

Cultural Belief Systems in Autism and the Effects on Families

Jaclyn Ecker
Barnard College
Cultural Psychology
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Autism has become widely known as the developmental disease defined by characteristics of impaired social interactions, such as lack of verbal communication and lack of eye contact, and disruptive behavior, such as repetitive actions and tantrums. Although the characteristics of autism are commonly found across cultures, the way a culture interprets the causation and constructs the experience of autism as an illness or not varies greatly. As a whole, families with autistic children have been perceived by their societies in different ways causing the families to be shaped by the beliefs systems of autism specific to their society. The different social implications of autism, the effects these implications have for a family, and the way in which the family responds to cultural beliefs about autism will be explored in families from South Korea and China as well as in Muslim families from Pakistan and Bangladesh, and Ultraorthodox Jewish families from Israel.

The Korean word for autism, *Chapae*, translates to “being closed in on oneself” and has been officially diagnosed since 2000 (Gringer 2007). The name stems from the withdrawn behavior that derives from the idea that autistic individuals are so involved in their own world that they are unaware of what is going on around them in the real world. The cultural views of autism in South Korea are very different from those of Western societies. To understand how autism is seen in South Korea, we must understand that autism, as a disease, carries different meanings in different societies, and results in a variety of different experiences of autism, as illness, across cultures.

In Western medicine, an illness is seen as an individual's problem caused by defects in the function of his or her body leading the individual being seen as a variant from the norm (Kwang Hwang & Charnley 2010). Thus, illness in Western medicine results in barriers, stereotypes, and personal suffering that the individual must fight to overcome or continue to suffer through. Western medicine has defined autism as a developmental disorder resulting from cognitive impairments and manifesting in various characteristics. The cause of the cognitive impairments in autism are unknown and widely debated. Autism is perceived in Western cultures as an incurable, disabling illness in which individuals are limited in many aspects of their daily lives.

While many people in South Korea do recognize autism as a cognitive disease of the individual, they also believe in autism as a disease of the family. The cultural belief about autism is that the cause of the cognitive disease is a result of punishment for the family's previous sins, the mother's neglect of the child, or wicked ghosts (Kwang Hwang et al. 2010; Grinker 2007). Grinker (2007) states that even in South Korean psychiatry, psychiatrists were more likely to conclude that "bad" mothers, mothers who are depressed and withdrawn, caused the child to become autistic, rather than considering the possibility that dealing with the hardships of having an autistic child for so many years may have caused the mother's depression. These psychiatrists also argued that the progress of Korean women in the work place caused them to neglect their child, causing their child's autism. This last statement reinforces the role the mother is expected to hold in South Korean society as the caretaker and not the breadwinner. While mother's neglect as the cause of autism is no longer as common as it used to be, the fact that this exists as a cause shows how culture can shape the beliefs about certain illness.

A mother's neglect and the presence of wicked ghosts are second to the most common belief for the cause of a child's autism -- punishment for the family's previous sins. In the majority of accounts, the reason a family has an autistic child is because the family is being punished for the bad things that they or their ancestors have done in the past (Kwang Hwang et al. 2010). Because of this stigma, there is a lot of discrimination not only of the autistic child but also of the family as a whole because the family is seen to be a part of the illness. Fear of discrimination and the stigmas surrounding disabilities lead many families to refuse to go to professionals to receive a diagnosis for their children. By refusing to be diagnosed, families can avoid having disability identities.

For families with a child diagnosed with autism in South Korea, having a disabled family member means having a disabled family. The concept of the disabled family is evident through *second experience*, in which families with an autistic individual feel abnormal compared to ordinary families because of the experiences they have with their autistic family member (Kwang Hwang et al. 2010). One way in which South Korean families feel abnormal from ordinary families is by *jjockpalida*, or losing face (Grinker 2007). Losing face is similar to being humiliated and dishonoring one's family name.

Not losing face is very important to South Korean families. Siblings of autistic children avoid talking about their autistic sibling to friends and strangers to prevent themselves from losing face or receiving pity (Kwang Hwang et al. 2010). Examples of losing face are evident in a study by Kwang Hwang et al. (2010) in which siblings of autistic children were interviewed. One example occurs when a girl's best friend tells the girl that she never understood why the girl studied so hard until she found out that the girl's brother was autistic. Other examples included public outings in which the autistic

child starts to misbehave causing the family to lose face. Loosing face is one way that family illness is reinforced through *secondary experience*.

In South Korea, families that have a child diagnosed with autism choose to cope in a variety of ways. Some parents deal with the stigma surrounding autism by choosing to take their autistic child out of the house as little as possible (Kwang Hwang et al. 2010). A great deal of shame and loneliness are associated with this type of coping mechanism as the family is unable to escape the cultural belief systems and thus is forced to be isolated, keeping a secret life at home (Kwang Hwang et al. 2010; Grinker 2007). In these and other families, parents and siblings keep peace of mind by justifying a lifestyle that is abnormal and strange to others. Many siblings reported knowing that they were strange in the eyes of the community but said that since being strange was a daily encounter for them, it was more ordinary to them than it was strange because they didn't know any other way of life (Kwang Hwang et al. 2010). Using this method, family members were able to make sense of and cope with their abnormal lives.

Living in urban areas where cultural stigmas were the most intense caused many families to seek a change in lifestyle. Many South Korean families found it is easier to raise an autistic child in rural setting rather than in urban cities, and thus many families either give up their jobs and moved to a village, or send their autistic child to live with parents or grandparents in a rural area (Grinker 2007). Grinker (2007) found that in South Korean villages, less pity and discomfort was evident in talking with people about autistic children, while in cities, it was reported that many people refused to even speak with them about autism for fear of further shaming the autistic child's family.

Unlike in Western societies, in South Korea autism is viewed as curable. For the family, recovering from autism meant restoring face to the family's name. Consequently, in many families there was a strong push for therapy. Siblings felt that if they worked hard to teach their autistic sibling to act appropriately or talk, they could help restore the family's face (Kwang Hwang et al. 2010). This line of thinking led many siblings spend a lot of time with their autistic brother or sister to try and help him or her recover.

Recovery is not the only means of restoring face to a family. This is evident in the example of Seung-Mee, a mother of an autistic daughter in South Korea (Grinker 2007). Seung-Mee believes that *han*, or her ancestors' shame and misfortune because of wrongdoings that are passed down from generation to generation, has caused her daughter's autism. Seung-Mee, like many Koreans, believes that by using *chonghan*, a positive outlook, she can overcome both the difficulties of autism and her family's *han*. By employing *chonghan* in her daily life, Seung-Mee has found a way to cope with the difficulties she faces daily with her daughter's autism as well as a way to work to restore face to her family through a positive mindset. Though Seung-Mee deals, like most parents, with loneliness and isolation, she hopes that one day she can restore face to her family's name and prevent the inheritance of *han* from being passed down to the next generation (Grinker 2007).

Many of the ideas that compose the cultural beliefs in South Korea are also evident in China. Autism was first diagnosed in China in 1982. The Chinese word for autism translates in English to "lonely disease." The translation of the Chinese word for autism can be reflective both of the individual with autism, who is in a world of his own, and of the family with an autistic member, as the family will become somewhat isolated

from society. Similar to South Korea, the isolation experienced by family members in China is due to negative cultural views of disabilities. Some studies found that Mainland China had the most negative attitude towards disability of any country in the world (Fond & Hung, 2002). The negative attitudes towards disabilities and autism lead to a lot of discrimination towards families with disabled individuals due.

Just like in South Korea, for the majority of autistic families in China, disability is seen as the result of previous wrongdoing by parents or ancestors -- primarily of the mother (McCabe 2007). The parents or ancestors are therefore blamed for having brought autism to their family. The stigma around autism has resulted in discrimination not only of the autistic child, but also of the family as a whole (McCabe 2007). A traditional Chinese saying exemplifies the relationship between the family and the autistic child. The saying goes, "In the first 10 years, observe the father and love the son. In the last 10 years, observe the son and respect the father" (McCabe 2007 p.43). In other words, in the beginning of life the father's influence is what shapes the son into a son to be loved, and at the end of life how well the father shaped the son to succeed will determine how well the father should be respected. With autism, the later success in the child's life will be very limited because of his sickness. Consequently, some parents try to hide their autistic children from society altogether to prevent the loss of respect of the father as well as the respect of the family in society.

Similar to South Korean culture, those in Chinese culture also have a fear of losing face. Many Chinese parents refused to put their children in general education classrooms despite the recent opportunities for inclusive schooling because parents believed that if their child was in a classroom with normal children, then their child

would not succeed with his or her classmates and therefore cause the family to lose face (McCabe 2007). Because of the stigma and blame surrounding disabilities and a fear of discrimination, many parents refused to seek professional help, leaving their child undiagnosed (McCabe 2007). At the same time, many parents who have found out that their child is autistic not only keep this information from society as a whole, but also keep the diagnosis from their extended family, fearing that one side of their family might blame them or the other side of the family. Just like in South Korean cities, families in China also reported moving to rural areas where stigmas about autism and disabilities were not as intense (McCabe 2007). In Chinese and South Korean cultures, the stigma surrounding autism and the implications for families themselves proved to be overwhelming for many families, causing them to result to extreme coping methods, where they were either forced to hide their home life with their autistic child or change the way in which they lived altogether.

These extremely negative views of autism were not constant across all cultures, and in fact completely opposed the views of Pakistani and Bangladeshi Muslims. These Muslims believed that an autistic child was a pure and innocent gift from Allah (Jegatheesan, Miller and Fowler 2010). Beliefs about the family's role in autism were also very spiritual. Parents believed that Allah chosen them to be the parents of an autistic child because of their love, hard work, dignity, and ability to nurture (Jegatheesan et al 2010). Allah was believed to help the families gain a deeper understanding of having an autistic child, and thus autism brought them closer to their religion.

While Allah gave the child to the family because of their caring nature, views on the exact reason for this choice varied from Sunni to Shiite Muslims. Sunni Muslims

believed in fate as an unquestionable act of Allah predetermined before the birth of the parents, where Shiite Muslims believed in reincarnation as the reason for being chosen to care for an autistic child (Jegatheesan et al. 2010). In reincarnation, the autistic stage of rebirth was seen as the “last rebirth” before the soul attains salvation. The last stage of rebirth is the purest form a human can have, as they are unable to commit intentional sin. It is also believed that mother and child are paired together because they had unfinished business between the two in their past life (Jegatheesan et al. 2010). Despite the different views on the exact causation of the child’s placement in the parents care, beliefs about the role the family must play in the child’s life and the different ways of ensuring these roles are the same for Sunni and Shiite Muslims.

Pakistani and Bangladeshi Muslims believed that Allah put the child in their care not only because of fate or reincarnation, but also because Allah was also believed to be testing the family to see if they would be moral or immoral to the child (Jegatheesan et al. 2010). In addition to inhumane treatment, immoral behavior also constituted falling into depression or resulting to addiction to cope with their life. The parents are expected to protect the child from all harm and maltreatment. Since the child is pure, he or she cannot defend him or herself. In order to protect their child from the maltreatment that other classmates may inflict, often times mothers would ride the school bus to school with their child to assure the safe delivery of their child to the teacher’s care (Jegatheesan et al. 2010). They would also stop by randomly at school to make sure their child was taken care of properly by the teachers (Jegathesan et al. 2010). Extreme examples showing the dedication of the mothers to their child’s well-being were common in the literature.

Mothers did their best to ensure that they were allowing for the child to reach his full potential as Allah wanted.

Siblings also played an important role in the lives of an autistic child. Siblings were to protect the autistic child when their parents were not around, and were to become the caregiver of the autistic child when their parents died (Jegathesan et al. 2010). In an effort to take on this role for the autistic child, research reported many instances of siblings getting into fistfights to protect their brother or sister from being bullied or teased (Jegathesan et al. 2010). Given the extreme positive outlook on autism and special meaning of the autistic child held by society, the teasing and bullying behaviors of other children can be attributed to the fact that these kids did not fully understand the meaning of this disorder for their culture. Similar to the children questioned in Kwang Hwang et al. (2010), Muslim siblings also reported trying to teach their autistic brother or sister to behave and to speak in an effort to normalize them so others would not find out the brother or sister was autistic, thus preventing them from being teased (Jegathesan et al. 2010).

As opposed to South Korean and Chinese families, Pakistani and Bangladeshi Muslims emphasized the importance of full inclusion into the extended family and community. Parents worked to immerse their child into every aspect of life, from huge family weddings to individual daily prayers. Fathers took a great interest in teaching their child to mimic prayer behaviors so that the child could be incorporated in the spiritual aspects of their religion (Jegathesan et al. 2010). Fathers even brought their children to mosque to pray. If an autistic child misbehaved in mosque, it was not seen as offensive to the community (Jegathesan et al. 2010). This is because the community itself is obligated

to assess, assist, respect and give equal opportunity to people with intellectual disabilities (Morad, Nasri, & Merrick 2001). The full immersion of an autistic child into family and community traditions shows the dedication of the family to the spiritual health of the child.

Pakistani and Bangladeshi Muslims also believed Allah wanted the parents to help enhance the child's abilities. This was done through various forms of therapy. Islamic society believes that the best therapy is one that enhances the health, psyche and soul of an individual (Morad et al. 2001). However, in seeking services from Western therapies, families were angered by the focus of Western medicine on the limitations of an autistic child (Jegathesan et al. 2010). Fathers refused to work with professionals who focused on the weaknesses of their child instead of their child's potential, and thus sought to find a therapist that would focus on the positive and not the negative (Jegathesan et al. 2010). Pakistani and Bangladeshi Muslims also turned to prayers and pilgrimages to seek help in having their autistic child reach his or her full potential and complete his or her life mission (Jacob 2004). The spiritual belief systems of the Pakistani and Bangladeshi Muslims greatly contrast with those of the South Korean and Chinese in that they focus on the child as a gift from Allah and therefore feel that they have been blessed with such a child, creating a positive outlook on autism.

While religious beliefs also govern the Ultraorthodox Jews' views of autism in Israel, a more complex relationship exists between Western medicine and Ultraorthodox Jewish spiritual beliefs. Ultraorthodox Jews live by strict version of *Halacha*, or Jewish law, in which they live as their ancestors did before modernization began "polluting" society (Shaked & Bilu 2006). The complex relationship exists because Ultraorthodox

Jews believe in both naturalist and metaphysical explanations for the causation of autism. Similar to the ways the South Korean families believed that autism was due to cognitive impairments, which were caused by previous family wrongdoings, the Ultraorthodox Jews believe that autism is caused by cognitive impairments which are caused by God's will. Ultraorthodox Jews believe that God's will caused these cognitive impairments for a reason that is too profound for the parents or any other humans to understand but it is for the best (Shaked et al. 2006). So therefore, metaphysical beliefs have priority over naturalistic beliefs.

Like the Pakistani and Bangladeshi Muslims, Ultraorthodox Jews believe that the physical characteristics of autism create a body, but that the soul of the individual with autism is actually of higher standing than most and thus cannot commit sin (Shaked et al. 2006). This is believed because through the transmigration of souls, the things that made them sin in the previous life were not transferred into the new life, therefore providing autistic children with an opportunity to rectify their righteous souls from the past life (Shaked et al. 2006). Thus, some families believed that autistic children came back to earth to carry out an important religious mission (Shaked et al. 2006).

Believing in a dual system of Western medicine and Ultraorthodox Jewish beliefs for the cause of autism, Ultraorthodox Jews seek both spiritual and Western medicine techniques for therapy. This responsibility falls on the mother, as the father spends most of his time working or studying scripture. Mothers initially seek Western medical cures in neighboring town in Israel for diagnosis and therapy, however the mothers are skeptical about whether these types of interventions work, so they also seek out spiritual interventions from within their communities, such as participating in exorcisms, drinking

holy water, or changing a child's name (Shaked et al. 2006). Because of their strict religious beliefs, responsibility was not solely limited to the family or the mother. In order to participate Western medical practices, mothers had to attain the permission of the rabbi (Shaked et al. 2006). Having a hierarchical system can relieve some of the stress a mother might feel when making life decisions about surgery or therapy, however it also limited the mother's ability to control the situation for what she thought was best for her child.

Cultural beliefs regarding suffering affected the way in which the family understood autism. Ultraorthodox Jews believe that suffering is an inevitable aspect of all human life. Therefore, suffering was not seen as a pure negative or an avoidable aspect of life, but rather as a necessity that would allow Ultraorthodox Jews to better understand God and serve in his name. For families with an autistic child, autism was seen as their family's form of suffering, which they must undertake because it is God's will. Findings showed that families believed that God not only granted them the autistic child that is the cause of their family's suffering, but God also granted them the tools to get through these hardships (Shaked et al. 2006). Because of the belief systems about autism of the Ultraorthodox Jews, the spreading knowledge of these belief systems in the community, and the known cases of autism in their community, Shaked et al. (2006) found that stigma surrounding the family had decreased, and therefore fewer families in the Ultraorthodox Jewish community hid their children from the public.

Although autism is distinctly defined by its characteristics that can be seen across cultures, the belief systems of these cultures vary drastically, creating different experiences of the illness across cultures. While in the South Korean and Chinese

cultures, these belief systems focused on the cause of autism through parent or ancestor faults, in the Pakistani and Bangladeshi Muslim communities as well as in the Ultraorthodox Jewish community, belief systems for causation of autism focused on their god's will. Because of these varying beliefs about autism, the family was shaped in these societies by autism in different ways, and different expectations and coping mechanisms were utilized by the varying cultures.

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