Chapter 5: Self-reported outcomes of autistic adults living in China and the Netherlands: Objective and subjective psychosocial outcomes

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Abstract

Despite an estimated population of 10 million autistic individuals in China, little is known about Chinese autistic adults. Cultural and contextual factors may impact objective and subjective psychosocial outcomes of autistic adults. In this descriptive study we aim to compare the psychosocial outcomes of autistic adults between China, an Eastern Asian country, and the Netherlands, a Western European country. Based on self-report online questionnaires we compared objective psychosocial functioning (employment, living situation, friendship), life satisfaction, and internalized autism-related stigma of 36 Chinese (23 males and 13 females) and 29 Dutch (18 males and 11 females) autistic adults. The majority of participants in both countries (Chinese: 66.7%; Dutch: 82.8%) self-reported having an IQ above 70. Chinese and Dutch participants exhibited similar levels of employment, quality of friendships, and life satisfaction (M_{Chinese} = 5.81; M_{Dutch} = 6.28). Chinese autistic adults more often lived with their parents and reported more autism-related internalized stigma than Dutch adults ($M_{Chinese}$ = 2.25; M_{Dutch} = 1.79, p<.001). Autism-related internalized stigma was negatively correlated with friendships and life satisfaction across both samples. Heightened internalized stigma among Chinese autistic adults compared to Dutch may reflect cultural differences in attitudes towards autism. Strategies aimed at reducing internalized stigma could help to improve the social connections and life satisfaction of autistic adults within the global autistic community. This cross-country study is a first step in understanding the psychosocial outcomes of autistic adults in China.

Key words

Autistic adults, cultural and contextual, psychosocial outcomes, employment, friendship, living situation, life satisfaction, quality of life

Introduction

Increased attention has been paid to the outcomes of autistic adults in Western, educated, industrialized, rich, and democratic (WEIRD) countries (Howlin, 2021; Steinhausen et al., 2016). However, very few studies have thus far focused on autistic adults in Eastern Asian countries, such as China (Mason et al., 2021; Sáez-Suanes & Álvarez-Couto, 2021). Autism was initially identified in mainland China in 1982 (Hobart, 2008; Kuo-Tai, 1987), almost four decades later than in Western countries (Kanner, 1943). Notably, China is estimated to have approximately 10 million autistic individuals, based on a 0.7% prevalence rate (Zhou et al., 2020). Yet, there is still a striking lack of knowledge regarding the psychosocial outcomes of autistic adults in China.

Cultural and contextual factors, such as societal values, norms, and autism awareness, play an important role in how autism is perceived, understood, and experienced. Western individualistic countries emphasize the independent self and autonomy, and have a longer history of advocating for the rights and empowerment of autistic individuals, creating an environment more accepting of neurodiversity (Szlamka et al., 2022). In these Western countries, a wide range of people, including individuals with average to high intellectual abilities and older adults, are diagnosed with autism (Brugha et al., 2016; Christensen & Zubler, 2020). The Netherlands, a Western European individualistic country, emphasizes accessibility and community-based mental health care (Forti et al., 2014), and provides comprehensive intervention programmes to increase independence and social integration of people with mental

health needs (van der Meer & Wunderink, 2019). There are also self-advocacy movements promoting the rights and empowerment of autistic adults in the Netherlands (Waltz et al., 2015). In a recent study a majority of Dutch autistic adults with (above) average IQ levels showed a fair to very good level of objective psychosocial functioning (based on employment, friendships and independent living) (Scheeren et al., 2022).

Unlike Western individualistic culture, Chinese traditional values prioritize the interdependent self, adherence to societal norms, and group concerns (e.g. collective harmony and family responsibilities) over personal achievements (collectivist culture) (Grossmann & Varnum, 2010; Meyer, 2010). In China, there is limited autism awareness (Yu et al., 2020) and a lack of expertise in diagnosing and supporting autistic adults (with average or high intellectual abilities) (Li & Qi, 2023). It is common that only children with obvious classic autistic symptoms are identified (Huang et al., 2013). In China, autism is mostly considered a disorder rather than a form of neurodiversity. Non-conforming autistic behaviours may be perceived more negatively by the general public in collectivistic culture (Kim et al., 2022; Someki et al., 2018), contributing to public stigma (Chan & Tsui, 2023; Mak & Kwok, 2010). Public stigma can lead to internalized stigma, including internalized negative bias and self-discrimination (Chan & Tsui, 2023; Yanos et al., 2008), resulting in lower self-esteem (Boyd et al., 2014). Consequently, autistic individuals and/or their families might conceal their condition and refrain from advocating for themselves.

Most Chinese autistic adults live with their families, relying on them for care and support (Fisher & Jing, 2008; Wang et al., 2023). This may be because of an

emphasis on parental obligations, filial piety and/or a lack of professional services and affordable housing. Living with parents may also result in extensive family and community support for autistic individuals, in turn fostering their mental health and well-being (Ghosh & Magana, 2009). In the Netherlands, Scheeren et al. (2021) found that 79% of autistic adults with mostly (above) average intellectual abilities live independently (Scheeren et al., 2021). The mental health care system in Western individualistic countries tends to support autistic adults to participate in society, enabling their transition to independent living (Forti et al., 2014; Gotham et al., 2015; Maddox & Gaus, 2019). Given the aforementioned contextual and cultural differences between China and the Netherlands, the psychosocial outcomes of autistic adults from China and the Netherlands may also differ. By comparing China and the Netherlands, we can investigate similarities and differences in outcomes of autistic adults in different cultural and contextual settings.

Although there have been some initiatives to enhance care services for autistic adults in China (Beijing Association for Rehabilitation of Autistic, 2018; Xiao, 2023), our current knowledge of the psychosocial outcomes of autistic adults relies on parent-reports (Jia, 2022). For instance, the report of Jia et al. (2022) suggests that Chinese autistic adults (n=144) show a low (11%) employment rate. Our own previous study (under review), focused on autistic adults with high support needs (99 autistic adults in China and 109 in the Netherlands aged between 18 to 30 years), also revealed low employment rates (27.3%) in Chinese autistic adults. Around 93% resided with their parents. Few of them had close relationships, and their life satisfaction was lower

compared to the general Chinese population. It is important to note that these findings relied solely on parental reports, which may not (fully) align with the experiences of autistic adults themselves.

In the absence of basic knowledge about the outcomes of autistic adults in mainland China, we focused on their life satisfaction and objective psychosocial functioning, including employment or productive activities, living situation, and social engagement (Sander et al., 2010; Scheeren & Geurts, 2015). Many autistic adults, including those with average to high intellectual abilities, continue to struggle in these areas (Mason et al., 2021; Wickstrom et al., 2021). In this descriptive study, we aimed to (a) describe the degree of independent living, employment, friendship and life satisfaction ratings as reported by Chinese autistic adults themselves and a comparable sample of autistic adults from the Netherlands, and (b) investigate potential differences in internalized stigma between both samples and explore whether internalized stigma plays a role in outcome differences. We expected that autistic adults in China would report (1) lower employment, friendship ratings and living situation, (2) lower life satisfaction, and (3) more internalized stigma compared to their counterparts in the Netherlands.

Methods

Procedure

In this study, we focused on autistic adults with the capacity to self-report in China and the Netherlands. This study was part of a bigger study on autistic adults with

varying intellectual abilities and daily life skills in China and the Netherlands (https://osf.io/m9e5s).

The Chinese participants were recruited via an online nationwide survey through the Autism Research Centre of Nankai University (NKARC), Tianjin, China. NKARC has built a network of over 100 service centres of adults with autism covering all major regions of China. Autistic adults were invited to self-report on the questionnaire. Chinese data were collected in the Fall of 2022. All of the Chinese participants were diagnosed with autism by clinicians (psychiatrists, psychologists, and paediatricians).

Dutch participants were recruited via the Netherlands Autism Register (NAR, https://www.nederlandsautismeregister.nl/english/), a nationwide autism register that collects information from autistic individuals and their parents/caregivers. All Dutch participants had a formal autism diagnosis. Dutch data were collected by the NAR in September 2022. All participants consented to participate by reading the informed consent statement and checking a box indicating their agreement. The data collection has been reviewed and approved by the ethics committee of the Vrije Universiteit Amsterdam (VCWE 2020-041R1) and Nankai University (NKUIRB2022127).

Study sample

In this study, 36 Chinese autistic adults aged 17 to 51 years completed a self-report questionnaire. We then selected 29 Dutch autistic adults from the NAR dataset

who matched the Chinese sample in terms of sex (female/male), self-estimated intellectual ability (below/above an IQ of 70), age and age of autism diagnosis (allowing for a difference of 7 years). Table 1 presents the demographic information.

Table 1 The Demographic Variables between China and the Netherlands

Variables	China		The Netherlands		Statistics
	N / *M*	% / SD	N / *M*	% / SD	
Total N	36	100.0	29	100.0	
Sex					χ^2= .02, p > .05
Male	23	63.9%	18	62.1%	
Female	13	36.1%	11	37.9%	
Mean age	26.43	7.59	28.00	7.35	t=-.85, p > .05, d = 7.48
Mean age of diagnosis	10.96	9.38	15.91	9.81	t=-1.85, p > .05, d = 9.57
IQ level					$\chi 2$= 2.54, p >.05
IQ below 70	11	30.6%	4	13.8%	
IQ above 70	24	66.7%	24	82.8%	
Missing	1	2.8%	1	3.4%	

Measurements

Outcome measures

Objective psychosocial functioning. Following Scheeren et al. (2022) we measured employment status, living situation, and friendship, with hierarchical ratings reflecting different degrees of attainment in these areas (see supplementary Table S16). Given expected country differences in living arrangements, we analysed employment, friendships and living situations separately.

Life satisfaction. Life satisfaction was measured by the 0 to 10 Cantrill Ladder scale: 'Where would you rate your life generally on a scale from 0 to 10?' with '10' indicating the best possible life and '0' the worst possible life. Higher scores indicate higher life satisfaction (Cantril, 1965).

Internalized stigma. The 10-item version of the internalized stigma of Mental illness (ISMI-10) was used to measure the internalized stigma associated with being autistic. (Ritsher et al., 2003) Each item rated on a 1 (strongly disagree) to 4 (strongly agree) Likert scale. Item 2 and item 9 are reversed scored. The ISMI has been widely used around the world like China and the Netherlands with good reliability and validity (Boyd et al., 2014; van Beukering et al., 2022; Young et al., 2016). The ISMI-10 score is calculated by dividing the sum of item scores by the number of answered items. The ISMI-10 showed adequate internal consistency ($\alpha_{Chinese} = 0.69$, $\alpha_{Dutch} = 0.76$). In this paper, the score was used as a continuous variable for analysis. We interpreted the score based on the 4-category method(Lysaker et al., 2007): minimal to no internalized

stigma (1.00–2.00), mild internalized stigma (2.01–2.50), moderate internalized stigma (2.51-3.00), and severe internalized stigma (3.01-4.00).

Demographic variables

Self-estimated intellectual ability was reported at seven levels, ranging from an IQ below 40 (severe intellectual impairment) to an IQ above 130 (gifted). First, autistic adults were asked whether they had ever taken an official IQ test or whether their IQ had ever been determined by a clinical psychologist or professional. If so, they were asked to select the appropriate IQ level that best described their intellectual ability. If the autistic adult had never taken an IQ test or their IQ score was unknown, they were asked to estimate their intellectual ability and select the corresponding level. Most IQ reports (Chinese: 75%; Dutch: 69%) were based on a prior IQ test. For the analyses, intellectual ability was categorized into below 70 and above 70. Proxy-estimated IQ has been found to correlate highly with adaptive functioning ($r = -0.71$).(Werkman et al., 2020) We also found an overlap between self-estimated IQ and highest educational level (IQ $\leq$ 70: 80% low, 20% middle educational level; IQ >70: 12.5% low, 25% middle, 62.5% high educational level). Both findings provide preliminary support for the validity of the self-estimated IQ measure.

Educational level was categorized into low, middle and high, based on the educational systems in each country. Primary schools and special schools were categorized into low level, secondary schools were categorized into middle level, and

university (Bachelor, Master, Doctoral) were categorized into high level of education in both countries.

Instruments Translation

All of the questions and questionnaires were originally developed in Dutch. The translation into Mandarin Chinese was conducted following a forward and backward procedure (Hall et al., 2017). Initially, the items were translated into Mandarin by two Chinese postdoc proficient in Dutch. Then, a Dutch translation agency back-translated these items into Dutch. This back-translated version was compared with the original by two native Dutch speakers, with discrepancies revised for accuracy. Finally, the Chinese version was reviewed and adjusted by the authors, ensuring it was linguistically equivalent to the Dutch original.

Results

Descriptive Statistics

Chinese autistic adults (23 males and 13 females) and Dutch autistic adults (18 males and 11 females) were included in this study. A majority of autistic adults in both countries self-reported an IQ above 70 (Chinese: 66.7%; Dutch: 82.8%) and over half of the samples in both countries reported middle to high educational levels (Chinese 66.6%; Dutch: 72.4%).

Objective psychosocial functioning, life satisfaction and internalized stigma

Contrary to our hypothesis, a similar majority of participants in both countries (68.5% in China and 75.8% in the Netherlands) were engaged in either regular paid or non-regular paid employment (See details in Table 2). Likewise, most of the autistic adults reported having friends in both countries (66.7 % in Chinese and 82.7% in Dutch sample). The majority of Chinese participants (62.9%) reported living with their parents and no one lived in a healthcare facility. In contrast, a smaller percentage (42.9%) of Dutch participants lived with their parents and 5 Dutch participants (17.9%) lived in a healthcare facility.

Chinese autistic adults reported a similar level of life satisfaction as Dutch adults (t=-.88, $p > .05$, $d = 1.91$), but a higher level of autism-related internalized stigma than Dutch adults (t= 4.22, $p < .001$, $d = .44$). See statistical details in Table 2.

Table 2 The Outcome Variables between China and the Netherlands

Variables	China		The Netherlands		Statistics
	N / *M*	% / SD	N / *M*	% / SD	
Total N	36	100.0	29	100.0	
Education level					$\chi 2 = .65$, $p > .05$
Low level of education	12	33.3%	8	27.6%	
Middle level of education	7	19.4%	8	27.6%	
High level of education	17	47.2%	13	44.8%	
Employment status					$\chi 2 = .45$, $p > .05$
Not any kind of employment	11	31.4%	7	24.1%	
Non-regular employment	6	17.1%	5	17.2%	
Regular paid employment/studying	18	51.4%	17	58.6%	
Living situation					$\chi 2 = 9.28$, $p < .05$
Living in a healthcare facility	0	0.0%	5	17.9%	
Living with parents or family	22	62.9%	12	42.9%	
Living independently with housing assistance	2	5.7%	0	0.0%	
Living independently	11	31.4%	11	39.1%	
Friend relationships					$\chi 2 = 2.92$, $p > .05$
Hardly any friends	12	33.3%	5	17.2%	
Other friends	14	38.9%	11	37.9%	
Close friends	10	27.8%	13	44.8%	
Life satisfaction	5.81	2.34	6.28	1.87	$t = -.88$, $p > .05$, $d = 1.91$
Internalized stigma	2.25	4.45	1.79	4.28	$t = 4.22$, $p < .001$, $d = .44$

Associations with internalized stigma

To detect a medium-sized effect (f=0.15) in a linear regression analysis, with 80% power and a 5% significance level, a smallest total sample size of 55 is needed (Cohen, 2013).Therefore we explored the associations between objective and subjective outcomes and internalized stigmas across both samples.

A linear regression analysis across both samples, with internalized stigma as a predictor, life satisfaction as dependent variable, showed that internalized stigma had a significant negative impact on life satisfaction scores (B = -1.58, R^2 = .13, $F(1, 64)$ = 9.48, $p < .005$).

Separate ordinal regression analyses with employment, friendship and living situation as categorical outcomes and internalized stigma as a predictor across both samples revealed that internalized stigma negatively impacted the quality of friendships, $\chi^2(1) = 4.30$, B = - 1.03. $p < .05$, but was not associated with employment, $\chi^2(1) = 2.81$, $p > .05$, or living situations, $\chi^2(1) = .96$, $p > .05$. Internalized stigma accounted for approximately 5.1% of the variance in friendship quality (Proportional Reduction in Error = .051), suggesting a modest yet significant negative relationship between internalized stigma and friendship.

Discussion

We compared self-reported levels of employment, friendship, living situation and life satisfaction of autistic adults in China and the Netherlands. Against our

expectation, Chinese and Dutch autistic adults reported a similar and fairly high degree of employment and most reported having friends. Life satisfaction ratings were moderate, but similar in both samples. As expected, Chinese autistic adults more often lived with their parents compared to Dutch autistic adults. Also, Chinese autistic adults reported more internalized stigma than Dutch autistic adults. Lower autism-related internalized stigma was linked with closer/more friendship and higher life satisfaction ratings across countries.

In contrast to our hypothesis, autistic adults reported similar and positive objective outcomes in terms of employment and friendships. Previous meta-analyses have reported that in Western countries the psychosocial functioning of autistic adults was on average poor, and a higher IQ appears to promote a better outcome (Howlin, 2021; Mason et al., 2021; Steinhausen et al., 2016). Gotham et al. (2015) and Scheeren et al. (2021) observed better objective psychosocial outcomes for self-reporting adults with high estimated IQ and/or a late autism diagnosis (Gotham et al., 2015; Scheeren et al., 2022). Despite the positive objective outcomes in our current study, participants in both countries generally reported moderate life satisfaction in both countries. Life satisfaction ratings were consistently lower than in the general population in each country, as indicated by the World Happiness Report in 2022 (with average happiness scores of 7.40 in the Netherlands and 5.82 in China) (Helliwell et al., 2022).

The similarity in positive objective outcomes between China and the Netherlands might be due to a majority of autistic adults in both countries with self-estimated IQ above 70 and the relatively high level of educational attainment. Another

explanation for the positive outcomes might be that potential beneficial impacts (e.g., policy commitments to include autistic adults in society and heightened family-based support in China (Fisher et al., 2011) mitigate the negative impacts of more autism-related stigma. For example, in China, there are newly initiated services, policies (Xiao, 2023), like 'recommendations on strengthening rehabilitation and care services for autistic adults', and programs promoting the employment of autistic adults, such as a Fujian courier station allowing autistic youth to sort and deliver packages (Li & Qi, 2023). Also, some family-based support may serve as a substitute for professional services to increase objective psychosocial functioning (Sun et al., 2013) and quality of life of autistic adults (Hayes et al., 2023). Supportive policies and family support may improve the inclusivity and well-being of autistic adults.

A high percentage (62.9%) of Chinese adults lived with their parents compared to Dutch adults (42.9%), possibly reflecting cultural differences in traditional family values and stronger family support in China. This finding aligns with observations by McCabe and Wu (2009), who found that even employed autistic adults crucially rely on their mothers' assistance to meet workplace expectations and to enhance their objective psychosocial functioning (McCabe & Wu, 2009). Other potential reasons why it may be more common for Chinese adults (autistic or non-autistic) to live with their parents and family are filial piety (children are traditionally expected to care for their elders when they grow up), high costs of living, and lack of affordable and adequate housing (Gan & Fong, 2020; Wang et al., 2021). An individual's living situation may

therefore not accurately reflect their psychosocial functioning and may have different meanings within different cultural contexts.

As expected, Chinese adults reported more autism-related internalized stigma than Dutch adults. The biggest group difference was found in the ISMI-10 item describing social withdrawal in order to protect family or friends from embarrassment (See supplementary Table S17 and Figure S6). This may reflect a cultural pressure on safeguarding social harmony and protecting their family's reputation among Chinese autistic adults, which is in keeping with prior findings that Chinese families with autistic individuals tend to conceal their condition and hide from the public (Chan & Lam, 2018; Mak & Kwok, 2010). Additionally, Chinese autistic adults more often endorsed the statement 'People without autism could not possibly understand me'. This tentatively suggests that the double empathy problem might be bigger in China. The double empathy problem is a theory which posits that the social communication gap between autistic and non-autistic individuals is created and felt by both autistic and non-autistic people (Milton, 2012; Mitchell et al., 2021). Thus, multiple factors, including but not limited to public stigma, may help to explain the higher levels of internalized stigma among Chinese autistic adults compared to their Dutch counterparts.

The strong negative correlations between internalized stigma and life satisfaction and friendship are in line with previous research (Botha & Frost, 2018; Cage et al., 2018; Chan & Tsui, 2023), highlighting the role of internalized stigma in the wellbeing of autistic adults. Internalized stigma can lead to reduced self-esteem, low self-efficacy, and reduced help-seeking behaviours, which negatively impact the

pursuit of friends, work and personal goals, further hampering life satisfaction (Corrigan et al., 2009; Li et al., 2023). Yet, despite a higher level of internalized stigma in the Chinese sample this did not result in a lower life satisfaction rating compared to the Dutch sample. We acknowledge that multiple factors, like social support, income, and access to support services, may influence life satisfaction (Li et al., 2023), so the effect of internalized stigma may be relatively small. Future research ideally includes quantitative and qualitative methods, focusing on social support, autism-specific services and autistic adults' personal needs, to provide deeper insights into the factors influencing objective psychosocial functioning and wellbeing of autistic adults in different countries.

Our study has some limitations. Firstly, we used self-estimated IQ reports (Scheeren et al., 2022), which are informative, but do not reflect objective measures of cognitive ability. Furthermore, the way we measured employment, living situation and friendship may not align with a Chinese context and culture. Thirdly, the relatively small sample sizes may limit our generalizability and stresses the importance of replication in larger samples. For instance, we detected a non-significant, but large country effect (d = 1.91) on self-reported life satisfaction, suggesting that an increase in sample size might potentially lead to statistically significant differences. Despite extensive efforts and a nationwide network in China, it proved challenging to recruit self-reporting autistic adults for research purposes due to the unavailability of autistic adults who can and want to self-report.

Given the study limitations and our own study findings, we suggest that future research focuses on what “appropriate psychosocial functioning” and quality of life means to autistic adults in different cultures by doing qualitative research. Future research should also develop suitable, accessible and culturally sensitive measures including person-environment fit indices for autistic adults and their families (Henninger & Taylor, 2013; Lai et al., 2020), This type of research will further contribute to learn more about and better meet the support needs of autistic adults across the globe (Georgiades & Kasari, 2018; Mason et al., 2021). Additionally, given the higher levels of autism-related internalized stigma among Chinese adults, we advocate further research to develop and examine effects of positive, neuro-affirmative approaches to support autistic adults (Han et al., 2023).

This cross-country study is a first step in understanding the psychosocial outcomes of autistic adults in China compared to autistic adults in the Netherlands. Despite obvious cultural and contextual differences, life satisfaction, employment, and friendship levels were surprisingly similar for Chinese and Dutch autistic adults. Heightened internalized stigma among Chinese adults may be caused by societal differences in the acceptance of autism. In both countries, higher internalized stigma was associated with lower levels of objective psychosocial functioning and life satisfaction. More research is needed to further investigate and support objective and subjective psychosocial functioning of autistic adults within the global autistic community.

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