

When Collaboration Meets Contrasting Beliefs — Navigating Autism Spectrum Disorder Treatment Within Cultural Expectations

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PREBRIEF

This scenario discusses cultural beliefs surrounding autism spectrum disorder (ASD) and how it affects a Chinese family in the United States. It provides a perspective regarding the way a family’s traditional Chinese beliefs surrounding disability and gender can influence their choices for service delivery. It also illustrates the importance of involving all family members in the decision-making process. Finally, it highlights evidence-based, best practices for treatment and how they may work in harmony with complementary and alternative medicine (CAM) practices.

OBJECTIVES

- Identify beliefs and perceptions surrounding autism and disability that may exist in the Chinese community.
- Understand complementary approaches to treatment, such as CAM, that may be considered in conjunction with evidence-based approaches.
- Explore decision-making processes for parents of children with autism, including approaches to selecting interventions.

CASE SCENARIO

Bo Zhao is a 4-year-old boy whose family speaks Mandarin Chinese. Bo is nonverbal and has recently been diagnosed with ASD by his pediatrician. Bo has a twin sister, Chen, who is typically developing. The children live with their mother, father, and grandmother. Their mother and grandmother care for them in the home. Bo does not attend preschool or day care. Bo’s family moved to the United States for his father’s job and have been there for 2 years. Mr. Zhao works for an international business, and the family lives a modest, middle-class life. The family hopes to move back to China in 5–10 years after Mr. Zhao’s work contract is over.

Bo’s medical history is unremarkable. His parents were surprised when they learned that they were having twins. As the children grew, the parents reported that Bo appeared to lag behind his sister, Chen, in all developmental milestones and described Chen as a “helper” who pushed Bo in his learning. When Bo at-

notes:

Definitions

Complementary and alternative medicine (CAM)—A broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period.

Speech-generating devices (SGDs)—Defined by the Centers for Medicare and Medicaid Services (n.d.) as “durable medical equipment that provides an individual who has a severe speech impairment with the ability to meet his or her functional speaking needs” (I. Proposed Decision, Speech Generating Devices section, para. 2).

tended his yearly medical checkup at 3 years old, his pediatrician shared concerns that Bo was not yet using words and did not appear to socially engage with anyone but his sister. The pediatrician suspected that Bo may have ASD and referred him for an early childhood evaluation. Bo was diagnosed with ASD shortly after his third birthday. The family reported that when they heard his diagnosis, they were shocked and confused.

Bo demonstrated behaviors typically associated with ASD, including arm-flapping, difficulty with joint attention, being easily agitated, and having a strong preference for playing with small action figures. Initially, his grandmother shared that she was disappointed that Bo was the twin with a disability and said it would have been “much better if it were his twin sister, Chen.” The parents expressed that when he was diagnosed, they felt as though “the sky was falling down.” After the diagnosis was briefly explained, the family appeared more hopeful about Bo’s prognosis and agreed to start therapy. The diagnosing speech-language pathologist (SLP) shared information with Bo’s parents about Child Find: a legal mandate under the Individuals With Disabilities Education Act of 1990. Child Find offered the parents the option of having the school evaluate Bo to identify possible educational disabilities and to provide needed services, should he qualify. Bo’s parents were appreciative of the information but declined this option. The family, instead, chose to seek home-based services through a local private practice.

Bo was offered an English-speaking SLP paired with an interpreter. However, the family wanted to find a bilingual, Mandarin-speaking clinician. They used a database from their state speech-language-hearing association and found an SLP who, although not fully fluent, knew conversational phrases in Mandarin Chinese and was familiar with Chinese cultural practices. When the clinician asked whether her abilities would meet the family’s needs, the family reported yes, that they felt more comfortable having someone who “understood their culture” providing services for Bo. He received private speech-language pathology services for 1 hour, twice a week, in the home.

Over the past year Bo demonstrated gains in his communication skills, including the ability to point to desired objects, make a choice between two objects or pictures, and tolerate hand-over-hand assistance. Bo learned to use some gestures to communicate, including pointing; clapping; and the signs for no, yes, and water/drink. Bo used primitive vocalizations (grunting, squealing, screeching) and exaggerated facial expressions to initiate communication.

The treating SLP recently introduced a picture-based communication system with extensive research supporting its positive outcomes in developing verbal communication (Flippin, Reszka, & Watson, 2010). The picture-based system was used to observe Bo’s responses. With this system, Bo was successful at pointing to a desired object in a field of two. This particular strategy helped to decrease his frustration when trying to communicate with his family and his SLP. Initial picture-based trials were successful during therapy. As a result, the SLP scheduled a consultation with a speech-generating device (SGD) company to trial digital devices for presentation of pictures.

When the SLP shared this news with the family, they became very upset. The family did not like the idea of using a computer to talk for their son. They expected Bo to catch up to his sister and speak like her after a few years of therapy. They shared that previous doctors and therapists had told them that this was possible. The strongest opponent to the use of the SGD was Bo’s grandmother, who warned that if he used a device to speak

like this in public, he would bring dishonor on their family. She believed that Bo's autism was a punishment for the misbehavior of an ancestor. As the only male child, it was incredibly important to the family that Bo learn to communicate verbally, and they shared they did not want to send him to school with typically developing children until he could speak "normally." The SLP listened respectfully to the family's opinions. She restated their statements and asked whether they may be interested in taking the SGD home, "just for a trial." The family agreed reluctantly. When they returned for a follow-up visit, the device was still in the box, unopened. The SLP politely asked how the device trials went, and Mrs. Zhao shared that they would be suspending speech therapy for the moment to pursue other treatments including acupuncture and medicinal herbs. Bo and his sister would be staying home so his mother could teach them.

CRITICAL THINKING AND DEBRIEFING QUESTIONS

1. In what ways can an SLP support a family's cultural beliefs regarding their child's care?
2. How can the SLP work with this family to address the cultural conflicts that occurred?
3. What resources can the SLP provide to demonstrate how SGDs can support Bo in his communication?
4. What are ways that evidence-based practice and CAM or other holistic approaches can complement each other during treatment?

COMMENTARY

According to recent Centers for Disease Control and Prevention data, about one in every 59 children has been identified with ASD (Baio et al., 2018). As awareness of autism increases, it is likely that the identification of children with autism will also increase. Over the years, early identification of autism has seen a dramatic increase, with some countries identifying cases relatively recently, such as in China where the first cases of autism were not diagnosed until 1982. Programs providing autism services to children and their families in China were not available until the 1990s. Although awareness about autism in China is growing, families with children who have developmental disabilities (autism included) continue to report the need for more support, professional help, and information about how to raise their children (S. Y. Wong et al., 2004).

Understanding cultural practices and views regarding Chinese beliefs about developmental disabilities, especially autism, is critical in working with the Zhao family. Their cultural background influences the way they view autism and the impact they feel it may have on their lives and Bo's success in life. In this case, Bo's family was candid about their feelings of disappointment especially that Bo, their male child, was diagnosed with ASD. Historically, China has enforced a family planning policy that restricted the size of families to one or two children per couple, with male children more highly prized. This policy was revised in 2013 to allow parents who were only children to have a second child (Bloomberg News, 2020). It can also be common for Chinese families to believe that disabilities are caused by fate. Understanding cultural beliefs and views surrounding disability provides a strong foundation for a treating clinician when working with all families.

Family involvement is critical when working with students who have communication disorders, and research has indicated that quality educator-parent collaboration is neces-

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sary to establish effective educational programs for students with disabilities, including ASD (Fish, 2008). A collaborative approach to decision making would have involved the SLP making the decisions with the family (Smith, Summers, Mueller, Carillo, & Villaneda, 2018) instead of for them, as occurred in this scenario. This approach may have resulted in a more effective treatment plan that combined traditional and nontraditional clinical

methods and demonstrated respect and value for the family's treatment desires. Some families may use alternative and holistic medicine as a primary approach to treat illness and disorder. Other families may use it as a supplement to other European American methods. Bo's family made the decision to use alternative and holistic medicine as a primary intervention for ASD when they became dissatisfied with the progress Bo was making with traditional speech therapy. Starting the therapy process in a collaborative way may have allowed the SLP and the family to have a more productive conversation regarding their concerns about Bo's progress and may have included opportunities to review treatment options and timelines that could better align with the family's expectations of Bo developing verbal language. It may also have provided an opportunity to consider ways that CAM could complement the evidence-based interventions provided by the SLP.

Collaborative decision making also considers the communication styles and language competencies of family members. It is possible that the parents and grandmother did not fully understand Bo's diagnosis and prognosis as explained by the pediatrician. Through collaboration, the SLP can assist families in understanding medical terms and technical concepts associated with diagnosing disorders and prognoses; the SLP can also help the family determine therapy approaches that use bilingual materials, interpreters, or both. This understanding can also provide for a better cultural foundation in working with the family.

The family may have been disappointed that their SLP did not directly align with their cultural beliefs, even though they had sought out a Mandarin-speaking clinician. Although the SLP was Chinese, her individual culture appeared to align more with standard European American values and practices. Discussing cultural beliefs and values before starting services could have shed light on this difference in expectations.

CRITICAL THINKING AND DEBRIEFING RESPONSES

1. In what ways can an SLP support a family's cultural beliefs regarding their child's care?

First, SLPs can research a client's culture before meeting with them to have an idea of general practices. If an SLP does not know a client's cultural background before the meeting, they can conduct a thorough interview and case history to provide more in-depth cultural information from the client. The client in this scenario noted that they hoped to return to China within the next 5-10 years. This information may have been an indication that the family valued their Chinese heritage and language even though they did not openly discuss their desire. The family also rejected the offer of an English-speaking clinician paired with an interpreter and chose a Mandarin-speaking SLP. By choosing a Mandarin-speaking SLP, the family may have been indirectly indicating that the knowledge of, respect for, and integration of the family's cultural practices were important for effective intervention.

A study on the decision-making processes of parents who had children with ASD and how

they chose interventions was completed by Finke, Drager, and Serpentine (2015); they noted that parents considered a variety of sources when making their intervention decisions for their children, including professional recommendations and anecdotal information from other parents through support groups or online, weighing each piece of evidence equally. This study also highlighted the need to have a collaborative decision-making process for parents because they felt solely responsible for the intervention decisions for their children. It may be helpful to demonstrate processes that can help families objectively assess information using evidence-based practices to help parents increase confidence in the decisions they make.

Given this information, the SLP may have avoided some possible conflicts by engaging the family in collaborative decision making. For most children, and Bo specifically, home is where most of their communication will occur. For that reason, it is paramount that his family supports his treatment plan and is involved in its design. If a family does not agree with a treatment approach, it is up to the treatment team and family to decide on another approach based on available evidence and the child's needs. The SLP should always strive to address potential conflicts by considering the family's and client's needs and preferences.

2. How can the SLP work with this family to address the cultural conflicts that occurred?

In this situation, the SLP could take several steps to address the cultural conflicts. The SLP could research and review literature that discusses traditional Chinese views of illness and disorder. These resources may include articles that discuss traditional Chinese views of ASD and the history of its treatment. The SLP may ask the family to share information with her about their cultural practices and beliefs in an attempt to integrate their traditions and practices into the therapy session.

For instance, in many Chinese families, it is common to place great value and deference to the opinion of elders (Battle, 2012). Traditionally in Chinese families, the decision maker is the father, whereas the mother is charged with the responsibility for care and education. In Bo's case, the decision makers were his parents and grandmother, as a respected elder. Additionally, his mother may have felt shame because of his disability (Richmond, 2011). Understanding the cultural dynamics at play could help the SLP when presenting diagnoses and prognosis, including information about programs available in the United States and possibly meeting with other families they could connect with. The shame that Bo's mother may feel has also been illustrated with families in China who do not send their children to school for fear of "losing face" if they attend school with "normal" children (Liu, 2003).

3. What resources can the SLP provide to demonstrate how SGDs can support Bo in his communication?

Although Bo's family rejected the idea of using an SGD, research overwhelmingly points to the use of SGDs as beneficial for nonverbal children. Kasari et al. (2014) demonstrated that intervention for minimally verbal, school-age children with ASD that included the use of an SGD improved their spontaneous output of novel utterances when compared with interventions that did not use SGDs. Drager, Light, and McNaughton (2010) demonstrated that augmentative and alternative communication (AAC) use can lead to increases in receptive vocabulary in young children. Providing this research to the family could help them to be informed decision makers in the care of their child. The SLP could also share

that using an SGD does not affect the motivation to use natural speech, and when therapy focuses on natural speech in conjunction with AAC use it can facilitate the production of natural speech (Millar, Light, & Schlosser, 2006).

To encourage maintenance of the home culture and language, the SLP may refer to research that cites specific considerations for programming an SGD in Chinese (Oxley & Ma, 2020). Smith and colleagues (2018) confirmed that the home language should be supported either directly or indirectly through intervention. This can be done through the use of a bilingual clinician or interpreter or by training caregivers through collaboration. These multicultural and multilingual approaches help to ensure the best treatment options for children who speak multiple languages. Providing the family with evidence that children with ASD who are bilingual are more flexible thinkers and that using the device can promote verbal bilingual output may provide the family with additional hope. Helping parents and families understand that total communication (spoken, gestured, or through a device) is the goal may also help bridge the gap between the family's ideas about treatment, ways to increase Bo's communication skills, and the SLP's ideas.

4. What are ways that evidence-based practice and CAM or other holistic approaches can complement each other during treatment?

In Bo's scenario, CAM is important to the family and something they have chosen as an alternative to the treatment practices selected by the SLP. A study in China demonstrated that 47% of parents of children diagnosed with ASD wanted to use both CAM and Western medicine (V. C. N. Wong, 2009). A review of multiple CAM treatments (Brondino et al., 2015) indicated that there was no conclusive evidence for the efficacy of CAM therapies in ASD. The authors suggested that all practitioners encourage patients and their families to discuss the safety and efficacy of all CAMs. CAMs can be used to augment conventional treatment but not as a replacement. A family may choose to use massage to reduce anxiety and enhance positive responses to behavioral and educational treatments. If interested, families should be advised to try one CAM at a time and consistently monitor any clinical changes or adverse responses.

In this scenario, the SLP may have asked more about the CAM treatments Bo was receiving and could have suggested a meeting with his healers to integrate their work into the speech sessions. The SLP can help to create a nonjudgmental environment and discuss with families the advantages and disadvantages of using CAM on the basis of empirical evidence. The SLP could use picture boards or program the SGD device with words for herbs, food, or other CAM that acknowledge this practice. It is important when working with all families to provide opportunities for them to share their cultural practices and beliefs at the onset and throughout intervention. This collaborative approach emphasizes the partnership when executing treatment and can lead to positive clinical outcomes.

TAKE AWAYS

- Clinicians should be aware of the many ways culture influences a family's decision-making process and develop collaborate and flexible plans that are congruent with a family's cultural practices.
- Recognizing alternative medicine in therapy approaches can result in positive and productive therapist-client relationships.
- Sharing information about families' and clients' use of CAM with members of the

interprofessional team improves intervention processes and clinical outcomes.

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ADDITIONAL RESOURCES

AUTISM IN CHINA

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BILINGUAL AUGMENTATIVE ALTERNATIVE COMMUNICATION (AAC) APPS: PORTLAND STATE UNIVERSITY

<https://sites.google.com/pdx.edu/multicsd/adult/other-toolstopics-for-slps/bilingual-aac-apps>

PRACTICE PORTAL ON AUGMENTATIVE ALTERNATIVE COMMUNICATION (AAC)

https://www.asha.org/PRPSpecificTopic.aspx?folderid=8589942773§ion=Key_Issues#AAC_Myths_and_Realities

SPEECH-GENERATING DEVICES

- An, S., Feng, X., Dai, Y., Bo, H., Wang, X., Li, M., . . . Wei, L. (2017). Development and evaluation of a speech-generating AAC mobile app for minimally verbal children with

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