Title: Intersectional Experiences of Black and South East Asian Parents with a Child with Autism

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Introduction: Much is known about the significant impact of parenting a child with autism on parents’ wellbeing. For instance, studies have found parents have higher levels of clinical depression, stress and anxiety (Ekas et al, 2009; Davis and Carter, 2008; Kuhn and Carter, 2006; Timmons & Ekas, 2018). However, there is paucity of information about how Black (African, Caribbean) and South East Asian (Indian, Pakistani, Bangladeshi) minority ethnic parents experience autism and how their experiences can be influenced, exacerbated and/or protected by social demographic factors such as ethnicity/race, generation status, gender, stigma, social economic status, religion, culture and acculturation. Using intersectional perspectives to explore this group has the potential to provide insights to the various contributors that influence BAME parents’ experiences in society, and of their child’s autism diagnosis, in particular. Family systems theory suggests that children’s outcomes and wellbeing will be associated with their parents’ wellbeing, justifying a focus on BAME parents of children with autism in research.

Methods: As part of a larger mixed methods study, Black (n = 10) and Asian participants (n = 10) were interviewed using parallel mixed data collection for a rich and more reliable understanding (broader and deeper) of a phenomenon than a single approach would yield. This paper focuses on interview findings, which aimed to get as close to the interviewees’ reality of their experiences in the ethnic community and wider context while caring for their child with autism. Parents’ experiences were explored using semi-structured interview questions developed from key themes and identified through a prior literature review conducted by the authors. Topics explored both systematic factors, such as racial and internalised stigma, as well as contextual factors, such as parents’ experiences of culture. The study recruited participants from a diverse background: economic status, gender, generation status, ethnic and religious group and employed a convenience sampling procedure to recruit potential participants of minority status. The main focus for this study was to advance the needs of underrepresented and marginalised populations in research.

Results: This study identified several themes. Parents in this study recognised the dominant role of culture on their experiences, from identifying that their child has additional needs, the diagnosis process and the acceptance of their child’s autism diagnosis by themselves and their wider BAME community. Cultural perceptions of autism, mainly as an invisible disability, also impacted parents’ heightened sense of isolation from their BAME community and the wider society in general. However, despite the high levels of isolation, the majority of parents - 75% - displayed high levels of resilience and psychological wellbeing, moderate levels of internalised stigma in both their BAME community and in wider society (Sixbey, 2005) in the face of challenges they experienced as a parent of a child with autism and minority ethnic parents. The role and power of education for BAME parents of a child with autism permeates their experiences: acceptance of the condition, daily management of their child’s needs, the level of internalised stigma parents accept from their community and exploring various ‘cures’ that would alleviate autism symptoms. Religion also influenced parents’ abilities to manage and cope with the shift and radical change of their lives, the day their ‘life changed’, with socio-economic status playing a major role in their perceived abilities as parents of a child with autism, including ‘hidden costs’ of care for families caring for both children and adults, the shortfall in benefits, loss of employment and relationship costs.

Discussion: Overall, parents shared experiences related to the impact of culture, acculturation, resilience and religion as on a continuum, with various variables intersecting on their experiences and perception of autism, its impact on their wellbeing and their family. Parents expressed negative thoughts about the impact autism has on their lives, yet seemingly separating the challenging behaviours associated with autism from their child and their unique characteristics. This finding supports the importance of having a balanced representation of parents’ experiences of autism (Hastings, 2016). Parents stressed the importance of accepting the diagnosis and likened the process to the five stages of grief. Additionally, it can be suggested that the resilience the BAME parents in this study seem to have, could be attributed to learnt coping mechanisms that they developed living as minority parents, the support/lack of support they experience and the inherent need to ‘get on with it’. Interestingly, parents draw strength and resilience from their religious practices and organisations yet identify the tension between faith and the practicalities of parenting a child with autism. Specific policy pathways identified are the need for joined up thinking and services across local educational authorities, Social Services Departments and Health Authorities at local level, and departments at government levels, ensure targeted community public engagement for BAME parents and communities to increase awareness and education of autism, early diagnosis and service provision for parents, children with autism and their siblings.
References/Citations:

- Sixbey, M. T. (2005). *Development of the family resilience assessment scale to identify family resilience constructs.* University of Florida