Review

Cultural Considerations in the Selection of Evidence-Based Psychosocial Interventions for Chinese-American/Immigrant Children with Autism Spectrum Disorders

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Just as treatment for children with autism spectrum disorders (ASD) does not follow a universal course of intervention, so should the design and implementation of evidence-based interventions not assume universal efficacy for all groups, especially those from non-dominant cultures. The scarcity of efficacy studies on psychosocial interventions for the Chinese-American/immigrant children with ASD calls for more research on the topic and challenges mental health and educational providers to consider cultural factors in various phases and at various levels when conducting interventions. This article presents specific cultural considerations in the selection of evidence-based psychosocial interventions for Chinese-American/immigrant children with ASD for professionals serving the population. Examples include considerations of cultural/linguistic characteristics of the child with ASD, his/her family and school context, and their cultural values. As Evidence-based Interventions (EBI) are necessary but not sufficient for effective interventions, strategies based on implementation science are recommended.

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INTRODUCTION

Autism, as defined by the Individuals with Disabilities Education Act, is a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The prevalence of autism spectrum disorders among Asian/Pacific children was 2.2 to 19.0 per 1,000 (the wide confidence intervals suggest that these findings should be interpreted with caution) compared to 12.0 per 1,000 for Whites, 10.2 per 1,000 for Blacks, and 7.9 per 1,000 for Hispanics (US Census 2008).² Four possible reasons were proposed to explain the high rate of identified Asian/Pacific children: Language, social skills, behavioral repertoire, and cultural differences.³ Many of these cultural factors may also impact psychoeducational interventions for the population.

For decades, treatment of autism has included a combination of psychoactive agents and psychosocial treatments, with more and more involvement of family and school.⁴

Commonly used psychosocial and educational treatments include structured teaching approaches, direct instruction, social stories, peer-mediated intervention, video modeling, and discrete trial instruction⁵ along with applied behavioral analysis. As these interventions and the research on efficacy of them were developed and conducted in the mainstream American culture, the current article explores cultural considerations in the selection of evidence-based interventions for Chinese-American/immigrant children with autism spectrum disorders (ASD).

In our discussion of cultural considerations, culture refers to "an organized set of thoughts, beliefs, and norms for interaction and communication, all of which may influence cognitions, behaviors, and perceptions." Race, ethnicity, language, age, gender, socioeconomic status, education, and level of acculturation are considered influential factors in an individual's culture. Race and ethnicity are not equated to culture. Acculturation refers to the process of psychological changes in values, beliefs, and behaviors when adapting to a new culture. It involves learning the language, norms, and values of the new culture and relinquishing some customs, values, beliefs, and behaviors of the old culture.

In this article, evidence-based intervention refers to identifying interventions with credible scientific evidence as essential for informing practice and improving outcomes.⁹

Cultural validity is an essential part of evidence-based intervention for culturally diverse children. The article will begin with an overview of cultural influences on the views of autism among Chinese, followed by a brief literature review on the efficacy of psychosocial interventions for Chinese-American/ immigrant children with ASD, specific cultural considerations for selecting evidence-based interventions for the population, and end with recommendations of strategies based on implementation science.

REVIEW

Cultural Influences on the Views of Autism Spectrum Disorders

The term autism when translated into Chinese () literally means a "closing-off-of-the-self disorder" or "solitary disorder" (pronounced as zi-bi-zheng or gu-du-zheng in Chinese). The diagnostic criteria for this disorder found in the Chinese Classification of Mental Disorders, 3rd edition (CCMD-3)¹⁰ are similar to the criteria used in the United States, namely impaired interpersonal interactions, impaired communication, the presence of repetitive and stereotyped behaviors, interests and activities. The awareness of autism as defined by the medical and mental health fields has been increasing in China and East Asia in the last three decades. More and more people are educated by the biological and psychological perspectives of ASD.

However, alternative perspectives contribute to current Chinese and Chinese-American's understanding of ASD. Traditional Chinese Medicine (TCM) views Autism as a 'Yin' (from the Yin-Yang framework) disorder. In ASD, it is believed that there is so much Yin that there becomes an imbalance in the Yin-Yang, resulting in imbalance in one's life. The dominance of Yin results in a lack of interest/enthusiasm in social engagement and deficits in communication.¹¹ TCM approaches such as acupuncture are believed to be conducive to strengthening the Yang and restoring the balance of qi (bio-energy) in the body in order to alleviate such disorders. ¹² Some traditional Chinese cultural beliefs concerned with attributions as to why some people are disabled include beliefs that 'past life' transgressions worked through karmic logic to lead to present-day situations, and that people are justifiably 'punished' for their past-life acts. The value of carrying on the family bloodline (through males) influenced Confucianism also impacts people's view of disabilities. In this light children born with disabilities are often seen as abominations towards this value. Other traditions, such as Taoism, take more of an accepting attitude towards disabilities, with the belief that all life forms are living out their unique 'Tao' or Way. 13

As to the extent contemporary Chinese-Americans/ immigrants hold these the aforementioned views on autism, it depends on their life experiences, education, religion and acculturation. ¹⁴ For instance, influenced by their own education and acculturation, some first-generation Chinese-American parents of children with ASD do not feel a sense of shame about their children's disabilities as other Asian American parents might. They may also be more active and involved in advocacy for their children, and more expectant of ongoing training and support.¹⁵

Research on Efficacy of Psychosocial Interventions for Chinese-American/Immigrant Children with Autism Spectrum Disorders

Currently, research on the efficacy of psychosocial interventions for Chinese-American/ immigrant children with ASD is very limited. As most of the empirical studies on autism are conducted in Western individualistic cultures, there is little information on the cultural validity of psychosocial interventions for Chinese-American/immigrant children with ASD. A literature search through major search engines in the fields of psychology, psychiatry, education and medicine yielded very few works on the topic. The available literature provides us some information regarding the following practical questions.

Should children with ASD be exposed to only one language?

Many Chinese-American children are from bilingual families. A unique issue with bilingual children with ASD is whether they should be exposed to only one language. The push to use only one language with autistic children from bilingual households is related to the belief that becoming bilingual is too challenging for children with ASD and might even cause additional language delays. 16 Based on interviews with bilingual Chinese-American immigrant parents of children with ASD, Yu (2009)¹⁷ found that all parents she interviewed shared this belief. She also found that nearly all educational and therapeutic programs were offered exclusively in English; special education programs did not offer English language learning (ELL) supports for the Chinese-American/immigrant students with ASD; and most parents assumed the responsibility of teaching English themselves, frequently by speaking more English at home. Although the communication difficulties reported for these parents' children were also common for ELLs, in this context they were often misrecognized as developmental difficulties associated with the ASD condition itself. Yu concluded that social, ideological, and institutional constraints can have significant influences on language use in families living with ASD. 17

Typically, the recommended language for children with ASD is English, as it is the dominant language of education and treatment services, despite the limited research on bilingualism and children with ASD. Park (2014) Park

(e.g., conceptual vocabulary, expressive and receptive communication skills, socio-communicative skills, age of first words/phrases, etc). Moreover, based on the lessons learned from case studies, Park concluded that bilingualism was a potential gateway to the increased development of social and emotional skills within their families and communities. Not having the opportunity to grow up bilingual resulted in social consequences for these children, including negative impacts on their participation in cultural activities (e.g., Church) held in the family's native language, affective communication and play in the caregivers' native language, and decreases in opportunities for social communication between family members. Research reveals a pressing need for linguistically and culturally appropriate educational and psychological services for ELL students with ASD, as well as better information dissemination to parents and professionals.1

What Psychosocial Interventions Have Efficacy Information for Chinese Children with ASD?

Huang and Wheeler (2007)⁵ synthesized the established research and best practices in enhancing social interaction, communication, and independent daily functioning skills for children with Autism in the United States. identified several research-based educational approaches and best practices in the field, including structured teaching approaches, direct instruction, social stories, peer-mediated intervention, video modeling, and discrete trial instruction, which have been proven effective in teaching social skills and in improving communication ability, as well as in decreasing inappropriate behavior in children with autism. These interventions look promising, but the cultural validity of them for Chinese-American/Chinese immigrant children with ASD has not been studied yet. Although intervention programs involving applied behavior analysis (ABA) have much evidence to support their utility when working with children with ASD²⁹ no studies were found detailing the use of ABA methods with Chinese-American children. A review of intervention studies with children in mainland China with ASD found that 28 out of 28 private rehabilitation centers reported using some form of ABA when treating children with ASD,³⁰ however, the details of the methodologies/ results of these interventions could not be found. Moreover, in an article written by a Chinese academic promoting the contribution of ABA in the training of parents and professionals working with children with ASD, the author did not mention any cultural considerations in the adaptation of programs " ... developed very well in Western countries ... " for the Chinese context.³¹

As we could not find efficacy studies of psychosocial interventions with Chinese-American/immigrant children with ASD, we looked up studies with Asians who shared many cultural characteristics with Chinese-Americans. One of the few intervention programs that has been studied with Asian children with ASD for efficacy is the Treatment and Education of Autistic and related Communication Handicapped Children (TEACCH) program. TEACCH, according to Texas Guide for Effective Teaching, ²⁰ is a

... comprehensive structured teaching approach designed for individuals with autism and communication disabilities and their families. The TEACCH program was developed by Eric Schopler in the late 1970s and is administered through the University of North Carolina at Chapel Hill. The principles of TEACCH's structured teaching include (a) understanding the culture of autism; (b) developing an individual person- and family-centered plan for each student, rather than using a standard curriculum; (c) structuring the physical environment in a way that will assist students with autism to understand meaning; (d) using visual supports to make the sequence of daily activities predictable and understandable; and (e) using visual supports to make individual tasks understandable.

A full-time center-based TEACCH program has been tested by a longitudinal study (12 months) with a control group among 34 Chinese pre-school children with autism in Hong Kong. 21 Children in the experimental group (n = 18) showed better outcomes at posttest in cognitive, social adaptive functioning, and developmental abilities. The study provided initial support for the effectiveness of using the TEACCH program with Chinese children. The efficacy of TEACCHbased group social skills training was also evaluated by a Japanese pilot randomized controlled trial (RCT) with eleven 5-6 year old children with high-functioning autism and their mothers.²² The program involved comprehensive group intervention and featured weekly 2-hour sessions, totaling 20 sessions over six months. The experimental group (n = 5)showed more improvement than the control group (n = 5) in adaptive behaviors and social reciprocity of the children, parenting stress, and parent-child interactions as assessed by the Strengths and Difficulties Ouestionnaire, Parenting Stress Index, Beck depression inventory-II, and Interaction Rating Scale. These two efficacy studies of TEACCH provide valuable references to practitioners serving Chinese-American/immigrant children with ASD, because Chinese children in Hong Kong and Japanese children with ASD many cultural characteristics with Chinese-American/immigrant children with ASD.

In addition to TEACCH, the effectiveness of Dolphin-Assisted Therapy for Children with Autism has been explored in Singapore with 15 children (ten boys and five girls, aged between 9 and 10 years) (people in Singapore share Chinese culture and language) with high-functioning autistic disorder through a 12-month dolphin encounter for special children program.²³ The program applied the principles from animal-assisted therapy in which an animal is introduced as a companion into a person's life to enhance the emotional well-being. Children in the program had weekly contact with the Dolphin which serves as an awareness initiator to these children with autism. After a year of the dolphin-assisted therapy, the authors reported significant reduction in stereotyped behaviors and a significant improvement in communication and social interaction based on a comparison between the pre- and post- tests. However, it should be noted that this outcome study does not have a control group and currently there are not many research studies on dolphin therapy to support its efficacy of treating children with autism.

It should be noted that, the three aforementioned studies in Asia were not designed to examine the efficacy of interventions for Chinese-American/immigrant children with ASD, although the participants in those studies share some cultural characteristics with Chinese-American/ immigrant children with ASD. We should keep in mind that there is no single intervention strategy that works for all in a particular racial/ethnic group because within each racial/ethnic group, there are many between-group (e.g., nationality, political) and within-group (e.g., gender, age, socioeconomic status, religion, language, and acculturation level) differences.8 Currently the complex dimensions of acculturation and English language proficiency are still not well addressed in evaluative research on intervention strategies. To address this issue that practitioners are facing, the following section explores cultural considerations from an ecological perspective when selecting appropriate interventions for Chinese American/immigrant children with ASD.

CULTURAL CONSIDERATIONS

Considering the Child's Cultural Characteristics

In general, professionals in mental health or education are likely to consider age, gender, health condition, intellectual and socio-emotional functioning, strengths and weaknesses when selecting an intervention for a person. However, when selecting an intervention for an immigrant child or adolescent, not everyone is aware of the importance of gauging the person's language dominance (Native language or English dominant) and proficiency. Such knowledge is crucial to ensure materials and/or procedures are provided in the person's native language or mode of communication along with his/her cultural values, views, and acculturation level. In addition, his/her responses to past formal and informal interventions should also be considered.

Considering the Family and School Cultural Context

To select culturally appropriate and responsive interventions for children with ASD, it is a prerequisite to understand the home/school context and how it affects the intervention. The school/daycare context includes the general school (including daycare) climate, the relationships between administrators and teachers (including care-providers in daycare), among teachers, among students, between teachers and students, between teachers and parents, and teachers' attitude toward autism and Chinese immigrant children and parents.²⁴ It also includes the experiences and training of the teachers in working with children with autism and parents from culturally and linguistically diverse backgrounds. In addition, it is important to know teachers' attitude toward the intervention that you want to implement.

The home context includes family economic status (e.g., family income, parental education), social support, parents' (or care-givers') language dominance and proficiency, parents' acculturation levels, parent-child differences in acculturation levels, intensity of cultural conflicts inside and outside the family, level of acculturation stress, and coping strategies.²⁴ Family economic status may determine the affordability of an intervention. Parents' (or care-givers')

language dominance and proficiency in their Native language and English have multiple implications to intervention selection and implementations for young children. For instance, if parents are Chinese language dominant with limited English proficiency, we should communicate with parents and select an intervention conducive to their preferred communication mode. Parents' acculturation levels have implications for the cultural appropriateness of an intervention and cultural adaptations needed for an intervention, because cultural characteristics impact caregiver perceptions of and attitudes toward children with disabilities. It is also important to know the caregivers' view of autism, their goals for the child, ways to treat autism, and attitude toward the intervention that you want to implement.

Critically Reviewing the "Evidence" for the Intervention

Once we know the characteristics and culture of the child with ASD, his/her Family and School context, and their cultural values, we are ready to select interventions fitting the child. Ingraham and Oka (2006) 9 have developed guidelines for making decisions about implementing an evidence-based intervention in a new setting. The guidelines emphasize two central factors: assessing the quality of evidence available to support a given intervention; and the generalizability and transferability of the given intervention to our intended setting and context. Assessing the quality of evidence for a given intervention often involves a review of relevant research. Research studies on efficacy are usually evaluated based on the quality of research methodology, the effect size of the intervention, and the relevance of the research sample to the clinical population receiving the intervention.²⁵ When assessing generalizability and transferability of a given intervention to our intended setting for a Chinese American/immigrant child with ASD, its cultural validity must be reviewed. Cultural validity, as defined by Quintana, Troyano and Taylor (2001),²⁶ is an authentic cultural representation of the research in terms of how constructs are operationalized, participants are recruited, hypotheses are formulated, study procedures are adapted, responses are analyzed, and results are interpreted for a particular cultural group. Assessing generalizability and transferability of a given intervention to the population we serve also includes examining how compatible the research study sample is to our patient/child in terms of individual characteristics such as language, age, gender, health condition, level of acculturation, socioeconomic status, and education. Demographic and contextual factors can affect the applicability and effectiveness of the intervention model, and therefore dictate the utility of a specific evidence-based intervention for the current need.²⁵ In addition, compatibility between the efficacy study setting and the target setting and the resources required for the intervention should be reviewed. Last but not least, the evidence-based intervention should match the home, daycare or school cultural values.

In summary, evidence-based interventions (EBI), as Shaw et al (2014)²⁵ point out, is a necessary but not sufficient step for providing effective services. The next step involves implementation science, which is the study of methods to

promote the integration of research findings and evidence into policy and practice (Forman et al, 2013).²⁷ The following question from Shaw et al (2014)²⁵ highlights the essence of implementation science:

The primary question of EBI is: What works? The primary questions of implementation science are: How does it work? How robust are the outcomes of the interventions to variations in implementation? Under what conditions does it work? What specific expertise is required? What are the negative unintended consequences of application (e.g., side effects)? For which populations or individuals does it work? What resources are required for it to work? Is it consistent with the culture and values of the setting and personnel in which it is implemented? These are the next and most important questions to be answered.

In the challenging reality of almost no established EBI for Chinese American/immigrant children with ASD, the above series of questions could help us apply the principles of EBI and implementation science in our evaluation of formal efficacy studies, intervention programs and informal interventions in home, school or clinical settings. These questions may also be useful for parents/caregivers/teachers or adolescents with high functioning ASD to review before meeting with professionals to select intervention strategies.

In addition to knowledge of EBI and implementation science, the multicultural competencies of practitioners are crucial for effective interventions for Chinese American/immigrant children with ASD. Multicultural competencies include cultural awareness, knowledge, and skills. ²⁸ Cultural awareness includes awareness of one's own cultural values, norms and worldview as well as the patient's/parents'/caregivers.' In the current context, service providers' awareness of the misunderstanding and prejudice of ASD in the child's environment is also important for helping the child with ASD to combat discrimination.

CONCLUSION

Overall, there is a severe shortage of formal efficacy studies psychosocial interventions for the American/immigrant children with ASD. Such scarcity of culturally validated tools calls for more research on the topic and challenges mental health and educational providers to consider cultural factors in various phases and at various levels when conducting interventions. Just as a diagnosis of ASD can provide a general framework for understanding an individual's behavior (but does not universally inform the experiences of or tailor the most appropriate/efficacious interventions for individuals) so can cultural considerations provide a map conducive to exploring interventions that match the lived experiences of individuals and families. Moreover, in the course of providing services to anyone from non-dominant groups, we would be amiss to assume a 'one size fits all' mentality in the design and implementation of evidence-based interventions. In the case of Chinese-American/immigrant children with ASD, it appears that the current practices of actively discouraging their bilingualism may have an unintended effect of restricting social opportunities and occluding aspects of their identity. Assumptions of cultural/linguistic homogeneity function dampen multicultural sensitivities and obfuscate elements

within a family's culture that could be harnessed as strengths. We hope that the cultural considerations highlighted in this article will help strengthen and expand evidence-based psychosocial interventions for Chinese-American/immigrant children with ASD in the mental health and educational fields, and therefore help to improve the lives of these children.

CONFLICT OF INTEREST

None.

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