ashamed of it. (ST3 SA)*

This quote also reflects the community expectation of keeping quiet or not doing anything about mental health concerns. In contrast, another participant shared a story of defying community expectations to access mental health services for her son:

> *My son was in Year 10 when he was diagnosed with diabetes, which caused him worry and affected his learning. He received counselling, but someone advised me not to send my son for counselling. They said that when he gets older, people might ask where he went and assume he had mental health issues. You start thinking, should I listen to them or not? However, in the end, we decided to send him for counselling. They spoke with him and offered support—and he finished school and is now at university (ST1 FHA).*

Discussion

This study achieved its intended aims. A key finding was the significant emotional and physical toll associated with long waiting times for occupational therapy. This echoes the work of Harding et al. [42], who similarly highlight the detrimental consequences of service delays on individuals' health and wellbeing. In addition, the impact of long waits reflects findings from a national survey conducted by the Care Quality Commission, which reported that 42% of respondents experienced deterioration in their mental health while waiting for care [43]. In our study, lengthy waits were also shown to undermine perceptions of occupational therapy within the Somali community. Addressing these concerns requires services to adopt transparent communication strategies about both the scope and timing of provision. Such approaches carry important implications for policy and service delivery, as they can foster trust, manage expectations, and promote more equitable access to care.

Prolonged wait times also reflect wider workforce challenges within occupational therapy in the UK [1]. However, existing workforce data do not adequately capture disparities in relation to vacant posts, limiting a comprehensive understanding of the scale and distribution of workforce shortages. This absence of detailed reporting has significant implications for policy and service planning, as it restricts the ability to target recruitment, allocate resources equitably, and develop long-term strategies to address systemic capacity issues. From a health justice perspective, such gaps risk reinforcing structural inequalities, in communities already facing barriers to healthcare [44]. Addressing workforce data limitations is therefore not only an operational priority but also a matter of advancing equity and accountability within health systems.

At present, evidence is limited on whether members of the Somali community experience longer waiting times for occupational therapy compared with white British individuals or other ethnic groups. Nevertheless, barriers to healthcare access among Somali populations have been documented in related areas. For instance, language difficulties and culturally specific concerns have been identified as significant obstacles preventing first-generation Somali women from attending cervical screening [45]. Comparable challenges have also been reported in maternity care, where migrant women born in Somalia encounter barriers such as language difficulties, ineffective communication, limited cultural awareness, and preconceived attitudes among some healthcare professionals, all of which hinder the development of trust with caregivers [44]. Although ethnicity-disaggregated data for occupational therapy access in the UK remain sparse, international literature suggests that inequalities in utilisation may occur. For example, evidence from the United States indicates that Black veterans were less likely to receive occupational therapy in inpatient psychiatric settings compared with white, non-Hispanic veterans [46]. Further UK-specific research is required, particularly the routine collection and transparent publication of ethnicity-disaggregated data within occupational therapy services, to address potential disparities.

Our study found that Somali parents expressed a strong desire for greater access to occupational therapy and demonstrated a willingness to engage with mental health services; however, it was also evident that trust in these services is essential to facilitate meaningful access.

This observation resonates with findings by Warfa et al. [47] who reported that Somali populations in the UK experience high levels of psychological distress but face barriers to disclosure and engagement arising from cultural stigma and mistrust of services. Similar themes are reflected in community research by Healthwatch Birmingham [48] which highlighted dismissive professional attitudes, problems with interpretation, and poor engagement as key drivers of distrust. Cultural stigma and lack of trust in health, social care, and mental health services therefore appear to inhibit open discussion and the effective addressing of such concerns. Our findings are also consistent with Linney et al. [49] who documented pervasive mental health stigma and scepticism towards professionals within the Somali community. Given their dual training in physical and mental health, occupational therapists must therefore be equipped with the skills required to engage effectively with mental health issues in Somali cultural contexts.

In our study, Somali parents adopted community-driven self-management strategies in response to gaps in occupational therapy provision. Participants described independently researching interventions online, forming peer support networks, and relying on informal systems of reciprocity. Our findings align with Australian research showing that Somali mothers are proactive in seeking support to ensure the well-being of their children [50].

These findings highlight the resilience and resourcefulness within the community and the importance of recognising and leveraging existing community networks in the co-delivery of therapy. Occupational therapists are well placed to facilitate such spaces. Group-based occupational therapy interventions have been shown to reduce isolation and enhance peer support, particularly in mental health and rehabilitation settings [51].

A novel issue raised by participants was the systemic exclusion of families living in temporary accommodation from receiving home adaptations. This reveals a profound gap in the equity of service provision. There is a need for further exploration of occupational therapy procedures related to environmental adaptations, particularly for individuals living in temporary accommodation. Recent data indicate that waiting times for social housing may exceed 100 years in some areas [52]. In the face of these delays, housing modifications have been shown to prevent a range of disability-related outcomes [53]. Nevertheless, access to such interventions remains highly inequitable, often influenced by property ownership. Property ownership is an important factor since landlords, who own the property, must give their permission, and may be required to contribute to adaptations to the building [54].

While our study found that Somali parents desired more therapy, one study [55] indicated that therapy quantity alone did not predict positive outcomes. A recurring theme within the narratives, in which parents often prioritised their children's needs above their own, also highlights the importance of family-centered approaches. It also illustrates how collectivist values may shape engagement with services, with the wellbeing of the child and family as a unit taking precedence over the individual. Additionally, family-based, home-visiting preventive mental health interventions have been found to be both feasible and acceptable among Somali refugees [56].

Participants found that securing Occupational therapy support required persistent follow-up and assertiveness. Many participants were unfamiliar with what Occupational therapy entails and were often introduced to it only after considerable effort or advocacy. A US study found that while physicians regard occupational therapy as essential, many are unaware of its full scope [57]. This highlights the need for therapists to critically reflect on how they define occupational therapy and the language they employ, especially considering that key terms may not exist in Somali and other minority languages. Although health literacy has been recognised as a central issue [58], greater attention is needed to how communication occurs in practice.

Strengths and limitations

A key strength of our methodology was that we adopted storytelling as a culturally grounded and equity-focused method. This methodology allowed us to prioritise the social and cultural contexts of participants' lives, and to remain reflexive about our own positionalities throughout the research process. Snowball sampling may have introduced bias by recruiting participants with similar views or experiences. The study intentionally avoided seeking data saturation, recognising the value of narrative variation over thematic redundancy [59] However, this choice may limit the transferability of the findings. That said, they may be applicable to other London boroughs with sizeable Somali communities, including Tower Hamlets, Ealing, Lambeth, and Camden. Beyond London, other UK cities also host significant Somali populations, such as Birmingham, Manchester, Liverpool, Cardiff, and Sheffield. In Bristol, Somali people represent the largest minority ethnic group in the city [60].

Despite efforts to co-develop recruitment materials with Somali community members, key terms such as occupational therapy did not translate clearly into Somali, which may have led to confusion or conceptual misunderstanding [61]. The presence of family members and children occasionally shaped group dynamics, potentially limiting disclosure on sensitive topics.

There were, however, additional limitations, as community members did not always arrive on time for planned research sessions, which at times disrupted the discussion and may have limited the depth and richness of some accounts. Nevertheless, we sought to mitigate these challenges by adopting a flexible and relational approach, recognising that rigid timetabling reflects research practices rooted in Western academic traditions. By contrast, our method prioritised accessibility and cultural relevance, enabling community voices to be expressed through their own rhythms and contexts, and thereby strengthening the authenticity of the findings.

Conclusion

While many participants described negative experiences with delays, inaccessible services, or case closures, there were also accounts of positive and valued interactions with occupational therapists. These mixed findings highlight that occupational therapy could have positive outcomes, but systemic barriers to access and amount of therapy often undermine its impact. Our study suggests that with strategic changes to improve accessibility, strengthen trust, and move towards more collaborative models of care, occupational therapy could deliver meaningful outcomes for this community. To promote more equitable outcomes, occupational therapists should address the structural and cultural factors shaping engagement, and commit to culturally responsive, community-informed practice to ensure services reflect the needs of Somali families.

Supplementary Information

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Supplementary Material 1

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Author contributions

AA – Conceptualization, Investigation, Methodology, Project administration, Writing – original draft, review and editing.VCG– Conceptualization, Investigation, review & editing.EN Investigation, Project administration, –review & editing.FH Investigation, Project administration, Writing review & editing.NP Methodology consultant, Project administration, Writing – original draft, review and editing.

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Data availability

The datasets generated during the study are available from the corresponding author on reasonable request.

Declarations

Not applicable.

Human ethics and consent to participate

This study was conducted in compliance with the Helsinki Declaration on Ethical Principles for Medical Research Involving Human Participants. Ethical clearance for this study was obtained from London South Bank University ethics committee – ETH2324-0215. Verbal and written informed consent to participate in the study was obtained from all participants.

Consent for publication

Not Applicable.

Competing interests

The authors declare no competing interests.

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