

HOW CULTURAL VALUES INFLUENCE DIAGNOSIS, TREATMENT AND THE WELFARE OF FAMILIES WITH AN AUTISTIC CHILD

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Abstract

While the cultural diversity in the United States is simultaneously increasing with the rate autism is being diagnosed, it's imperative that educators understand the role of culture. Religion and family values determine how a culture perceives etiology, signs and symptoms, diagnosis and treatment of autism and thus determines the welfare of families.

Introduction

When faced with a life changing event, what plays the biggest role in how one interprets the new situation? Family and cultural values shape our thoughts and perceptions of new events more than any other factor. In fact, family is the most basic unit of socialization, as well as important in defining roles and rules of conduct. According to Mandell and Novak (2005), "Culture is a group of people's way of life, consisting of predictable patterns of values, beliefs, attitudes and behaviors which are past down through generations" (p. 110). Cultural variables can be crucial in determining how well a family accepts a medical diagnosis and thus the outcome. It is imperative to take culture into account when establishing a treatment plan for a devastating disability such as autism. Autism is a disorder present at birth or may be diagnosed before age three in which behavioral, communication and social abilities are impaired (Wilder, Dyches, Obiakor, & Algozzine, 2004). There is no cure for autism and it is considered a severe disability because of the life long effects on individuals and families (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). Parents of autistic children suffer from an increase in stress, a poorer quality of marriage, depression, anxiety and increased anger when compared to parents of typical children (Magana & Smith, 2006). As a clinician, it's important to be aware of how cultural values, such as religion, can be influential in the diagnosis, treatment and welfare of families with an autistic child. Our job is to open our minds to what we can learn from other cultures in order to better meet the needs of our autistic children.

Etiology

Autism has only been formally recognized since the 1940's and we still have many unanswered questions (Silberman, 2001). People of Anglo descent most commonly believe the etiology of autism is genetic or environmental. Some experts in the Anglo group feel that highly intelligent families with a propensity for science, math, literature or art are more likely to produce offspring with autistic features (Dyches et al, 2004). For example, Thomas Jefferson and Albert Einstein are known to have suffered from autism. A second theory that is popular but controversial in the Anglo community is the idea that autism is related to environmental factors. Autistic children tend to have high levels of mercury in their blood. It's thought that the mercury in their body is from the multiple immunizations they receive as

infants. Mercury is used in vaccines as a preservative to extend their shelf-life without refrigeration. As you can see Anglos are more likely to believe in physical reasons for the cause of autism. Conversely, African-Americans are more likely to believe in non traditional factors, such as diet, to be the cause of autism. Additionally, Asians and Navajo Indians are less likely than African-Americans to believe there is a physical cause for autism. They frequently feel an autistic child is a punishment from God. Also, they may feel that autism is due to parental missteps such as witch craft, the mother seeing a dead animal while pregnant or conceiving a child by a man other than her husband (Dyches et al., 2004). Latinos tend to have a more optimistic view of autism. They feel that their autistic child is a gift from God and this is an opportunity to become a better person. Even if we don't fully understand why autism occurs, it's in the best interest of the child to view the diagnosis as a chance to make a difference in the world. This type of acceptance has a better chance of leading to a successful outcome.

Ultra Orthodox Jewish families living in Israel have a theory on etiology involving three aspects. First, the naturalistic view relates labor difficulties, immunizations and genetics as the reason for autism (Shaked & Bilu, 2006). The psychological theorists believe that parental neglect or teasing from other children is responsible for autism (Shaked & Bilu, 2006). The final theory is metaphysical which purports the idea that "it was God's will" (Shaked & Bilu, 2006). Those of this belief feel that autism is the transmigration of the soul which is the Jewish form of reincarnation. The positive aspect of this theory is that it gives the child's soul, from a previous life, privileged status. It also gives the parent meaning to the diagnosis and a mission in life. Mothers who believe in the metaphysical cause experience more spiritual growth. Western ideology views the brain as the central organ of the body whereas Jewish ideology views the soul as the central organ in a person (Shaked & Bilu, 2006). While the brain of an autistic child may not be intact his soul is unblemished. This theory denotes the pure holiness of autistic children. Personally, I have always felt special needs children have a higher spiritual connection than typical children. As stated by Shaked and Bilu (2006), "Autistic children get to see the divine presence, their spirit sees it because they do not care about their bodies, they are all spirit" (p. 14).

Diagnosis

Diagnosing autism can be a difficult and lengthy procedure; however for some families of minority cultures it can be even more challenging. Clinicians have different expectations when treating African-American patients compared to Anglo patients. Physicians screen for Autism Spectrum Disorders with Anglo patients at an earlier age compared to African-American patients. This could be related to the fact that African-American families are less likely than Anglo families to have regular visits with a primary care physician. It's important to have a relationship established with a pediatrician because they will be more likely to notice developmental milestones. As a result African-American children are diagnosed with autism one and one half years later than Anglo children. Once the African-American child is in treatment they need three times the number of visits and three times a longer period of time before given an autism diagnosis compared to Anglo children (Mandell & Novak, 2005). Once the diagnosis is made it's important to be aware of cultural values that can provide support for the family.

Influence of Religion

The role of religion in all cultures provide a major source of support for autistic families including emotional comfort, strength for daily tasks, meaning to the diagnosis and hope for the future. Catholicism, the dominant religion in the Latino culture, plays a major role in the acceptance of an autistic child. The majority of Latino mothers view their role similar to that of the Virgin Mother, one of

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sacrifice and dedication (Blacher & McIntyre, 2006). Their faith gives them strength, patience and a feeling that God is with them on a daily basis. Because of God's presence Latino parents feel less depressed, have the strength to accomplish daily activities pertaining to their child and they have faith their child's condition will improve. However, it's interesting that Latino mothers report higher levels of faith than Latino fathers, 70% and 54% respectively (Skinner, Correa, Skinner, & Bailey, 2001). This could be due to the fact that mothers are the primary caregivers in the Latino culture. These parents also feel they become more religious after the child is diagnosed. Maria, one of the mothers interviewed in Skinner's research (2001) stated, "I have faith that God will not abandon me. I have faith that God is with her and with me". Fifty-five percent of Latino parents feel that their child's autism is a sign from God. Of these parents, 68% feel that it's a blessing from God or a sign of their worthiness as parents. Eleven percent feels that the autistic child is a test for them to demonstrate their worthiness. A small 3% of parents feel that their child's diagnosis is a punishment for past sins (Skinner et al., 2001). The Anglo culture can learn a lot from Latinos in the positive way they frame their child's diagnosis.

Other minority cultures also have positive outlooks on autism due to their strong faith. The parents of the Ultra Orthodox Jewish community feel God will give them the strength to handle any situation. They have a saying in their culture, "Those who do not believe have no answers and those who do believe have no questions" (Shaked & Bilu, 2006). This statement has a very calming effect. The African-American culture views all children as important members of society (Dyches et al, 2004). Also, the Native Hawaiian culture feels that children are valued members of the community regardless of their abilities. Native Americans focus on the abilities of their children rather than their disabilities (Dyches et al, 2004). Again, the minority cultures have a lot to offer the Anglo culture in regards to accepting autistic children.

Signs and Symptoms

Culture also affects the way parents view signs and symptoms of autism. Anglo parents are more likely to see general developmental delays or regression of language before social issues (Mandell & Novak, 2005). This could be due to the fact that language is emphasized in the Anglo culture more than social skills. It's not uncommon for parents to make excuses for poor social behavior. On the contrary, Eastern Indian parents notice social problems in their children before speech issues, 45% and 32% respectively (Mandell & Novak, 2005). This could be related to the high value the Indian culture places on social conformity. In fact, Indian parents are not alarmed when their three year old boys are not speaking yet because they feel girls talk before boys (Wilder et al, 2004).

The Role of Family

Other than religion, family cohesion and support are two of the most important cultural values for Latinos. They embrace the "Marianismo" ideology. This means they view raising a family in terms of self sacrifice or charity in which they expect to give more than they receive. As a result they find greater satisfaction in child rearing compared to the Anglo culture (Blacher & Mandell, 2006). The positive perception and the increased number of family members involved in child care results in a decrease in the amount of depression in Latino mothers of autistic children compared to Anglo mothers. The Latin culture also incorporates the idea of "Familismo" which is, as stated by Magana et al (2006), "...the strong feeling of loyalty, reciprocity and solidarity among family members" (p. 347). A common theme of Latinos is "we take care of our own". However, because families tend to rely so much on one another

they often do not seek professional help. This can be a detriment to the successful treatment of an autistic child.

Family Welfare

Across cultures the female is viewed as the main care taker of the child. However, depending on the cultural values the mother's well being can vary. As stated previously, Latino mothers believe in "Marianismo" which is trying to emulate the Virgin Mary. These mothers view motherhood as their main role in life. Because of this philosophy, Latino mothers are less angry, less fatigued, feel more environmental mastery and have better overall psychological well being when compared to Anglo mothers (Magana & Smith, 2006). What's fascinating is that the Latino mothers have overall better well being despite being younger, having a lower income, less likely to be married, less likely to be employed and having poorer health than Anglo mothers. This is a true testament to the importance of religion and family in cultural values.

Unfortunately, not all cultures have positive values when evaluating autistic children and this can led to difficulties for the well being of mothers. The most surprising research points out that the Greek culture has a negative attitude toward intellectually disabled children. Many Greek mothers feel a prolonged sense of loss, despair and hopelessness if they have a child who is intellectually disabled. This loss frequently leads to decreased self-esteem, shame, guilt and an increase in marital problems. In the Greek culture one is not fully accepted by society if one's child is disabled. Women often find themselves in social isolation. In order to have psychological survival one must have connection. This is a huge loss for these women. It's not uncommon for someone to make the sign of the cross if they see a disabled child. The Greek culture places higher importance on social status compared to the Anglo culture (Argyarakouli & Zafiropoulou, 2003). This leads the Greek mothers to a feeling of isolation.

However, some aspects of the Greek culture lead to positive self-esteem for the mothers. Studies show that mothers who have a higher education and more qualifications have an increased self-esteem (Argyarakouli & Zafiropoulou, 2003). This could be due to a more realistic view of their child's situation and the ability to seek out appropriate care. Also, positive self-esteem was associated with larger family size. This suggests the idea that the typical child will "make-up" for the disabled child.

Treatment

As a clinician, one must keep in mind that the magnitude of an autistic diagnosis may overshadow the cultural issues but cultural values must be kept in mind in order to have a successful treatment plan. Cultural mores may determine which treatment goals families will accept and which goals they will decide not to work towards. Also, parenting style will determine which goals are viewed as important. Anglo families value individualism whereas minority cultures prefer to teach children collectivism. The collective theory places a high value on interdependence, cooperation and compliance (Trembath, Balandin, & Rossi, 2005). A common goal for autism is to teach independence through academic learning, language, communication and decreasing behavioral issues. This goal is clearly of an Anglo view point but one can imagine how minority cultures may not accept this type of treatment plan.

With reservations, Ultra Orthodox Jewish families will seek advice from the medical community first and then seek council from a rabbi. However, if the medical advice conflicts with the advice of the rabbi they will follow the religious recommendations. Interestingly, if the family sees the child making progress, they will attribute the success to God's intervention rather than a professional treatment (Shaked & Bilu, 2006). Latino children are six times more likely to use non-traditional treatment

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methods compared to Anglo children (Mandell & Novak, 2005). African-American families seek help from family, friends and church groups before they will get professional help for their child (Dyches et al., 2004). Finally, South Asian families are hesitant to seek professional help if their autistic child is a girl for fear of repercussions if they want her to have an arranged marriage (Dyches et al., 2004). As you can see, cultural values play a major role in the treatment of autistic children.

Conclusion

Cultural values shape our thoughts and feelings about ourselves and the world around us, including how we deal with autism. As clinicians, it's crucial to understand what's important to our clients as a treatment plan is established. We can become more effective in treating autistic children by becoming aware of how some of the minority cultures accept disabled children. As stated by Kozel (Wilder et al., 2004), "Children, whatever the color of their skin or the condition of their birth, bless us by their mere existence on this earth. The great unanswered question of our age is whether our society plans to bless them in return" (p. 109).

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