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Sociocultural Perspective on Autism Intervention

Elizabeth Hughes Fong and Helen Lee

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Abstract

The landscape of the population in the United States is diversifying, as are the individuals who have a diagnosis of autism spectrum disorder. Autism spectrum disorder now affects one of out every 68 children. Although the diagnostic criteria do not differ, there are differences in time of diagnosis, treatment and acceptability of the diagnosis in various cultures, which is important for clinicians to understand. One approach to autism intervention is applied behavior analysis (ABA), which seeks to intervene on socially significant behavior. In addition, to using an approach such as ABA, which emphasis social significance, individuals may also use a cultural broker. The cultural broker can help to bridge the gap between parties and promote more effective treatment experience and thus help to ensure a more culturally sensitive approach to intervention.

Keywords: autism spectrum disorder, cultural competence, applied behavior analysis, cultural broker, social validity, culture

1. Introduction

According to the *Diagnostic and Statistical Manual of Mental Disorders* [1], autism spectrum disorder (ASD) is a neurodevelopmental disorder which can be broadly characterized by deficits in social communication and restricted interests and repetitive behaviors. Autism spectrum disorder has implications in the individual's ability to develop and maintain social relationships and function in society, and its symptoms can be recognized and diagnosed by 3 years of age.

Autism is considered a global health issue affecting individuals across diverse cultures [2, 3]. The prevalence of ASD in the United States is high, affecting roughly 1 in 68 children. However, this rate may be even higher considering that the ethnic and racial minority children are currently believed to be underdiagnosed due to barriers with accessibility to

evaluation, diagnosis, and services [4]. Together with greater awareness across the world, there has been increasing interests both nationally and internationally to develop effective autism intervention treatment.

Among the number of intervention approaches that are currently available to treat autism, the literature suggests that behavior-focused interventions are arguably the most widely used and accepted in the field [5, 6]. Based on the science of applied behavior analysis (ABA), behavior analytic intervention programs are primarily designed to teach new skills and modify problem behavior by manipulating some aspects of the environment [7]. In particular, behavior therapists are taught to develop the intervention goals, methods, and implementations in line with clients' needs and the norms of social community [8, 9].

With the greater recognition of cultural diversity of individuals with ASD and their families across the world and in the United States, there is also a growing need to develop culturally sensitive ASD intervention programs. A culturally sensitive intervention program recognizes that clients from diverse cultural backgrounds can be best served when their needs are addressed with respect to the sociocultural contexts of their past developmental histories and current adaptive environment [4]. Such a program integrates an appropriate cultural view in assessing, designing, and implementing the program, and in approaching clinician-client relationship. Moreover, culturally sensitive intervention programs are embedded within a larger social cultural context of support, especially within a community of professionals who work as cultural mediators between the mainstream culture and the autism community. Such mediations between the mainstream and autism communities create a crucial social space or buffer for exchanges of ideas and conversations and adaptive interaction to take place, and it strengthen the long-term intervention effect.

We first discuss the cultural role in conceptualization and treatment of autism and disability in general, and then the importance of considering culture in developing behavior analysis interventions. We also discuss the role of greater professional community as cultural mediators between the mainstream and the autism spectrum community, highlighting the importance of cumulative efforts from the ABA perspective and professional community support in intervention outcome. Ultimately, we point out that in order for an intervention to be successful, it needs to be sustainable over time not only in the individual and family levels, but also in the social cultural community level as well.

2. Disability, autism and culture

The discovery of autism as well as the development of its intervention treatment have been largely originated in Western cultures and thinking. The significant early work by American doctor Leo Kanner and German doctor Hans Asperger in the 1940s have significantly contributed in establishing autism as a disorder that is currently known in the modern world. Similarly, ABA interventions are based primarily on the scholarly work of behaviorism, particularly by Skinner's [10] radical behaviorism, which highlighted the importance of deciphering particularities of environmental condition on organism's behavior.

Understandably, beyond Western cultures, there is significant variance regarding the meaning of disability and autism, and different ways individuals and families cope with the impact of the conditions. Some cultures may perceive the symptoms of a disability as a part of individuals' personality traits such as "stubbornness" or "laziness," and avoid seeking a necessary treatment. A mismatch on the cultural perceptions about behavior between ethnic and racial minority families and health professionals from the mainstream culture can also influence how families cope and seek help for treatment. For example, studies suggested that European American parents may be more likely to agree with the assessment of their child's behavior by a teacher than Asian/Pacific Islander and African American parents [11]. As a result, such culture-specific responses can potentially impact the interventions recommended by a treatment team, with European American children more likely to participate in intervention programs and receiving treatment via parent support more immediately than Asian children. On the other hand, the cultural differences in perceiving behavior have also contributed to over-diagnoses of behavior problems of minority students due to the cultural biases of educational and mental health administrators [12, 13].

Culture may also impact the diagnosis of autism, the time of diagnosis, as well as the access to services. For example, in the US, European Americans are diagnosed on average 1.5 years before their ethnic minority counterparts [14], allowing European American children for more immediate access to interventions for autism, in comparison to their minority counterparts. Across the world, in Egypt, autism has been often considered analogous to mental retardation or even a curse by folk belief, and children have been sometimes caged as a result [15]. In China, autism has been conceptualized as a disease of the 'rich and lazy' and its treatments included walking long distances in heavy clothing and weight training [16]. In Ethiopia, many individuals believed that children who have autism were possessed by the devil due to their parent's sins and attribute largely to supernatural explanations as the cause of autism, and the families live with high levels of stigma [17]. However, nowadays, there are growing global health initiatives to enhance understanding for autism and its symptoms and to stimulate greater acceptance of those who are diagnosed with ASD by their community [18].

Consequently, the treatment of autism in some parts of the world has included the use of folk healers and religious rituals, or forced isolation from the community. For ABA therapists, when treating families whose cultural beliefs and practices related to autism may be different from the therapists, it may be important for the therapists to not only educate themselves about their client's culture but also educate their clients about the evidence-based literature findings which is guiding the therapists' intervention practice [4]. Furthermore, the clients who are disconnected from the community may need to be educated about the process and best ways to navigate some of the challenges to obtaining care from their state and federal level systems (e.g., health care and educational systems).

In sum, differences in cultural notions about typical human development and disability can influence different ways in which individuals perceive autism and seek treatment [4]. When there is perceived cultural difference between the therapists and clients, it is more critical for the therapists to understand their clients' cultural views and strategy the best way to create common treatment goals, procedures, and outcome assessments together with their clients and families.

3. Culture and behavior analysis

In discussing various intervention programs to teach individuals with ASD socially appropriate behaviors and communication skills, it is often ignored that there is social cultural diversity in human behavior across communities. Culture refers to the historical patterns of meanings embodied in various forms of symbols that pervade in a community and which are transmitted to the next generation of offspring [19]. It shapes individuals' values, beliefs, and behaviors including different ways they display emotion, communicate needs and wants to others, and approach inter-personal relationships. Skinner [10, 20] has also noted that culture represents the collection of operants or contingencies unique to a social community.

Applied behavior analysis is one of the most common interventions used with individuals who have autism and has been used to develop a number of popular behavior-focused intervention programs used today, including pivotal response training, early intensive behavioral intervention, and positive behavior interventions [21]. Behavior analysis focuses on teaching and shaping-specific behavior by manipulating the behavior's functional relationship with the environment [7]. Environmental variables such as conditions which precede (antecedents) and follow (consequence) the behavior and motivational factors like individuals' state of deprivation and satiation are analyzed in order to identify reasons for the prevalence of the behavior, i.e., increasing or decreasing manner in the given context.

Considering that defining characteristics of autism are concern with difficulties in social interaction and verbal and nonverbal communication [1], the key goals of ASD intervention have traditionally focused on addressing these deficits. However, the traditional methods of teaching communicative skills and other living skills have largely occurred in restricted learning environment with limited considerations for social cultural norms and values.

There are a number of ways cultural knowledge can help develop effective behavior analytic programs, especially for naturalistic setting-based intervention. Cultural knowledge can guide behavior analysts to design more contextually appropriate intervention programs by helping them to recognize variations of different forms of antecedent and reinforcers and understand their functional relationships. The different forms include verbal and nonverbal behaviors of individuals and agencies or structures at the institutional level that control contingencies. For example, all verbal relations are considered operants with different verbal forms controlled by consequences, all of which are unique to different cultural communities [10, 20, 22]. A verbal community shapes speaker and listener behavior by teaching specific and shared verbal forms and their consequent behavior through group practices [10, 20]. At a basic level, when an English speaker says, "give me an apple," the linguistic 'form' or meaning for the request can only elicit proper action from the same linguistic community (English), not from other linguistic communities. Moreover, when an individual with autism from an English-speaking North American community hands an apple to the speaker in response, s/he may be considered to have mastered fluency skill level. However, a child from a culture that emphasize social hierarchy and respect toward authority figures and elders may need to be further trained on how to properly hand the apple to an authority figure or elder with two hands and a posture for respect to be considered mastered the fluency. As Vargas [22] has

noted, language does not exist in static symbolic forms but rather in dynamic action forms including utterances, writings, and bodily gestures which carry with them implicit meanings that are not directly communicated. Skinner [20] also emphasized that verbal behavior is not restricted to any particular mode of behavior but any behavior reinforced through mediation of other people (speaker) and can include any movement capable of affecting another organism.

When programs are culturally sensitive, they integrate culturally appropriate forms of antecedents and reinforcements from the natural environment. Individuals' perception of what is desired or aversive of symbolic systems of objects, events, and behaviors is often heavily influenced by the prior experience in the social environment. For example, children may respond better with a type of tangible reinforcement (e.g., food or toy) when it is more familiar and desirable to them. Children in northern Europe may respond more favorably to liquorish candy than sesame snacks which are more popular in Asia. When providing social praise for positive reinforcement, behavior analysts can consider different ways cultures express emotion and praise or disappointment. Studies have shown that Western cultures encourage their children to value autonomy and independence while Asian cultures encourage their children to value collective needs and group harmony and emotional control in public [23, 24]. An individual who grew up in a culture that values emotional control and avoids high intensity social expression of affect may be unfamiliar and uncomfortable by loud and highly energetic praise which individuals who grew up in Western cultures may prefer. In such settings, more toned down subtle forms of praise may work better as positive social reinforcement, while the high intensity expression of praise may serve an aversive function. Therefore, a culturally sensitive program considers not only different types of reinforcement but also different potential functions, they may serve related to their environmental history. In addition, a culturally sensitive program can help individuals to generalize better across contexts by minimizing the gap between the teaching session and everyday interaction.

In interpersonal communication, cultural knowledge can enhance the ABA therapists' ability to communicate with their clients about the intervention more effectively. When therapists understand ones' own cultural biases and cultural differences in their clients' values, beliefs, and communication styles, therapists can develop ways to build rapport and quality relationships with clients and communicate more effectively [25].

In order to ensure social relevance of intervention, ABA frequently employs various social validity assessments [26]. When working with culturally diverse clients, utilizing social validity measures frequently to ensure the goals, methods, and outcomes of intervention are accepted by the clients would be particularly critical. Although more work is needed to modify currently existing validity forms in culturally sensitive ways, it would be important to be aware of them. They include Lennox and Miltenberger's [27] 12 factors for treatment acceptability, Winett et al.'s [28] epidemiological conceptualization of social validity, Gresham and Lopez's [29] conceptualization of social validity as the accumulation of multiple sources of information from culturally relevant key stake holders, Kennedy's [30, 31] maintenance model of social validity, or Carter's [32] distributive model of treatment acceptability. Examples of format treatment acceptability measurement instruments include the:

Treatment Evaluation Inventory, Treatment Evaluation Inventory-Short Form, Treatment Acceptability Rating Form, Treatment Acceptability Form Revised, Intervention Rating Profile, Intervention Rating Profile 1.5 m, Children's Intervention Rating Profile, Behavior Intervention Rating Scale, Intervention-Process Rating Scale (IPRS), and Abbreviated Acceptability Rating Profile [33].

4. Cultural brokers of autism intervention

A comprehensive treatment intervention for autism often involves a number of service professionals with diverse areas of expertise from the community. The role of the professionals as essential cultural mediators is often shadowed by the social interest for the effectiveness of the intervention service as a product they deliver to the clients [34]. However, it should be acknowledged that various professionals in the community such as those working in education, health, and social service systems also serve a critical role as social mediators. As a collective, they help to bridge the gap in knowledge between the broader cultural community and the autism community. Through their cultural mediation, the cultural broker helps to create an important inclusive social environment or space, one that which disabled individuals can practice, make progress and connect with the general population [34, 35].

In the field of education, cultural brokers may be teachers, instructional aides, school counselors, community members, after school program staff, students, siblings, school liaisons, and parent liaisons [34]. On the behalf of the student and family, within the educational setting, brokering activities may include, translation, assistance with navigating, interpreting the educational system, development of advocating skills, assistance with social skills, and potential employment opportunities for the student and their family. In addition, cultural brokers might inform the school staff about the cultural practices of the student and their family, as well as how to successfully work within any differences [34]. Ultimately, use of a cultural broker in the educational process can help address barriers between the student, family and school, which is important as the previous literature outcomes emphasize the importance of a school home collaboration for student success.

Professionals serving as cultural brokers or intermediary can help to translate information between the autism community which include individuals with ASD and their families and the mainstream social cultural communities which they are part of. According to Lo [36], professionals can serve as cultural brokers who help to bridge, link, or mediate between groups or persons from different cultures. Cultural brokers work to reduce conflict, or bring about change by bridging or linking groups of culturally different individuals together [37]. This often involves rapport, trust, long-term relationships, building of networks, and cultural labor, which can take considerable times and effort on the part of the clinician.

According to Jezewski and Sotnik [37], there are three stages of brokering process. The first stage involves identifying problem of a breakdown or conflict in the communication between the parties. Second, the intervening condition stage involves integrating culturally relevant factors in analyzing the problem, devising appropriate strategies, and evaluating outcomes.

During this stage, the intervention strategies are examined critically with respect to the potential explanations for the success or failure interventions. Here, cultural brokers might advocate for particular strategies, mediate between groups for greater understanding, help professionals and clients network to broader community, and help negotiate different views different parties may have. In the process, much work is devoted for professionals' ability to establish trust and rapport and bonds with their clients. In the final stage, the intervention outcomes are evaluated and deemed to be successful or unsuccessful. An intervention is deemed successful when bonds are established between individuals from different cultures but unsuccessful when intervention continues to involve a breakdown in services.

5. Conclusion and future direction

Autism has become a global health concern, affecting individuals across diverse cultural populations. The effective treatment of autism, especially involving teaching of socially adaptive skills, needs to consider appropriate sociocultural contexts of their clients' living environment [4]. Cultural values, beliefs, and practices which play key roles individuals' conceptualization and choice for treatment of autism are not consistent across cultures, and it behooves therapists to be informed about cultural perspectives that are different than their own.

To develop culturally sensitive intervention programs for individuals with autism, it would be important for therapists to be aware of their own biases, as these biases related to treatment, cause, and diagnostic views may not be in agreement with how a family or their culture conceptualizes the process [25]. Thus, it is recommended that regular validity checks are performed with the family and other stakeholders to ensure the proper representation of the family culture during intervention team meetings.

By taking the time to understand the needs of the clients and families in the context of their social cultural environment, therapists motivate greater family engagement in treatment services, compliance with treatment planning and recommendations, all of which contribute to better treatment outcomes. Together with the supports from cultural brokers from diverse fields of expertise in the community, socioculturally grounded intervention programs for individuals with autism can offer valuable opportunities to acquire skills that are more functionally adaptive to their cultural environment.

Author details

Elizabeth Hughes Fong^{1*} and Helen Lee²

*Address all correspondence to: efong@sju.edu

1 Saint Joseph's University, Philadelphia, United States of America

2 University Boston, Boston, United States of America

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