Title: “The Doctor said ‘Google It’”: Exploring African-American Caregivers’ Help-Seeking for their Child with Autism

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Introduction: Previous research suggests that differences exist in service access for racial and ethnic minorities with autism spectrum disorder (ASD) which are not accounted for by actual differences in need for services (Durkin, et al., 2017; Benevides, et al., 2016). Additional studies identify that parental beliefs, knowledge, and expectations may influence help-seeking specifically African-American (AA) caregivers (Burkett, et al., 2017). Understanding reasons for differences in care from a family systems perspective is necessary to develop effective solutions to address differences in service access. The purpose of this study was to understand AA caregivers’ beliefs, knowledge, and expectations that impact help-seeking, and the specific help-seeking steps caregivers used to obtain care for their children with ASD.

Method: Using grounded theory methodology (Charmaz, 2006), we conducted semi-structured interviews to ascertain how and why AA caregivers sought and obtained services from pre-diagnosis to present time. Beliefs and knowledge were probed, as were formal and informal help-seeking steps. Purposive and snowball sampling was used to obtain a sample of caregivers of children with ASD in one southern U.S. state (n=11); sampling is ongoing. Inclusion criteria required caregivers to be self-identified AA adults with a primary caregiver role (>50% time spent caring for child) of a child with autism (confirmed at the time of interview via a caregiver-provided medical or educational report). Additional data sources included field notes and a follow-up focus group to member-check findings with caregivers midway through analysis. Qualitative analysis occurred throughout data collection, involving hand coding for beliefs, knowledge, and expectations reported during help-seeking actions. We organized coding schemes using MaxQDA software.

Results: Caregivers were predominantly female and socioeconomically diverse, with an average age of 38.7 years. Preliminary themes from the analysis include: “Just don’t know/just didn’t know…” (importance of knowledge in taking action); “[the doctor] told me to Google it” (impact of ‘trusting’ in providers on help seeking); the reliance on ‘mother intuition’ about their child which influenced help seeking; and the importance of others during the process (“they actually know what you go through”). Caregiver’s knowledge acquisition was obtained primarily through lay and internet “network of others”; in contrast, caregivers reported asking for information from medical and education providers and not receiving desired guidance.

Discussion: Despite well-documented racial/ethnic disparities in service access, little progress has been made to implement culturally-appropriate approaches to meet AA caregivers’ needs for service and supports. Although findings are not widely generalizable, lessons for future research and practice include: helping parents connect with other parents is essential; the provision of resources regarding decision-making needs to be balanced by parent’s reliance on ‘intuition’ about providers and services; and future work to improve help-seeking and reduce disparities should involve caregivers in all phases of planning and implementation to identify preferred means to receive information. System-level interventions indicated include: provider training to facilitate care pathways, easily searchable and readable community resources, and increasing parent advocacy skills.

References/Citations:
- Benevides TW, Carretta HJ, Mandell DS (2016). Differences in perceived need for medical, therapeutic, and family support services among children with ASD. *Pediatrics*, 137(Supplement 2), S176-S185.