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THE EXPERIENCES OF CULTURALLY DIVERSE FAMILIES WITH AUTISM

OTİZMLİ VE KÜLTÜREL FARKLILIKLARA SAHİP AİLELERİN DENEYİMLERİ

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Research Article

ABSTRACT

Autism Spectrum Disorders (ASD) are considered to be the fastest-growing developmental disability in the United States. ASD are neurodevelopmental disorders that are characterized by difficulties in verbal and nonverbal communication, social relations, and restrictive and repetitive behaviors. Although the prevalence of ASD stays the same regardless of race, ethnicity, or culture; culturally diverse families may have different experiences. In this article, the term "culturally diverse" refers to immigrants and minorities. This literature review aims to explore culturally diverse families' experiences with having children with ASD. The review of nine relevant articles suggests that families demonstrate differences between concerning treatment and diagnosis, service utilization, beliefs, and coping mechanisms. There is a need for further research that investigates differences between different cultural groups and contexts.

Keywords: *Autism, culturally diverse, immigrant, refugee*

ÖZ

Otizm Spektrum Bozukluğu (OSB), Amerika Birleşik Devletleri'nde en hızlı artan gelişimsel engel grubudur. OSB'nin belirgin özelliği, sözlü ya da sözsüz iletişimde ve sosyal etkileşimde zorluklar ile kısıtlayıcı ve tekrarlayıcı davranışlardır. OSB'nin prevalansı ırk, etnik köken ya da kültüre göre farklılaşmamakla birlikte, kültürel farklılıklar ailelerin deneyimlerini etkilemektedir. Bu literatür taramasının amacı, farklı kültürlere mensup ve çocuğu OSB teşhisi almış ailelerin deneyimlerini anlamaktır. Farklı kültürlere mensup terimi bu makalede göçmen ve azınlık anlamına gelmektedir. Konu ile ilgili tespit edilen dokuz makalenin analizine göre aileler tedavi ve teşhis, hizmet kullanımı, inançlar ve baş etme mekanizmalarında farklılıklar sergilemektedir. Farklı kültürel gruplar ve farklı bağlamların etkisini anlamak için yeni çalışmalara ihtiyaç duyulmaktadır.

Anahtar Kelimeler: *Otizm, kültürel farklılık, göçmen, mülteci*

The Experiences of Culturally Diverse Families with Autism: A Literature Review

The prevalence of Autism Spectrum Disorders (ASD) has displayed a dramatic increase since the 1980s (Tincani, Travers, & Boutot, 2009) and ASD is considered to be the fastest-growing developmental disability with a 109.2% increase in cases from 2000 to 2001 in the United States (Luong, Yoder, & Canham, 2009). ASD is one of the neurodevelopmental disorders characterized by difficulties in verbal and nonverbal communication, social relations, and restrictive and repetitive behaviors (American Psychiatric Association, 2013). In the previous version of the Diagnostic and statistical manual of mental disorders (DSM IV), the major types of the disorder included Autistic Disorder, Aspergers Syndrom, Rett Syndrom, Childhood Disintegrative Syndrom, and Pervasive Developmental Disorder NOS. In the fifth edition of DSM, these distinct diagnoses are merged under "autism spectrum disorder." Although the current evidence suggests that the prevalence of ASD remains the same regardless of race or ethnicity, ASD is under-identified and/or diagnosed late in minority children or children from culturally diverse families (Montes & Halterman, 2011; Tek & Landa, 2012; Tincani et al., 2009). Moreover, the reports of the National Early Intervention Longitudinal Study acknowledge that minority children are overrepresented in special education and underrepresented within the population of families receiving early intervention services (Hebbeler, Spiker, & Mallik, 2003). Therefore, children with ASD from culturally diverse families might be dealing with unique problems.

The population trends also indicate the importance of addressing the needs of culturally diverse families. Immigrant children, who constitute a large subpopulation within the category of culturally diverse families, are the fastest-growing part of the U.S. population. Children of immigrants are "the fastest-growing part of the U.S. population" (Migration Policy Institute, 2018). While immigrants are 13.5% of the total population, children of immigrants make up 25.2% of the population of children under the age of 6 (Migration Policy Institute, 2018). African American families, which constitute another subpopulation of the category of culturally diverse families, also have unprecedented challenges in experiencing ASD and accessing services. The study by Montes and Halterman (2011) highlighted a racial disparity in the receipt of family-centered care between parents of white and black children with ASD: among parents with a child with ASD, being African American was associated with lower reporting of family-care.

Considering that family-centered care has different components such as a collaboration with parents, the sensitivity to parents' ideas and providing information on ASD to the parents, African American parents may lack the support they need in dealing with ASD. Delayed diagnosis of autism in black children compared to white children may also pose challenges for African American parents, who may be deprived of the facilities of services. Therefore, they may be experiencing problems in both understanding their children's issues and in developing appropriate coping skills. It is also known that African American parents have difficulties not only in interacting with professionals about their children but also in being able to involve in their children's education in both general and special education (Brandon & Brown, 2009).

There are studies on families' experiences related to autism in general, and the condition is reported to cause feelings of frustration, uncertainty about expectations for their child, anxiety about their child's future well-being, poor social relations and a financial burden (Sofronoff & Farbotko, 2002). On the other hand, there is a limited number of studies on the unique experiences of culturally diverse families since there are not enough researchers interested in the topic. Besides, the recruitment of culturally diverse families continues to be a challenge in research. Several factors such as geographical, cultural and language barriers, mistrust, fear and a misunderstanding of research agendas, participants' uncertainties about the risks, benefits, and protection of confidentiality might have been playing a significant role in the low research participation rate (Welterlin & LaRue, 2007).

The primary aim of this review is to perceive the experiences of culturally diverse families which include the minority and immigrant families with ASD.

Research Method

The main purpose of this study is to determine how the Autism Spectrum Disorders (ASD) phenomenon in our study affects the lives of families from different cultures and to present the relationship between this situation and the salient cultural characteristics of the families. To present the studies carried out from this perspective in a holistic way, this study was carried out with the meta-analysis method. A meta-analysis, which can be defined as evaluating the results obtained from independent researches on a specific subject and analyzing those results together with statistical methods for achieving a more reliable finding, is a method to obtain more generalized and reliable results. (Çarkungöz, 2009, p.33).

The meta-analysis method, which was first used by Karl Pearson in 1904 for vaccine studies, began to be applied after the 1970s with the works of Rosenthal, Rubin, Schmidt, and Hunter (Dinçer, 2014.s.7) in the field of social sciences. While meta-analysis is generally implemented in quantitative studies, it also undertakes the task of explaining the studies having a causal relation between them, as well as the studies with no causal relation. (Akgöz, Ercan, et al., 2004, p.108). Meta-analysis application is known as a reliable application for researchers in reaching more generally accepted results and leading effects of results obtained from studies to a more meaningful level by facilitating the researchers to evaluate those results objectively and observing the findings with a holistic view.

The meta-analysis, which can be summarized generally as above as the method of our study has emerged from a need. More than one large scale researches are needed to understand how families with children with Autism Spectrum Disorders (ASD) examined in our study, coming from different cultures and beliefs are effected and to interpret the extent of the relationship between these effects and cultures.

The meta-analysis method, which was first used by Karl Pearson in 1904 for vaccine studies, began to be applied in the field of social sciences after the 1970s with the work of Rosenthal, Rubin, Schmidt, and Hunter (Dinçer, 2014.s.7). While meta-analysis generally finds application in quantitative studies, it also undertakes the task of explaining the studies with causal links among them, as well as the studies that do not have any causal link between them (Akgöz, Ercan, et al., 2004, p.108). Meta-analysis application; It is known that the results of the studies obtained from the researches reach a more meaningful level, provide the researchers with ease in attaining the more general-valid results by facilitating the researchers to objectively evaluate the results and integrating the findings.

The meta-analysis, which can be summarized in this way, in general, emerged from a need to determine the method of our study. More than one large scale research is needed to understand and interpret the effects of families from different cultures and beliefs with children with Autism Spectrum Disorders (ASD) examined in our study and the extent of their relationship with their cultures. Thus suggesting how a single run in will be held a certain sample group for measurement and evaluation of the evaluation the typical characteristics of families from different cultures holistic particularly the situation of refugee families in Turkey and children in the future will provide an important methodological point of view to improve predictions for that impressed. By considering the aspects mentioned above, it is aimed to comprehend the adversities of the families having children with the diagnosis of Autism Spectrum Disorders (ASD), to present and interpret the studies that have been carried out so far — in the context of the current situation and the results — in a fictional framework.

Research Strategies

A search was conducted to investigate the experiences of culturally diverse families with ASD. Key search words were autism, culturally diverse, minority, immigrant, refugee, African American, Black, Latino, Hispanic, Asian, and Native American. Searches were conducted in the Multiple Resources Database, Psych Info, and Medline databases. As a result, fifteen journal articles were identified in seven journals including the Journal of Autism and Developmental Disorders, Pediatrics, The Journal of School Nursing, Journal of Family Social Work, Research & Practice for Persons with Severe Disabilities, Disability & Society, Focus on Autism and Other Developmental Disabilities. The content of these articles was reviewed, and nine of them were found relevant for the review. Six of these articles were research studies and three of them were conceptual articles.

Results

Table 1: Experiences of culturally diverse families with a child with ASD.

Study	**Article type and Journal title**	**Study Design**	**Sample**	**Findings**
Burkett, Morris, Manning-Courtney, Anthony, & Shambley-Ebron (2015)	Research article Journal of Autism and Developmental Disorders	Qualitative study	28 African American family members caring for their child with autism and 28 ASD professionals	Families practiced "culture care" through the means of (1) protecting their children through promoting independence in self-care and being watchful over child's safety, (2) Taking action for the child and the family; and addressing lack of knowledge and lack of acceptance within African American community.

Dyches, Wilder, Sudweeks, Obiakor, & Algozzine (2004)	Conceptual article Journal of Autism and Developmental Disorders			The majority of current literature reports a higher prevalence of autism among immigrants. Little information is known regarding how multicultural families adapt to raising a child with autism (family appraisal/ perception of the stressor- different beliefs on etiology-, social support – family and organizational/ service access/ fear of stigma -). Future research is warranted.
Lin, Yu, & Harwood (2012)	Research articles Pediatrics	Quantitative study	2007 National Survey of Children's Health data	Comparison of children with ASD and select DDs from immigrant and nonimmigrant families on measures of a medical home and insurance coverage. Compared with nonimmigrant families, children with ASD and select DD from immigrant families were more than twice as likely to lack the usual source of care and report physicians not spending enough time with family. Insurance coverage is an important factor in mitigating health care barriers for immigrant families.
Luong, Yoder, & Canham (2009)	Research article The Journal of School Nursing	Qualitative study	Nine first-generation Southeast Asian parents with children with ASD (ages 3-10). – California	Nine coping style patterns: denial/ passive coping, empowerment, redirecting energy, shifting of focus, rearranging life and relationships, changed expectations, social withdrawal, spiritual coping, acceptance.
Magana & Ghosh (2010)	Research article Journal of Family Social Work	Quantitative and qualitative study	Latina maternal caregivers of persons with autism (n=29) and schizophrenia (n=33). (Children with autism eight years or older, mean= 16.7).	The mothers of youth/adults with autism reported higher levels of psychological well-being compared to mothers of children with schizophrenia. Co-residing with their young or adult child was significantly related to lower levels of depressive symptoms.

Tek & Landa (2012)	Research article Journal of Autism and Developmental Disorders	Quantitative study	19 minority (African American, Asian, Hispanic) and 65 Caucasian toddlers and their parents (majority upper class) – Pretreatment data from an ongoing early intervention study.	Early symptom presentation may differ in toddlers with ASD from ethnic minority backgrounds: minority children with ASD had scores that were indicative of more delayed or atypical language and communication scores on standardized tests. Early detection of ASD is more likely to occur in highly educated families possibly due to better financial and educational resources. The communication gap between parents and health care providers: respecting doctor's comments and decisions, not expressing concerns.
Tincani, Travers, & Boutot (2009)	Conceptual article Research & Practice for Persons with Severe Disabilities			Current evidence indicates that the prevalence of ASD is the same regardless of race, ethnicity, or country of origin. However, ASD is under-identified in racially and ethnically diverse children. Culture plays a role in how parents perceive disability. African American mothers reported lower levels of the negative impact of having a child with ASD than did Caucasian mothers.
Welterlin & LaRue (2007)	Conceptual article Disability & Society			Culture affects how disability is interpreted. Families challenge the medical model. Need for an "Ecocultural theory." Beliefs about the etiology of disability differ. Understanding what is normal may be different in immigrant families.

Jegatheesan (2010)	Research article Focus on Autism and Other Developmental Disabilities	Qualitative study	3 South Asian Muslim families	Beliefs about having a child with ASD: a blessing from God. Full inclusion of the child in life. Challenging medical definition of deficiency.

Themes

Theme I: Diagnosis and Symptoms.

There are respectively conflicting research findings on the prevalence rates of ASD across different races (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). While earlier studies claimed that ASD was more frequent in Western countries, there have also been academic studies indicating a higher prevalence among immigrants. According to the most current evidence, the determined frequency of ASD does not show a difference across race, ethnicity or country of origin (Tincani et al., 2009). On the other hand, ASD is reported to be under-identified in racially and ethnically diverse children (Tek & Landa, 2012; Tincani et al., 2009). The literature reported that African American children received the diagnosis a year and a half later than White children on average (Tincani et al., 2009). African American families were surprised to see that ASD was as common in African Americans as Caucasian children (Burkett, Morris, Manning-Courtney, Anthony, & Shambley-Ebron, 2015). The study by Luong, Yoder, and Canham (2009) on Southeast Asian parents also showed that parents experienced late referral to services, delayed diagnosis and false reassurance from knowledgeable professionals. Besides, among the students receiving special education services, racially diverse students are underrepresented in the autism category. Children who were African American, Hispanic, or of other race or ethnicity are less likely to have been documented as having an ASD than are White children and minority children with ASD are more likely to receive a proper diagnosis other than autism such as ADHD, conduct disorder, or adjustment disorder (Tincani et al., 2009).

The typical symptoms of ASD may also vary across children from different cultural groups. The study by Tek and Landa (2012) showed that early detection of ASD was more likely to occur in highly educated families possibly due to better financial and academic status. The authors discussed the communication gap between parents and health care providers as a potential factor behind delayed diagnosis such that parents might be too withdrawn to voice their concerns and to challenge the provider's reassurance about the child's development. According to the authors, cultural barriers could be another consideration and clinicians needed awareness training. It should also be considered that some symptoms of autism such as avoiding eye contact or aggressive behaviors may not be considered as problematic and this may contribute to delayed diagnosis (Dyches et al., 2004). To support this argument, it has been noted that making direct eye contact with adults or imitating the behaviors of parents may be considered disrespectful in some Asian cultures (Tek & Landa, 2012). Moreover, parents of children with disabilities from diverse ethnic backgrounds have been reported to regard early developmental difficulties as temporary (Tek & Landa, 2012). The study by Tek and Landa (2012) also pointed out the difference in the way symptoms were presented in toddlers, despite the lack of socioeconomic status differences between Caucasian and minority families, the clinical presentation of symptoms differed. The minority children with ASD had scores that were indicative of more delayed or atypical language and communication on standardized tests.

Theme II: Barriers to Service Utilization.

Only two articles mentioned the barriers that culturally diverse families encounter in their access to services. Using the data from the 2007 National Survey in Children's Health, Lin, Yu, and Harwood (2012) compared children with ASD and other developmental disabilities from immigrant and nonimmigrant families on measures of the medical home and insurance coverage. It should take into account that the study does not establish any distinction between nonimmigrant white families and nonimmigrant minority families and uses immigration status as the sole criterion. The authors found out that compared with nonimmigrant families, children with ASD and select developmental disabilities from immigrant families were more than twice as likely to lack an established source of care and reported physicians not spending enough time with family.

Furthermore, insurance coverage found to represent a critical factor in mitigating health care barriers for immigrant families.

Dyches et al. (2004) implied that the fear of stigma, which reported to be important for African American families, could be a determinant that hinders the families' access to the services provided by professional organizations.

Theme III: Beliefs about autism and coping mechanisms.

Six of the eight articles focused on culturally diverse families' beliefs on autism and their coping mechanisms. The following sub-themes identified:

Non-organizational sources of support. It was noted that African Americans seek professional services only after relying on other sources of support such as family, friends, religion, and church support (Burkett et al., 2015; Dyches et al., 2004). This situation highlights the importance of the community for African American families and of incorporating the social support systems in preventive and rehabilitative services.

Various beliefs about etiology. The families' beliefs about the etiology of autism portray a crucial role in whether families perceive disability as a positive or negative condition (Dyches et al., 2004). Dyches et al. (2004) and Welterlin and LaRue (2007) cite several examples of distinct cultural perceptions on the etiology of autism. Some Native Americans, Latinos, and Asians are reported to believe that family members are accountable for their children's disability or the child's disability is considered as a form of punishment on the family for past sins (Welterlin & LaRue, 2007). Navajos supposed that the child's autism may be the fault of the parents or the result of witchcraft (Dyches et al., 2004). In addition, they thought that the mother may have seen a dead animal while pregnant or that the child was conceived by a man other than the mother's husband.

Coping mechanisms.

The coping mechanisms the families use are closely related to their beliefs about their children's condition. As indicated by Dyches et al. (2004), perceiving the child as a blessing from God is a prominent factor in managing the stress that stems from the disability. The literature reveals that the family's culture and religious beliefs play a pivotal role in the way the families deal with their children's autism. For example, some Latino and African American families accept the child as a blessing or gift from God and feel that they have been found worthy of such a child (Dyches et al., 2004; Welterlin & LaRue, 2007). Similarly, the study by Jegatheesan (2010) revealed that South Asian Muslim parents perceived their children with autism as a blessing from God and felt that their family was selected by God to raise "His special child."The families thought that they were chosen because of their resilience or perceived the situation as a test for their spiritual and moral qualities. Because culturally diverse families may possess various insights of disability in general and autism in particular, their level of stress may differ as well. For example, Tincani et al. (2009) reported that African American families' caregiver burden and level of stress were less than those of Whites and their satisfaction was greater while caring for children with developmental disabilities. In their comparison of the well-being of the mothers of children with autism and children with schizophrenia, Magana, and Gosh (2010) found that the mothers of youth or adults with autism had more superior levels of psychological well-being compared with the mothers with children with schizophrenia. The authors attribute this difference to the fact that the mothers of children with autism learn about their children's condition earlier in life and as a result, may be more accepting of their child as someone special in their lives that can contribute to their purpose of life, accepting of themselves and feeling like they have grown independently.

In their qualitative study, Luong, Yoder, and Canham (2009) found out nine Southeast Asian parents' coping styles on raising children aged from three to ten years old and came up with nine major coping mechanisms that the parents used in common: denial/passive coping, empowerment, redirecting energy, shifting of focus, rearranging life and relationships, altered expectations, social withdrawal, spiritual coping and acceptance. While there is a need for further research and comparison to see whether these coping styles are common to other parents in a similar situation or not, the parents in the study attributed some of their strengths and weaknesses to their cultural and minority status. For example, when parents were in the phase of redirecting their energy towards being more involved in their children's treatment, they tried alternative methods such as herbal medications, particular nutrition, dietary supplements, or sound therapy. The parents also reported that they had experienced social withdrawal and were left out in social circles. They attributed this exclusion to the fact that autism was perceived as a stigma in Southeast Asian culture. The belief that the child's autism was the result of the sins in their past lives was also found to be a stress factor for the parents. On the other hand, some parents were happy they were paying these past debts in a form of love and would enter their next lives debt-free. Spiritual coping was a key coping mechanism for most of the parents.

It was also reported that African American parents empower their children to promote their independence and preserve them from discrimination due to their minority status (Burkett et al., 2015). Similar to Asian parents, African American parents emphasized the lack of acceptance and the disability stigma within their communities and actively challenged this stigma through educating the family members, friends and the community (Burkett et al., 2015).

Another theme that emerged from the review was the fact that families challenge the medical model, which emphasized the deficiencies of the children instead of the strengths and potential (Jegatheesan, Miller, & Fowler, 2010; Tincani et al, 2009). In the study by Jegatheesan et al. (2010), South Asian Muslim families emphasized the potential of their children instead of deficiencies and indicated the children’s full inclusion in family and community life was their goal. The definition of success in therapy may also be different for culturally diverse families. For instance, minority families may not expect their child to be as independent as Western norms suggest Welterlin & LaRue, 2007). On the other hand, African American parents reported to actively promote their children’s independence through teaching self-care (Burkett et al., 2015). Promoting independence was the families’ way to protect their children from discrimination.

CONCLUSION

The reviewed literature suggests that culturally diverse families have unique circumstances while they cope with their children's ASD. These families have their challenges and strengths, risks and resilience factors that need further investigation. There is still a need for further in-depth and large scales studies that will consider factors such as culture, language, immigration status and socioeconomic status of the families.

The researchers also need being cautious about the difficulties of exploring issues of culture. One of the potential pitfalls in investigating the experiences of culturally diverse families is one can easily fall into the trap of essentialism and can conclude that those experiences are unique to minority families. To avoid this, the experiences of culturally diverse families should be compared with those of non-minority families to disguise which common features those families share and which differences they experience. Moreover, the way the families experience ASD should be unattributed solely to their ethnicity, race, country of origin, religion, immigration or socioeconomic status. Consequently, there is a need for research that will include more of these variables and investigate the experiences of families across a larger spectrum.

The context is also very crucial in analyzing families' experiences with ASD. The current review solely includes the studies conducted in the United States, where the terms "immigrant" and "minority" have specific connotations. The definitions and meanings of these terms differ in different contexts. Therefore, studies on the families' experiences with ASD in other countries will enrich our understanding of the cultural influences. Studies on the experiences of refugees are of particular importance in today's world due to the global refugee crisis. Further studies on the experiences of immigrant and refugee families experiencing ASD in Turkey and other refugee-hosting countries will be of particular importance.

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