

Autism in China

A biosocial review

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Introduction

With a true artist's musicality, Jordan stands up before his peers at NYU Steinhardt's Nordoff-Robbins Center for Music Therapy to play an improvisational xylophone solo. In Kunming, China, at the MoreToBaby Center for Mental Health Therapy, Chenxuangu enthusiastically beats his tambourine to the tune of a Chinese children's rhyme.

Though thousands of miles apart, Jordan and Chenxuangu have much in common—they are both five-year old boys who have been diagnosed with autism spectrum disorder, a neurodevelopmental disorder that manifests in social, communicative and behavioral impairments (CDC, 2011).

Both seem content; however, their drastically different surroundings influence the way they experience autism. Jordan plays well-crafted musical instruments in a research facility; Chenxuangu plays with donated plastic tambourines in a center with fading posters, peeling paint and aging equipment. Next year, Jordan will likely return to the same building to continue his therapy; due to constant relocation and closure, it is unclear whether Chenxuangu will return to the same center. Two therapists tend to Jordan and four other boys; with the center severely understaffed, Chenxuangu has to have a parent attend class with him every day. Each attends one of the best centers in his respective region, yet one is underfunded compared to the other.

Such examples prompt the need for a biosocial analysis that studies the influence of environmental, social and political factors on biological diseases. After all, it is impossible to understand human behavior, abnormal psychopathology or mental health care without accounting for social and cultural phenomena (Jenks, 2005; Chiang & Hadadian 2010; Lin, Tseng & Eng-Kung, 1995). The relationship between symptoms and social stigma is especially worth examining because it may have a strong and enduring effect on the well-being of those who face mental health problems (Kleinman, 1986; Pearson, 1995; Link et al., 1995).

Psychiatry in China is a fusion of Eastern and Western thought, a canvas onto which cultural ideas have fostered various interpretations of autism spectrum disorder. In addition, politics impact the manner in which resources are allocated for treatment. Though there have been many studies on the development of Chinese psychiatry and mental health, few have focused on the diagnosis and treatment of autism. This paper provides an overview of how historical, cultural and political factors affect an autistic individual's experience.

Problem

Historical Influence

While the development of Chinese psychiatry paralleled that of Western psychiatry, there existed a constant internal struggle that rejected more effective Western techniques. Tension grew between the desire to practice Western psychiatric theories and to create a purely Chinese form of psychiatry (Pearson, 1995).

Before 1949, little was known about the state of Chinese psychiatry (Zhao & Miao, 2007; Pearson, 1995). Though ancient records of psychiatric and mental illnesses existed, psychiatry was not formalized until after the revolution in 1948 (Liu, 1981). Indeed, whereas only one psychiatric hospital for Chinese citizens

was present in 1906, there were 80 hospitals after the revolution. By 1978, an additional 190 hospitals had been built (Collins, 1982). Academic psychiatry began in 1932 with the establishment of the Peking Union Medical College (Pearson, 1995).

The many pioneers of Chinese psychiatry were either from the West or trained in Western methodology (Pearson, 1995). However, during the Cultural Revolution in the 1960s, the nationalistic movement rejected Western influence, including notions that leading practitioners believed were capitalistic, such as mental health.

In addition, the heterogeneity of Chinese culture as evidenced by the variety of dialects spoken across the country in diverse provinces and regions prevented the creation of a standardized practice of psychiatry. The disparity is most notable in the treatment provided in urban versus rural areas, where centers like MoreToBaby do not even exist and must rely on patients traveling long distances and making sacrifices to receive the treatment they need and deserve.

Due to its tumultuous political and ideological history, mental health is not looked upon favorably. Stigma, defined as "the psychological and interpersonal experiences of being discredited and discriminated against because of a particular condition," is prevalent (Jinhua & Kleinman, 2011).

Cultural Context

The treatment of psychiatric disorders, especially autism, can vary by nation due to cultural differences in diagnosis and interpretation.

For instance, many Chinese psychiatrists prescribe to the Chinese Classification of Mental Disorders, 3rd edition (CCMD-3), instead of two more well-known diagnostic manuals, Diagnostic and Statistical Manual (DSM) and International Statistical Classification of Diseases and Related Health Problems (ICD). Chinese psychiatrists, who have expressed doubts with the constant updates and diagnosis-associated changes of DSM and the awkwardly translated ICD, thus resort to the culturally appropriate CCMD (Kleinman, 1986). Even the director of MoreToBaby preferred CCMD-3 over other forms of diagnostic criteria.

Though symptomatic diagnosis is largely standard, there are variances in interpretation and categorization between CCMD-3 and DSM-V. For example, CCMD-3 diagnosis of autism involves "interpersonal harm" with "qualitative damage" and "significantly impaired ability" in communication, as opposed to the more politically correct emphasis on "deficits" as found in the proposed DSM-V (Zhang Yue Heng, 2009).

Furthermore, thousands of years of cultural history have culminated in a socially-accepted framework, which affects society's interpretation of autism. Five common themes are:

- (1) As a basic life value, the Chinese stress a harmonious attitude toward nature;
- (2) Influenced by traditional medical concepts, the Chinese are concerned with balance and conservation for optimal health;
- (3) In their social organization, the Chinese value the family as the basic unit of life and resource for support;
- (4) The Chinese emphasize social and interpersonal relations in life situations; and
- (5) For coping with life situations, the Chinese sanction practical and flexible adjustment" (Lin, Tseng & Eng-Kung 1995).

In accordance with the first two points—harmonious attitude toward nature and the need for balance—mental illness is commonly believed to be the result of imbalance between self and society, with the self suffering from an imbalance of yin and yang, hot and cold or the five elemental phases (Kleinman, 1986). To give birth to a special-needs child is to sin against the ancestors or to have been cursed by the gods (Chiang & Hadadian, 2010). In Traditional Chinese Medicine (TCM), mental disorders are viewed as physical diseases or manifestations of physical disorders (Jinhua & Kleinman, 2011).

Traditional Chinese Medicine (TCM) regards the blockage of qi, the vital force of energy that controls the functioning of the human mind and body, as the result of an internal imbalance between yin, the passive component, and yang, the active component (AT, 2009; NCAAM). Acupuncture helps to improve pain or other medical complaints by inserting fine needles into certain meridians, or channels of the body, to clear a pathway for the qi and fix the imbalance (CYWH).

In addition to its role in the treatment of chronic pain, acupuncture can be used to change the cognitive state (Hui et al, 2010). According to Chinese medicine, autism is a “yin” disorder that manifests in social isolation, lack of communication and apathy (Clark & Zhou, 2005). As many of these symptoms are related to underlying neurological aberrations, acupuncture is thought to influence the regions of the brain associated with autism.

Studies have shown that acupuncture can be effective in allowing attention and receptive semantics, especially if paired with other means of therapy, such as language therapy, a form of therapy prevalent in Western tradition (Clark & Zhou, 2005). This fusion of culture demonstrates Lin, Tseng and Eng-Kung’s fifth point: that practical and flexible adjustment in adapting and being open to various therapies across cultures is necessary when coping with life situations (1995).

The third point highlights the family as a central point of organization and of mobilization. Progress, Confucius taught, was the cultivation of self towards the raising of a family, to the governing of society and to regulation of the world (Lin, Tseng & Eng-Kung, 1995). Each person is a member of a family that is connected to greater levels of society (Pearson, 1995). As a member of the family, each individual has rights and responsibilities. Acting in a socially unacceptable manner is very much unfavorably representing the family, even if the actions are uncontrollable or due to mental illness.

This leads to the fourth point, which states that much of Chinese culture is based on social interactions. Though the widespread theory of Confucianism states that all humans are born “good” and in need of respect, this seemingly positive and unbiased view is not as prevalent in practice, especially with regards to individuals with disabilities (Yang, 2001; Chiang & Hadadian, 2010). When individuals with disabilities are placed into a system that upholds binary and ethnographic definitions, they are viewed as aberrations because they do not conform to the “norm” (Chen, 2003).

An important concept in Chinese society is “saving face,” a form of social currency earned by interacting in the public sphere (Cardon, 2003). Saving face is the preservation of the public appearance of the patient and family for the sake of community propriety (Kramer, 2002). In order to uphold the family’s honor, individuals with disabilities are often locked up at home as a family secret (Yang, 2001). At MoreToBaby, parents often wonder about the future of children with autism because they rarely see autistic individuals in public.

With their inadvertent disruptions of social order, autistic in-

dividuals face heavy stigma from their verbal and nonverbal actions (Philips, 1998). Given that much of Chinese society is intolerant to such faux pas, societal acceptance and understanding for such actions are difficult to achieve.

Examination of the cultural factors that influence the perception of the disorder highlights the idea of “local moral worlds,” the mindset of people toward those with diseases. Understanding the local moral worlds is important not only on the scale of possible interventions to assuage the social suffering of the individuals, but also to the opening of dialogue to sustain conversation among nations.

Political Climate

During China’s pre-reform era, medical costs were kept low. As the market opened up, the cost of care increased dramatically (Philips, 1998). But the lack of understanding of the disorder led to an inability to properly implement policies to support families with children with mental health disorders.

Mental health in China is shameful not only on an individual or familial level, but on a national level (Pearson, 1995). The government, unwilling to be open about people living with mental illness, tries to ignore or hide mental health issues, as evidenced by their reticent acknowledgment, but the Five Year Plan will bring mental illnesses into the field as a “major field of research” (Moore, 2009). Only a few child mental health centers exist in China, with the Nanjing Child Mental Health Research Center being the sole location to train child mental health workers (Lin, Tseng & Eng-Kung, 1995).

Furthermore, family planning policies created a dilemma for those with children suffering from poor mental health. The one child policy, enacted in 1978, reduced fertility rates but increased socioeconomic problems (Hesketh, 2005). Expected and pressured to raise the “single healthy child,” parents pinned hopes and dreams onto their spoiled “Little Empress” or “Little Emperor.” It also placed great pressure on the one child, especially those who faced autism and had trouble learning. The government’s response, which allows for the birth of a second child in the event that the firstborn has a mental illness, did nothing to aid the marginalized population and in fact perpetuated the idea that individuals with mental health problems could not carry out social obligations and were worthless (PBS, 1998).

But many cannot afford to have another child because taking care of a child with special needs in China is costly and difficult. Given that mental health is seen as a private problem, a lot of time and energy is spent on disadvantaged children at home. This care forges strong family and community relationships, but, at the same time, it proves difficult for families with autistic children to maintain a work-life balance (Kelly, 2007).

At the MoreToBaby Center, a family member must accompany the child at all times due to shortage of staff members. This often makes it difficult for one parent to work during school hours. Even for those who do not need parental accompaniment in school, many times a family member will serve as the unpaid caretaker, reducing their chances of income. According to par-

ents at MoreToBaby, despite stipends that allow families to alleviate some of the costs, livelihood is still grueling.

This also brings to light how the lack of government support for education can make it difficult for families. Even though the MoreToBaby Center is less than state-of-the-art with its fading posters, old equipment and biennial location change, it is considered one of the best centers in Yunnan, with a waitlist of children from all over the province, including the more rural areas. Sometimes, people will rent expensive flats in the city to facilitate access to the somewhat shabby public schools (Ying, 2010).

Oftentimes, all the children who are mentally challenged will be grouped together, making individual care a rarity (Ying, 2010). These are simply not the appropriate measures for intensive care and attention that are necessary, as shown by the low education attainment for

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disabled children (Yang, 2001). Furthermore, the government does not provide a substantial “mainstreaming” program, making it difficult for children with autism to transition into a public school or school for typically developing children, and ultimately, into society. Of the few companies that offer jobs to graduates of schools for individuals with mental health disabilities, all are China-based foreign companies (Ying, 2010).

Families with autistic children undergo much unrecognized sacrifice and suffering. The implicit and explicit costs prove to be particularly burdensome for the average family. Some public schools can cost almost half the average annual salary; private schools may cost twice or thrice the amount (Ying, 2010). Additional costs include tutors or therapists.

But even nongovernmental organizations are helpless and few such groups provide services or support (Pearson, 1995). Due to the stigma of mental health illness, it is difficult for parents to speak up for their children with autism and rally support from community members.

On the other hand, these obstacles can inspire these individuals to overcome their discrimination (Yang, 2001). As the government’s ineptitude is revealed, demand for mental health services increases; this will lead to a market of financial incentives for public and private sector organizations to provide services (Phillips, 1998).

Through pressure with the developing trends around the world, China has begun to realize the importance of early intervention and special care. Though the national strategy for Early Childhood Care and Education has brought the issue into the public sphere, it is not tailored specifically to children with disabilities (Corter, 2006). However, autism has been written into the 11th Five Year Plan, as the government looks to have autistic training facilities in 31 pilot cities, one for each province (Ying, 2010). Yet, many are still skeptical about the inclusion of autism in the plan, thinking that this would just give a label for discrimination once again (Feinstein, 2010).

Wrapped up in the politics of it all, legislators find it difficult to create policies adequate for individuals with autism fitting for the political climate. However, these political reforms are only part of the necessary solution to improve the quality of life of autistic individuals.

Solution

Stigma is an unintended consequence of political and social actions (Merton, 1936). In order to change the current mentality on mental health, solutions must account for all possible unintended repercussions.

In regards to the political situation, reform of the policies that are aggrandizing the social suffering of the individuals would prevent bureaucratic rationality. Due to the societal structure that is based heavily on family, compensating the families, beginning with their explicit costs of education, would be a start. Then, moving on to help families with implicit costs of time, energy and opportunity cost should follow. This would help the families to free up resources to help the individuals with autism.

Funding could also be extended to institutions to expand their resources for autism. Centers like MoreToBaby could accommodate more individuals with more staff members, school and therapy supplies and space in a permanent home. Another step would be to change the infrastructure of the educational system. This would involve creating centers able to concentrate on specific disorders, but at the same time, creating a channel to mainstream individuals into public schools and eventually into positions in society.

However, these are short-term solutions to a long-term problem. Though they relieve some of the difficulties surrounding living with autism in China, they will only cover up the underlying stigma of autism and other mental health disorders.

A major change would be to overturn the secrecy surrounding mental health. By opening dialogue about mental health, more mea-

asures can be taken. Going deeper into the cultural foundations for the inappropriate or insensitive policies, awareness campaigns would help individuals with mental health disabilities and their advocates to stand up for their rights while rallying parts of the community. In the past, some similar campaigns have succeeded in the context of malaria, but others have not had as much luck (Kleinman, 2011). Though the awareness campaigns will spread information about the disorder, they still have to overcome the fundamental stigma.

Uprooting stigma and misunderstanding surrounding autism would cut off nourishment from the metaphorical weed of policies and practices. Research, for example, is one potential venue for greater understanding. After all, much of the disorder is still ambiguous. Looking at the causes, diagnoses and treatments of autism will help clarify disparities between different cultures.

For example, determining the cause, be it genetic or environmental, will overturn some cultural beliefs and prompt the need for socially acceptable ways to regard individuals with autism. The clarification of the diagnosis of autism will contribute to the ability to distinguish between mental illnesses and complications, better tailoring treatment mechanisms. And, most importantly, discovering and verifying the effectiveness of treatments will save families time and energy looking for the best way to help their child.

With this approach comes the clash of local moral worlds, the differences in perception based on differences of values, with a tinge of medicalization, and the increasingly scientific approach towards medicine. Though numbers and data can be generated, the interpretation of the data is dependent on cultural aspects. However, conducting research in China and combining this research with that of investigators in other countries will provide a more complete perspective on the disorder. The research and understanding will take more time and effort than the other actions. It is difficult to try to put time and resources into preventative care when there are more imminent interventions that need support.

Multiple levels of different types of solutions are necessary in order to comprehensively improve the quality of life for autistic individuals. To start, energy and resources need to be placed into research; more effort should be put into advocacy and awareness. Finally, above all the infrastructural changes is the need to make the reforms toward accommodating the special needs of children with autism.

Conclusion

China has the potential to improve the situation for autistic individuals. Currently, the mental health services available to children with autism are in the early stages of development. Though the standards of living are progressing, there is still much to be done. Assessing the fallbacks of the current situation can help point out areas of focus such as educational provisions or economic inequalities. For example, assessment of the social, political and economic imperatives that direct the development of mental health services in China suggest that both the quality and accessibility of services will decrease in the future (Phillips, 1998).

This is not to say the story of autism is unparalleled. Other mental health disorders in China such as schizophrenia, depression and neuroanesthesia have gone through the same dynamics (Pearson, 1995; Kleinman, 2010). Similarly, the history of HIV/AIDS and its stigma in China could be juxtaposed with that of mental health illnesses, resulting in obstacles to proper treatment and care (Jinhua & Kleinman, 2011).

It was only decades ago that the now-prominent awareness of autism in America was in its basic stages; hopefully a similar growth trend can occur in China. Beginning with vocal parents speaking up for their children’s needs and rights, a movement was initiated in America. Parents mobilized those in the community who interact-

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ed with autistic children and then expanded into social networks, until autism awareness spread throughout the country as a hot topic (AutismSpeaks).

With both the cultural and political context in mind, the biosocial framework can help to empower individuals with autism. By taking into account all the factors of the disease, not just those that are biological, future approaches can be more horizontal, as opposed to the vertical approaches of the past. Further research into socially constructed approaches to the origin and treatment of the disorder could lead to a better understanding of autism, both in America and China.

Looking back at Jordan and Chengxuan, it is evident that they themselves have no control over their situation. It is up to those around them, their families and their communities, to help them make the best of their situation.

References

- American Psychiatric Association (2012). DSM-5 Development. Retrieved from <http://dsm5.org>
- Acupuncture Today (2012) Qi, Jin, Blood and Jin Ye: The Body's Vital Substances. Retrieved from <http://acupuncturetoday.com>
- AutismSpeaks: It's time to listen. Autism Speaks. Retrieved from <http://www.autismspeaks.org>
- Centers for Disease Control and Prevention (2011). Autism Spectrum Disorders (ASDs). Retrieved from <http://cdc.gov>
- Cardon, P.W. & Scott, J.C. (2003) Chinese Business Face: Communication Behaviors and Teaching Approaches. *Business Communication Quarterly*, 66(4), 9-22.
- Center for Young Women's Health: Children's Hospital Boston (2012). Acupuncture. Center for Young Women's Health: Health information for teen girls around the world. Retrieved from <http://youngwomenshealth.org/acupuncture.html>
- Chen, N. (2003). *Breathing Spaces: Qigong, Psychiatry, and Healing in China*. New York, NY: Columbia University Press.
- Chiang, L.H. & Hadadian, A. (2010). Raising Children with Disabilities in China: the Need for Early Intervention. *International Journal of Special Education*, 25(2), 113-118.
- Clark, E. & Zhou, Z. (2005). Autism in China: From Acupuncture to Applied Behavior Analysis. *Psychology in the Schools*, 42(3), 285-295.
- Collins, J.L. (1982). Psychiatry in China. *Journal of the National Medical Association* 74(10):993-998.
- Corter, C., Janmohammed, Z., Zhang, J. & Bertrand, J. (2006). Selected issues concerning early childhood care and education in China. *Remedial and Special Education*, 28 (1), 58-64.
- "Diagnostic Criteria for Autism: China's Standard – CCMD3" (Translated from the Chinese) Second Affiliated Hospital of Harbin Medical University.
- Feinstein, Adam (2010). *History of Autism: Conversations with the Pioneers*. Malden, MA: Wiley-Blackwell.
- Hesketh, T., Lu, L. & Xing, Z.W. (2005). The Effect of China's One-Child Family Policy after 25 Years. *Health Policy Reports: New England Journal of Medicine*, 353(11), 1171-1176.
- Hui, K.K.S., Marina, O., Liu, J., Rosen, B.R. & Kwong, K.K. (2010). Acupuncture, the limbic system, and the anticorrelated networks of the brain. *Autonomic Neuroscience: Basic and Clinical*, 157, 81-90.
- Jenks, E.B. (2005). Explaining Disability: Parents' Stories of Raising Children with Visual Impairments in a Sighted World. *Journal of Contemporary Ethnography*, 34(2), 143-169.
- Jing, J., Kleinman, A., Sing, L., and Yunxiang, Y. & Zhang, E. (2011). *Deep China: The Moral Life of the Person*. University of California Press.
- Kelly, T.A. (2007). Transforming China's Mental Health System: Principles and Recommendations. *International Journal of Mental Health*, 36(2), 50-64.
- Kleinman, A. (1986). Social origins of distress and disease: depression, neurasthenia, and pain in modern China. New Haven: Yale University Press.
- Kleinman, A. (2010). Four Social Theories for Global Health. *Lancet*, 375(9725), 1518.
- Kleinman, A. (2011). Case Studies in Global Health: Biosocial Perspectives. *Societies of the World* 25, Fall 2011.
- Kramer, E.J., Kwong, K., Lee, E. & Chung, H. (2002). Culture and Medicine: Cultural factors influencing the mental health of Asian Americans. *West J Med*, 176, 227-231.
- Lin, T.Y., Tseng, W.S. & Eng-Kung, Y. (1995). *Chinese Societies and Mental Health*. Oxford University Press.
- Liu, X.H. (1981). Psychiatry in Traditional Chinese Medicine. *British Journal of Psychiatry*, 138, 429-433.
- Merton, R. K. (1936). The Unanticipated Consequences of Purposive Social Action. *American Sociological Review*, 1, 894-904.
- Moore, M. (2009). China has 100 million people with mental illness. *The Telegraph*, 28 April 2009. Retrieved from www.telegraph.co.uk
- National Center for Complementary and Alternative Medicine (2011). *Acupuncture: An Introduction*. National Institutes of Health. Retrieved from <http://nccam.nih.gov>
- PBS (14 February 1984). *Family Planning Law and China's Birth Control Situation*. Nova. Retrieved 13 October 2009.
- Pearson, V. (1995). *Mental Health Care in China: State Policies, Professional Services, and Family Responsibilities*. London: Gaskell.
- Phillips, M.R. (1998). The Transformation of China's Mental Health Services. *China Journal*, 39, 1-35.
- Yang, J. (2001). The Positive and Negative Impact of Traditional Culture on Disability Policies in China. *International Disability Alliance*. Retrieved from www.internationaldisabilityalliance.org
- Ying, T. (2010). Autism in China: Parents Struggle for their Children's Future. *Xinhuanet*. Retrieved from <http://news.xinhuanet.com/>
- Zhao, X.D. & Miao, S.J. (2007). Development of Cultural Psychiatry in China. *World Cultural Psychiatry Research Review: Official Journal of World Association of Cultural Psychiatry*, 2(4), 104-109.

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Submit to JGH!

Mental health is a large component of the global burden of disease, yet it is often neglected or categorized as a "luxury item" on many agendas. The World Health Organization has only recently started to address the gap between those in need of mental health care and the resources available to them, but the majority of developing countries allocate less than 2% of their health budget on mental health. Amidst the numerous other diseases/conflicts that plague the international community, how do we justify the importance prioritizing mental health?

The Fall 2012 issue of JGH will highlight the theme of "Looking Inside: Justifying Mental Health." We specifically encourage submissions that address relevant issues such as: the underlying factors of the stigma associated with mental health, varying interventions such as medicine and psychosocial services and their accompanying barriers, and how breakthroughs in understanding the brain will affect the mental health gap.