Autism Awareness and Technology-Based Intervention Research in China: the Good, the Bad, and the Challenging

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Abstract

Impressive advances have been made to further our understanding of the psychological and neurobiological processes that underlie *Autism Spectrum Disorder* (ASD) since it was first reported by Leo Kanner in 1943. Research on assistive technology for ASD has also substantially increased in both quality and quantity for aspects pertinent to individuals living with ASD (including their family members, caregivers and special education teachers). However, mainland China is only now awakening to the realities of ASD - there were few publications addressing fundamental issues such as assessment, diagnosis, treatment and (technology-based) early intervention strategies in China until recently [Autism Daily NewsCast 2015, Li et al. 2011, Sun et al. 2015, Wang 2015, Tang et al. 2015], and researchers are not even sure how many Chinese people have ASD [Sun et al. 2013a, Autism Daily NewsCast 2015, Wang 2015, Tang et al. 2015]. Earlier studies sought to explore the psychological and cultural issues surrounding the public awareness and acceptance of ASD in China. In this workshop paper, we draw a current picture of technology-based ASD research in China from two recent surveys. Coupling this with a discussion of our recent design and testing experiences, we call for increased research efforts in this area, as well as raising public awareness of ASD in China through the publication of this research. In addition, as a group of prominent autism research scientists pointed out that "intervention research should include socially and culturally diverse populations and evaluate familial factors that may affect participation, acceptability and outcomes of therapeutic approaches"[Zwaigenbaum et al 2015], it is high time for researchers to include mainland Chinese autistic children and their families in the research cycle so as to see how technology can be accepted, adapted and deemed helpful when compared to those currently applied in other populations.

Author Keywords:
China; Autism; ASD; Technology; Survey

Paper accepted to the Autism and Technology: Beyond Assistance & Interventions Workshop held at CHI 2016 in San Jose, California, USA.

Autism + Technology Research in China

The Good: The absence of a systematic prevalence study of ASD in China leaves huge potential for such research.

The Bad: Based on our interactions and interviews with parents of children with ASD and special education teachers, one of the biggest obstacles is the continued shortage of affordable government and community-support intervention centers.

The Challenging: Since technology use in ASD diagnosis, assessment and intervention is extremely rare, and China holds a deep-rooted negative cultural prejudice toward mental illness, the road to the wide application (not to mention benefits) of TBI in China is long and dark. Increasing international collaborations are especially valuable to opening new opportunities for such a long-term effort.

Introduction

People with Autism Spectrum Disorder (ASD – a neurodevelopment disorder), exhibit heterogeneous conditions including stereotyped repetitive behaviors, restricted interests, and impairments in social interaction and communication [World Health Organization 1993]. It is known that early intervention might lead to improvement in reduced anxiety and improved social skills [Lai et al. 2014], and that early intervention mostly occurs in family and schools for children with ASD [Lai et al. 2014]. Recent work on Technology-Based Intervention (TBI) has achieved positive medical and clinical outcomes (e.g., [Carter and Hyde 2015; Carter et al. 2014; Hong et al. 2015, O'Malley et al. 2014, Tentori and Hayes 2010, Escobedo et al. 2012, Tang et al. 2015]. However, compared to the diverse research efforts on the design and evaluation of technology-based interventions for ASD in the U.S. and Europe, similar work in East Asia lags far behind [Sun et al. 2013b, 2015], especially in China (except for two recently-published works [Zhu et al. 2015; Tang et al. 2015]). To make matters worse, widespread ASD prejudice in China has resulted in a large number of 'hidden' families living with ASD [Compton 2015, Wang 2015, Autism Daily NewsCast 2015, Sun et al. 2013a, 2015, Tang et al. 2015]. Mainland China did not officially recognize ASD as a disorder until the early 1980s, and the country is still uncertain of how many of its population (including adults and children – especially in rural mountain areas) have ASD [Sun et al. 2013, 2015, Wang et al. 2013; Autism Daily NewsCast 2015, Wang 2015]. Previous studies on Chinese people affected by ASD sought to examine the psychological and cultural issues surrounding the public awareness and acceptance of ASD in China [Mak and Kwok 2010, Fung et al. 2007, Lu et al. 2015], and until recently, there were few published works addressing fundamental issues such as assessment, diagnosis, and early intervention strategies in China. In light of these issues, we founded the first dedicated Autism Research Network in May 2015 in Wenzhou – a large southern Chinese city where our university (Wenzhou Kean University) is situated. Wenzhou Kean (founded 2012) is a Sino-American collaboration that provides an American education within a Chinese city. We have formed strong research alliances among researchers from the U.S., Hong Kong, the U.K., and mainland China. In this workshop paper, we draw a current picture of technology-based research on ASD in China from different perspectives, coupled with a discussion of our recent design and testing experience to call for more research efforts to this end, as well as to raise public awareness of ASD in China.

The Current Research Landscape of Autism (+ Technology) in Mainland China

In order to provide researchers and practitioners initial insights into the current situation in China, we report: 1) a small-scale survey (n=104) to measure public awareness of and their attitudes towards people with ASD; and 2) a literature survey on technology-based intervention for Chinese children with ASD.

A Survey on ASD Word Associations Among Young College Students in China

In China, the word 'autism' is associated with mental disorder, which is often regarded as a source of shame and an indication of failure for parents if their children are associated with it [Fung et al. 2007]. As a result, public awareness about ASD is very low for a nation that has been battling the long-term prejudice over it [Clampton 2015, Wang 2015]. Driven by the

uncertainty over the degree of public knowledge and awareness of ASD, we conducted a small-scale survey to investigate the public awareness, knowledge and attitudes towards ASD. 104 students (70 female) took part in our survey (convenience sampling). The survey asked respondents to pick both strengths and weaknesses that they associate with autism from among 21 and 30 words respectively (modified from [Dillenburger et al. 2013]). The figures below show the results as reflected in two tag clouds (Figure 1 and 2).

Figure 1: The strengths students associate with ASD.

Figure 2: The weaknesses students associate with ASD.

Latest Literature Survey on Chinese Autism Research

In order to form an understanding of recent ASD research including TBI related one in China, we used the keywords Autism (自闭症), Autism (孤独症), ASD (自闭症谱系障碍), Pervasive Developmental Disorder (PDD, 广泛性发育障碍) and Asperger's Syndrome (阿斯伯格综合症) to search for published reports between 1983/1989 (the earliest year that can be set in Zhi Wang and Wei Pu databases respectively) to 2015 in three most popular Chinese scholastic databases: Baidu Scholar[1], Zhi Wang Database (知网)[2] and Wei Pu Database (维普)[3]. We limited our search to studies that had been conducted with individuals with ASD in mainland China (thus excluding Taiwan and Hong Kong). The keywords we used follow those suggested in [Lai et al. 2014].

	Zhi Wang Database (知网) (1983-2015)			Wei Pu Database (维普) (1989-2015)			Baidu Scholar (百度学术) (1989-2015)		
Keywords	Total Number of Papers	Number of Paper on TBI for ASD	Percentage	Total Number of Papers	Number of Paper on TBI for ASD	Percentage	Total Number of Papers	Number of Paper on TBI for ASD	Percentage
Autism (自闭症)	22,752	2	0.01%	2,671	3	0.11%	4272	9	0.21%
Autism(孤独症)	19,926	0	0.00%	2,653	1	0.04%	4570	6	0.13%
ASD (自闭症谱系障碍)	986	0	0.00%	80	3	3.75%	293	11	3.75%
PDD (广泛性发育障碍)	3,771	0	0.00%	5	0	0.00%	816	3	0.37%
Aspergers Syndrome	485	0	0.00%	5	0	0.00%	43	0	0
Total:	47920	2	0.0042%	5414	7	0.13%	9994	29	0.29%

Figure 3: The latest ASD research landscape in China.

Papers addressing technological intervention for ASD are rare. The two papers in Zhi Wang focus on the adoption of virtual reality for behavioral intervention

[1] http://xueshu.baidu.com

[2] http://eng.oversea.cnki.net/kns55

[3] http://www.cqvip.com

and computer graphics for improving children with ASD and communication skills. Among the seven papers in Wei Pu Database, two are related to technology news [Newman 2014, Microsoft 2015]; the rest attempt to provide technology-based intervention with the help of a robot [Zhang 2013], touch screens, motion games [Hu et al. 2015], and computers(among many, [Carter et al 2014, Hong et al 2015]). Our findings confirm the huge gap in ASD research between mainland China and the rest of the world [Yu et al. 2012]; the total number of English ASD-related research papers is 20.5 times that of their Chinese counterparts in the Wei Pu Database, and 9.9 times in the Zhi Wang Database. Guo [2012] examined 10 years of Chinese ASD research and summarized that the majority follows two main research paths: social science and clinical medicine. With the rapid advance of technology, use of social media, and affordable smartphones in China, more people (especially those living with ASD) are calling for portable devices, mobile applications, toys and robots that can be of help. However, due to the lack of interdisciplinary research in China, social science and clinical researchers remain unware of promising technologies and how they might provide maximum benefit. Our research attempts to fill the gap by exploring technology-based intervention. We now report some of our key findings and reflect on the challenging issues that are specific to our population.

Reflections on Current Research on Autism+Technology in China

Our current understandings of the possible benefits of motion-based application/games for individuals with ASD are extremely limited, partly due to the limited number of empirical studies, particularly in China. So far, our research focuses on (affordable) wearable, sensory and interactive technology solutions.

A Touchable Plant

We developed a touchable singing plant and evaluated it in a children's autism educational center in Wenzhou [Tang et al. 2015]. The Ardunio-enabled plant accepts multiple user touches leading to various music playing. A pilot study with five children both supported (the children were reluctant to touch the plant [Seo et al. 2015]) and contrasted with previous work (our children had higher intensity touch actions [Tang et al. 2015]).

Hand-Gesture Motion-based Application

To get a valuable first glimpse into the acceptability and usability of motion-based games for Chinese children with ASD, we designed and pilot-studied two hand gesture controlled applications. Our studies with five parent/child pairs and five children with ASD added to previous knowledge by showing that mid-air finger-gesture interaction is challenging for younger children with ASD, but hand-gesture interaction adds fun and playfulness to the learning process. However, we expect resistance from some parents and special education teachers who remain highly suspicious of the use of such games and applications.

Frauenberger [2015] points to participatory design to make applications more adapted to different users. However, we found that most of our participants who support children with ASD (especially special education teachers) lack up-to-date training due to insufficient government support, hence a large number of their suggestions negatively influenced the design process.

China is just starting to come to grips with ASD; its first ASD prevalence study started two years ago [Clampton 2015] and government-funded special education is available, but is expensive and limited in terms of quality and quantity. Technology-based intervention (such as our Touchable Plant and Gesture-Controlled Applications) could help families living with ASD. We look forward to engaging researchers from the CHI community to engage in such research in China.

Acknowledgements

We thank Relic Wang, Leila Huang, Christine Chen, Esther Tang, and Tina Fu for their assistance and the Student Partnering with Faculty Program from Wenzhou Kean University for funding. Special thanks to Wenzhou Xinle and Xingzhi Jia Children's Educational Development Centers for participating in our research.

References

1. Autism Daily Newscast. (2015). China struggles to understand autism. Autism Daily Newscast, May 25, 2015. Accessed on Dec.11, 2015.
2. Carter, E. J. and Hyde, J. (2015). Designing autism research for maximum impact. CHI'15, 2801-2804.
3. Carter, E. J., Williams, D. L., Hodgins, J.K. and Lehman, J.F. (2014). Are children with autism more responsive to animated characters? J. Autism and Developmental Disorders 44, 10: 2475-2485.
4. Clampton, N. (2015). China moves to tackle autism with first study of prevalence. South China Morning Post, 2013. Retrieved Sept. 16, 2015.
5. Compton, N. (2015). Autism in China: a silent epidemic. Special Educational Needs (SEN). Accessed Dec.11, 2015.
6. Dillenburger, K., Jordan, J-A., and Lyn McKerr, L.(2012). Autism Spectrum Disorder: Public awareness and attitudes (Research Update Number 84), Northern Ireland Life and Times Survey.
7. Escobedo, L., Nguyen, D.H., Boyd, L.A., Hirano, S., Rangel, A., Garcia-Rosas, D., Tentori, M. and Hayes, G. (2012). MOSOCO: a mobile assistive tool to support children with autism practicing social skills in real-life situations.CHI'12, 2589-2598.
8. Frauenberger, C. (2015). Rethinking Autism and Technology. Interactions, 22(2):57--59.
9. Fung, K.M.T., Tsang, H.W.H., Corrigan, P.W., Lam, C.S. and Cheng, W.M (2007). Measuring self-stigma of mental illness in China and its implications for recovery. International Journal of Social Psychiatry, 53, pp. 408–418.
10. Guo., W. Fang, J. and Chen., Q. (2012). Autism research focus of co-word analysis based on keywords. The North West University Research Journal, Issue 1 (in Chinese).
11. Hong, H., Gilbert, E., Abowd, G.D. and Arriaga, R.I. (2015). In-group Questions and Out-group Answers: Crowdsourcing Daily Living Advice for Individuals with Autism. In CHI'2015, 627-636.
12. Hu, Y., Lei., X and Hu., X. (2015). A review of foreign research into interventions in autistic children by using somatic games and its enlightenment. Chinese Journal of Special Education, Issue 5, pp. 51-56. (In Chinese)
13. Lai, M.-C., Lombardo, M. V., & Baron-Cohen, S. (2014). Autism. The Lancet, 383(9920), 896–910.
14. La Valle, C. (2013). Chinese Cultural Factors Impacting the Educational Schooling of Children with Autism in China. DePaul Discoveries: Vol. 2: Iss. 1, Article 10.
15. Li, N., Chen, G., Song, X., Du, W. and Zheng, X. (2011). Prevalence of autism-caused disability among Chinese children: A national population-based survey. *Epilepsy & Behavior*, 22, 4:786–789.

16. Lu, M., Yang, G., Skora, E. Wang, G., Cai, Y. and Sun, Q. (2015) Self-esteem, social support, and life satisfaction in Chinese parents of children with autism spectrum disorder. Research in Autism Spectrum Disorders, 17 (2015) 70–77.
17. Mak, W.W.S. and Kwok, Y.T.Y. (2010). Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. Social Science & Medicine, 70, pp. 2045–2051.
18. Microsoft. (2015). Mood-sensing scarf the latest in wearable research from Microsoft. Digital Daily. Accessed on Dec.11, 2015.
19. Newman, Judith. (2014). To Siri, With Love. New York Times.
20. O'Malley, P., Lewis, M., Donehower, C., and Stone, D. (2014). Effectiveness of using iPads to increase academic task completion by students with autism. Universal J. of Educational Research, 2(1): 90-97.
21. Seo, J. H., Sungkajun, A. and Suh, J. (2015). Touchology: Towards Interactive Plant Design for Children with Autism and Older Adults in Senior Housing. In Proc. of CHI 2015, 893-898.
22. Sun, X., Allison, C., Matthews, F., Sharp, S., Auyeung, B., Baron-Cohen, S. and Brayne, C. (2013a). Prevalence of autism in mainland China, Hong Kong and Taiwan: a systematic review and meta-analysis. *Molecular Autism* 4:7.
23. Sun, X., Allison, C., Auyeung, B., Matthews, F., Baron-Cohen, S., and Brayne, C. Service provision for autism in mainland China: Preliminary mapping of service pathways. Social Science & Medicine, 98 (2013b), pp. 87–94.
24. Sun, X., Allison, C., Auyeung, B., Zhang, Z., Matthews, F., Baron-Cohen, S. and Brayne, C. (2015). Validation of existing diagnosis of autism in mainland China using standardised diagnostic instruments. To appear, *Autism Rese*arch.
25. Tentori, M. and Hayes, G.R. (2010). Designing for interaction immediacy to enhance social skills of children with autism, Ubicomp'10), pp 51-60.
26. Tang, Y. T., Relic, W., Hui, Y., Leila, Huang., and Christine, C. (2015). Supporting Collaborative Play via an Affordable Touching + Singing Plant for Children with Autism in China. In Proc. of ACM UbiComp'15/ISWC '15, Adjunt, pp. 373-376.
27. Wang S. (2015). China's uncounted children with autism. Wall Street Journal. Accessed 12/11/15.
28. World Health Organization. (1993). International statistical classification of diseases and related health problems, 10th edition (ICD-10). Geneva: World Health Organization.
29. Yu. R-R., Lin., L., Xu. Y., Li. X., and Zhu., X. (2012). Analysis and comparison of hot topics about childhood autism at home and abroad. Maternal and Child Health Care of China, volume 27, Issue 3. (In Chinese).
30. Zwaigenbaum, L., Bauman, M.L., Choueiri, R, Fein, D., Kasari, C., Pierce, K, Stone, W.L., Yirmiya, N., Estes. A., Hansen, R.L., McPartland, J.C., Natowicz, M.R., Buie, T., Carter, A., Davis, P.A., Granpeesheh, D., Mailloux, Z., Newschaffer, C., Robins, D., Roley S.S., Wagner, S., Wetherby, A.(2015). Early Identification and Interventions for Autism Spectrum Disorder: Executive Summary. Pediatrics. vol. 136, Suppl 1:S1-9.
31. Zhu, G. Cai, S., Ma, Y. and Liu, E. (2015). A Series of Leap Motion-Based Matching Games for Enhancing the Fine Motor Skills of Children with Autism. ICALT'2015, IEEE Press, pp.430 - 431.