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Increasing Autism Awareness in Inner-City Churches: A Brief Report[1,2]

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Autism diagnosis rates trail significantly in the African American community. This pre-test post-test pilot study evaluated an African American inner-city church health ambassadors (HAs) autism spectrum disorder (ASD) awareness training session. The participants included 12 HAs who attended the 1 hour training session organized by the National Baptist Convention, USA, Inc. Results of surveys showed higher mean scores post training for (1) HA attitudes about the potential for children to improve with applied behavior analysis therapy; (2) HA self-efficacy for having information about ASD screening materials; (3) strategies HAs could use to help parents/caregivers of children with developmental delays and challenging behaviors; (4) HA confidence in referrals for children with signs of ASD; (5) HA knowledge of measures to take to maximize a child's chance of receiving an ASD evaluation; and (6) HA comfort for talking to parents about children with challenging behaviors. Several of these effects were maintained 3 months later. Findings underscore the usefulness of the intervention for increasing the dissemination of knowledge about ASD and the opportunity to positively affect ASD screening, early intervention, and policy standards applicable to this vulnerable population.

IDENTIFICATION OF AND early intervention for children with autism spectrum disorder (ASD) impacts optimal child and family health outcomes (Agency for Healthcare Research and Quality [AHRQ], 2009; Myers & Johnson, 2007). Children diagnosed with ASD display persistent pervasive deficits in: (1) social–emotional reciprocity, (2) nonverbal communicative behaviors and (3) relationships appropriate to the developmental level (American Psychiatric Association, 2013). The prevalence of ASD is estimated at approximately 1 in 68 children in the USA (about 3 million Americans), with four times more boys diagnosed than girls (Centers for Disease Control and Prevention, 2012). Although the behavioral and social delays characteristic of ASD are generally present by 2 years of age, the diagnosis is often made much later (Zwaigenbaum, Bryson, Lord, et al., 2009).

African-American children receive an ASD diagnosis on average 2 years later than Caucasian and Hispanic children do (Kerfeld, Hoffman, Ciol, & Kartin, 2011; Mandell, Cao, Ittenbach, & Pinto-Martin, 2006; Valicenti-McDermott, Hottinger, Seijo, & Shulman, 2012). Research suggests that they are more likely to be diagnosed with an intellectual

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disability than Caucasian children (Jarquin, Wiggins, Schieve, & Van Naarden-Braun, 2011). When referred to a specialty clinic for evaluation of suspected developmental delay, African-American children are more likely than Caucasian children to be diagnosed at first with a behavioral disorder, such as attention deficit hyperactivity disorder, adjustment disorder, or conduct disorder instead of ASD (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007).

Autism awareness is a challenge for African-American families delaying diagnosis. Without awareness of the signs of ASD, it is difficult for family members to report subtle developmental concerns that are indicative of the disorder. Literature shows that family members typically only notice and then report more noticeable milestones that children have accomplished (e.g. walking and first words) (Wetherby, Brosnan-Maddox, Peace, & Newton, 2008). Further, while there has been a reported increase in screening for ASD since the American Academy of Pediatrics recommendation for screening of all children at 18 and 24 months of age (Myers & Johnson, 2007), the rate of screening remains low. In a 2012 study, a sample of 157 primary care physicians reported a 55% consistent use of autism screening tools (Keil, Breunig, Fleischfresser, & Oftedahl), up from 28% in 2009 (Gillis, 2009), and up from 8% in 2006 (DosReis, Weiner, Johnson, & Newschaffer, 2006). Barriers to screening included lack of time for screening, inadequate reimbursement for the screening, lack of office staff, and lack of training on the use of the screening tools (Keil et al., 2014). Another barrier to screening is the health care provider's (HCP) own lack of self-efficacy for the screening (Golnik, Ireland, & Borowsky, 2009). Self-efficacy is defined as a person's belief in his or her ability to perform a designated task (Bandura, 1977). Thus, the lack of ASD awareness for families and the other barriers to screening contribute to later identification of ASD in the African-American population.

Churches are important in inner-city African-American communities. Their importance has led to the development of feasible small-group, church-based training sessions that seek to increase rates of cancer screening (Allen et al., 2014) and self-management of diabetes (Johnson et al., 2014). Currently in the USA, the Health Outreach Prevention Education Ministry (H.O.P.E.) of the nationwide Baptist Convention trains lay people to serve the community by screening for many health conditions (The National Baptist Convention, 2014). In Milwaukee, Wisconsin, the Urban Diagnostic Initiative is a local and community-based education and outreach effort, working in collaboration with the Milwaukee Center for Independence and the General Baptist State Convention. This initiative seeks to train "first lady" (i.e., pastors' wives or husbands) to be "health ambassadors" (HA) for their communities. In this HA role they contribute to: (1) recognizing ASD, (2) dispelling myths and blame, (3) emphasizing the importance of intervention, (4) coaching in how to approach parents with possible ASD children, and (5) what to do to get children diagnosed, followed by the most appropriate services. With the present pilot study, we sought to describe how participation in an ASD-curriculum impacted knowledge, attitudes, behaviors, and self-efficacy of the HAs in the community who observe children with the behaviors indicative of ASD. A long-term goal is the development of an HA with the knowledge and confidence to approach families of children with signs of ASD in an effort to obtain a referral for ASD screening and appropriate resources.

Purpose

The purpose of this study was to measure how training for inner-city church HAs in the signs of ASD improved their knowledge, attitudes, and self-efficacy for referral for ASD evaluation and treatment. We hypothesized that there would be improvements in HA knowledge, attitudes, and self-efficacy, and that these improvements would be maintained at 3 months.

Methods

Design

The study used pre-survey and post-survey methodology to evaluate the impact of the curriculum. Approval was obtained from the university's institutional review board.

Data were collected from the community HAs before participation, after participation, and 3 months later.

Sample/Setting

Subject sampling was by convenience, and there were no exclusion criteria for participation in the study. Fourteen HAs, who were attending an advocacy training session conducted by a local branch of the National Baptist Convention, volunteered to participate in a study that examined the effectiveness of the ASD module in their HA training. Written consent was obtained from each participant. Participants who declined were not penalized in any way, and remained at the ASD training.

The fourteen HAs were women, between the ages of 43 and 76 years (M = 53.8, SD = 9.24). They completed the pre-training questionnaires, and of them 12 completed the post-training questionnaires and the 3-month telephone follow-up (Table 1). The women were pastor or deacons' wives, or church leaders, in the Milwaukee area Baptist Convention. The twelve (85.7%) participants had children of their own, and nine (64.3%) had grandchildren. A substantial portion did not have friends or relatives with ASD (n = 8, 57%), and the majority did not have any prior ASD training (n = 10, 71.4%).

Educational Intervention

The intervention was a 45-minute long PowerPoint, instructor-led, ASD awareness-training module. The curriculum was based on the self-efficacy theory (Bandura, 1977). In this theory, mastery experience, vicarious experience, emotional states, and social persuasions from others, are believed to account for feelings of competence, and confidence about performing a specific task, ultimately impacting how people behave (Bandura, 1977). Specifically, self-efficacy perceptions help determine what people do with the knowledge they obtain (Bandura, 1977).