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Brief report: Parenting stress among Chinese and Dutch caregivers of children with autism

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ABSTRACT

Background: Parenting stress is higher in caregivers of autistic compared to typically developing children. Culture and context may impact parenting stress. Some studies suggest that Asian caregivers with autistic children experience more stress compared to European/American caregivers although similar levels have also been reported. Child and caregiver factors (age, gender, income and educational level) may affect parenting stress differently in Asian and European countries. We compared parenting stress levels between caregivers of autistic children from China and the Netherlands, and examined the impact of caregiver factors (age, income, educational level) and child factors (gender) on parenting stress in both countries, and exploring the association with caregivers' worries about COVID-19.

Method: We used the 11-item Parenting Distress Subscale (PD) of the Nijmegen Parenting Stress Index (NPSI-PD) to compare parenting stress between two groups: 95 Chinese caregivers (76 boys; 19 girls) and 118 Dutch caregivers of autistic children (93 boys; 25 girls) aged 2–16 years. Controlling for child's gender, caregivers' age, income, educational level and COVID-19-related concerns.

Results: Chinese caregivers of autistic children reported higher parenting stress levels than Dutch caregivers, despite fewer COVID-19 worries. Younger caregivers reported more parenting stress in both countries.

Conclusion: Culture and context may play a role in the parenting stress of caregivers with an autistic child. Factors influencing parenting stress in different socio-cultural settings are an important issue that requires further study.

All caregivers experience some degree of parenting stress (Reitman et al., 2002; Tharner et al., 2012). Due to the developmental, behavioral and social challenges associated with autism (Barroso et al., 2018), caregivers of children with Autism (Autism Spectrum Disorder) generally experience higher than average levels of stress, with negative effects on well-being (Shorey et al., 2020), marital satisfaction (Ilias et al., 2017), parenting quality and children's development (Tharner et al., 2012).

Some studies have suggested that Eastern Asian caregivers of autistic children experience more stress than their Western European

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counterparts (DeLambo et al., 2011; Giannotti et al., 2021), though similar stress levels were also reported (Smith et al., 2021). Eastern Asian countries (e.g., China) emphasize interdependence and in-group (family, community, and society) norms compared to Western European countries (e.g., the Netherlands), where individualism and independence are valued more (Meyer, 2010). Chinese caregivers tend to value their own needs less and fear the non-conformity of their autistic child (McCabe, 2007). This promotes self-sacrificing behavior and social isolation, which negatively impact caregivers' well-being (Smith et al., 2021). Knowledge about autism may be lower in the Chinese community (Yu et al., 2020), and stigmatization and discrimination may be higher (Chan & Lam, 2018; Mak & Kwok, 2010).

In addition, the availability, accessibility, affordability, and acceptability of support services differ between the high-income countries (e.g., the Netherlands) and low and middle-income countries (e.g., China). The Netherlands has adequate formal support services in education and healthcare, along with sufficient financial support for families with special needs nationwide (van Kessel et al., 2019). While, China has a scarcity of child psychiatrists (Wu & Pan, 2019), limited government financial support and professional support is concentrated in large cities (Sun et al., 2013). When comparing country differences in parenting stress of autistic children, contextual backgrounds, such as socioeconomic status (SES) and stressful situation (e.g. Covid-19 worries) need to be taken into account.

Previous findings suggesting that the level of parenting stress may differ across cultures were based on small samples of autistic children (Giannotti et al., 2021) or a narrow focus on racial and ethnic variations within a single country (DeLambo et al., 2011). In addition, older age (Smith et al., 2008), female gender of the child (Mandell & Salzer, 2007), and higher parental education and income level (Athari et al., 2013) are associated with lower parenting stress, while the effects of socioeconomic status (SES) and parent's age vary across countries (DeLambo et al., 2011; Jiar & Xi, 2012). Therefore, in this study, we will examine child and caregiver factors of parenting stress in China and the Netherlands.

In this pre-registered study (XXX), we will (a) compare parenting stress levels between caregivers of autistic children from Eastern Asian (China) and Western European countries (the Netherlands) using the abbreviated Parenting Stress Index (Brock et al., 1992), and (b) examine the impact of caregiver (age, income, educational level) and child (gender) factors on parenting stress in both countries. As we collected the data during the COVID-19 pandemic, we will also explore whether caregivers' worries about COVID-19 are associated with parenting stress. We expect that caregivers of autistic children in China experience higher levels of parenting stress than Dutch caregivers.

1. Method

1.1. Study sample

Participants were 99 Chinese caregivers (caregivers of 79 boys and 20 girls), and 197 Dutch caregivers (caregivers of 160 boys and 37 girls) of children with autism diagnosed according to DSM-IV or DSM-5 criteria. In China, researchers of the Autism Research Center, Nankai University, Tianjin City, invited caregivers with autistic children to participate in our study via an online survey between December 2020 and March 2021. Tianjin City, one of the four provincial cities in China with a population of approximately 13.63 million (https://www.tj.gov.cn/sq/tjgb/202303/t20230317_6142972.html?eqid=9508506200004f300000000564893326), plays a leading role in providing autism rehabilitation service. It has established more than 100 service centers for autism, 64 of which are designated rehabilitation institutions (out of 2304) by the China Association of Persons with Psychiatric Disability and their Relatives (CAPPDR), indicating a well-organized distribution of rehabilitation facilities and high capacity and quality of professional service (source: https://www.cappdr.org/). To ensure a representative sample and wider geographical coverage, the survey was distributed to caregivers across multiple provinces in China, such as Zhejiang, Guangdong and Jiangsu.

The Dutch data were collected via the Netherlands Autism Register. The Dutch data were collected between June and August 2020. In both China and the Netherlands, data were collected after the first wave of the COVID-19 virus, when governmental restrictions had loosened up (e.g., schools, restaurants, and public transportation were reopened). The average numbers of reported deaths from COVID-19 per week were below 5 in both countries.

1.2. Measurements

The 11-item Parenting Distress Subscale (PD) of the Nijmegen Parenting Stress Index (De Brock et al., 1992), a modified Dutch version of the Parenting Stress Index-Short Form (Abidin, 1983; McStay et al., 2014) includes questions like: "Being a parent of this child is harder than I thought". Answers range from 1 (totally disagree) to 6 (totally agree), resulting in a total stress score, with higher scores representing more stress. The translation of the Chinese version of the 11-item NPSI-PD was done by three researchers, following the forward and backward procedure (Hall et al., 2017). The Cronbach's alpha reliability of the NPSI was between.92 and.95 (De Brock et al., 1992). High internal consistency was found in this study in both the Chinese (Cronbach's alpha =0.84) and Dutch (Cronbach's alpha =0.90) samples.

Caregivers' educational level was categorized into the low, middle and high level of education based on the Chinese and Dutch educational system separately. Primary school and special school were categorized into low level of education, secondary school were categorized into middle level of education, and university (Bachelor, Master, Doctoral) were categorized into high level of education in both countries.

Family income was categorized into low (China: 0-¥4000 a month, €0-€6252 a year; Netherlands: €0-€30000), middle (China: ¥4000 - ¥10000 a month, €6252- €15629 a year; Netherlands: €30000-€70000), and high income (China: above ¥10000, above €15629

a year; Netherlands: >€70000) based on country-specific percentiles (low: below 30th percentile; middle: 30th-70th percentile; high: above 70th percentile) of the National Bureau of Statistics of China (2020) and Statistics Netherlands (CBS; 2020) separately.

COVID-19-related worries were assessed by self-reported worries about 1) the COVID-19 pandemic, 2) getting sick, and 3) someone close getting sick. The first item "how worried have you been about the COVID-19 crisis in recent weeks?" was rated on a 10-point scale ranging from "not worried" (rated as 1) to "extremely worried" (rated as 10). Two items asking worries about "getting sick yourself" and "someone close to you getting sick" were each rated on a 5-point scale, ranging from "never" (rated as 1) to "always or almost always" (rated as 5). The score from the latter two items were multiplied by two, resulting in a standardized rating out of 10 for each. By summing up the scores from all three items, a maximum total score of 30 was achievable. A higher score indicates more COVID-19-related worries. High internal consistency was found in this study in both the Chinese (Cronbach's alpha =0.83) and Dutch (Cronbach's alpha =0.82) samples.

1.3. Data analysis

Prior to the main cross-country comparison analysis, we tested the factorial validity of the NPSI-PD to investigate whether the questionnaire assesses the same construct in China and the Netherlands. We conducted confirmatory factor analyses (CFAs) on the NPSI-PD using *Mplus* version 7 in Chinese and Dutch samples separately. A hierarchical multiple regression analysis was used to examine predictors of parenting stress, such as caregiver factors (age, income, educational level) and child factors (gender) and COVID-19 worries (step 1), followed by country (step 2) and the interaction terms between caregiver/child factors and country (step 3).

Based on a power of 0.95 and an alpha level of 0.05, the required total sample size to detect a medium effect (f = 0.15) in a multiple regression analysis is 160 participants. This sample size criterion was met (Cohen et al., 2003).

2. Results

Due to missing values on caregivers' age, family income and educational level, 95 Chinese and 118 Dutch participants (25–57 years) were included in the final analysis (see Table 1 for participant details). Caregivers included in the analysis did not differ from caregivers excluded from the analysis regarding their age, gender, Covid-19 worries, and parenting stress (see supplementary Table 1). Most caregivers in both countries were well educated (middle to higher educational level; 92%) and had middle to higher-level family income (83%). A majority of the respondents were mothers (91%). Children with autism were aged between 2.0 and 16.1 years (M = 9.64 years, SD = 4.24) in both countries. Chinese children were significantly younger than the Dutch children ($M_{Chinese}$ = 6.01, M_{Dutch} = 12.56, t = 17.538, $p < .001$). Dutch caregivers reported significantly more Covid-19 worries than Chinese caregivers (t = 3.92, $p < .001$, d =0.53).

The scree plots for both the Chinese and Dutch data confirmed the one-factor model of NPSI-PD (see Supplementary Figure 1 and Supplementary Table 3), in line with the original NPSI-PD subscale (De Brock et al., 1992). The CFA results partially confirmed the fit for the one-factor model (See factor analysis details in supplementary materials).

Table 2 shows the results of the hierarchical multiple regression analysis. Pearson correlation coefficients between child/caregiver factors and parenting stress are shown in Supplementary Table 2. As child's age was highly correlated with the country ($r = -0.770$, $p < .0$), we excluded child's age in the multiple regression analysis but examined the association with child's age separately in the

Table 1
Parent and child demographics and characteristics according to cultural background[a].

	Chinese (n = 95)		Dutch (n = 118)		t / χ^2
	n (%)	*M* (*SD*)	n (%)	*M* (*SD*)	
Child's gender					0.045
Boys	76 (80)		93 (78.8)		
Girls	19 (20)		25 (21.2)		
Child's age (2–16 years)		6.01 (2.70)		12.56 (2.73)	17.538**
Informant					13.246*
Mother	79 (83.2)		115 (97.5)		
Father	16 (16.8)		3 (2.5)		
Caregiver's age		35.99 (4.62)		45.13 (5.28)	13.263**
COVID-19 worries (5–30)		13.59 (6.07)		16.64 (5.30)	3.917**
Primary caregiver educational level					9.957*
Low educational level	10 (10.5)		5 (4.2)		
Middle educational level	17 (17.9)		42 (35.6)		
High educational level	68 (71.6)		71 (60.2)		
Family income level					2.021
Low income level	13 (13.7)		25 (21.2)		
Middle income level	51 (53.7)		58 (49.2)		
High income level	31 (32.6)		35 (29.7)		
Parenting Stress (11–66)		43.36 (8.45)		32.92 (11.69)	-7.56**

SD: standard deviation.
* $p < .01$, **p < .001
a. Final samples included in the hierarchical multiple regression analysis

Table 2
Hierarchical Multiple Regression analyses of demographic variables and country as predictors of parenting stress in ASD.

Predictors	b	SEb	β	R^2 change
Step 1				0.15**
Constant	51.15	6.72		
Child gender	0.46	1.85	0.02	
Caregivers age	-0.58	0.11	-0.34**	
Family income level	-0.99	1.14	-0.06	
Caregivers educational level	1.72	1.28	0.09	
COVID-19 worries	0.48	0.13	0.24**	
Step 2				0.16**
Constant	2.60	9.31		
Child gender	1.54	1.68	0.05	
Caregivers age	0.05	0.14	0.03	
Family income level	-0.97	1.03	-0.06	
Caregivers educational level	1.73	1.16	0.09	
COVID-19 worries	0.66	0.12	0.33**	
Country	12.92	1.88	0.56**	
Step 3				0.03
Constant	-23.50	23.51		
Child gender	7.19	5.13	0.25	
Caregivers age	-0.11	0.41	-0.06	
Family income level	-0.50	3.13	-0.03	
Caregivers educational level	6.21	3.69	0.33	
COVID-19 worries	1.49	0.39	0.75**	
Country	30.06	14.82	1.29*	
Country × Child gender	-4.15	3.36	-0.31	
Country × Caregivers age	0.11	0.28	0.15	
Country × family income level	-0.28	2.11	-0.04	
Country × educational level	-2.96	2.32	-0.42	
Country × COVID-19 worries	-0.56	0.24	-0.50*	

* $p < .05$ ** $p < .001$

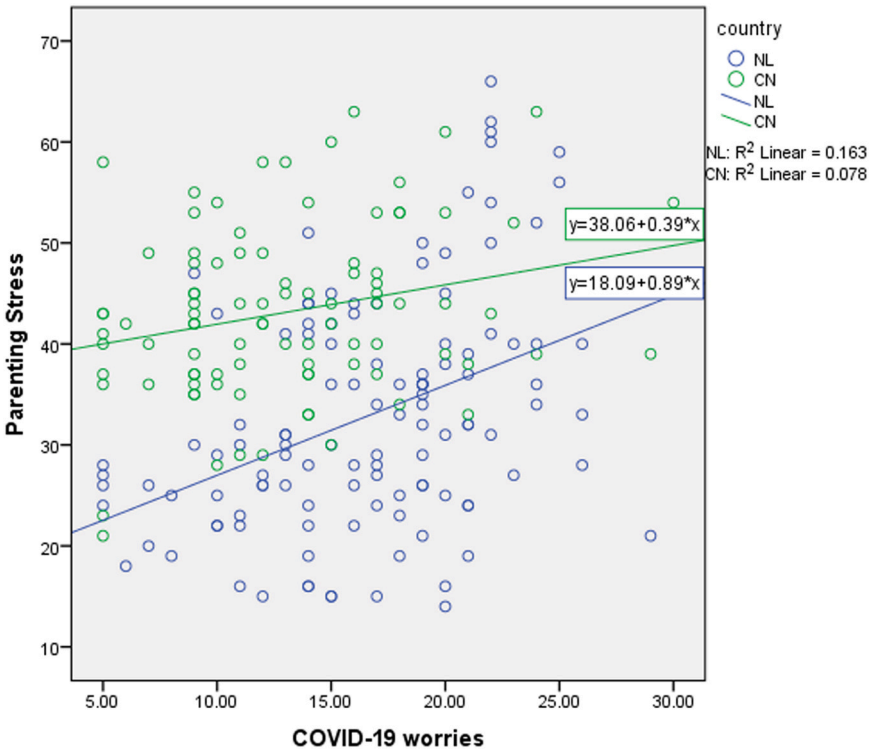

Fig. 1. The association between COVID-19 worries and parental stress in both countries.

Chinese and Dutch samples. Within both groups, children's age and parenting stress are not significantly correlated (Chinese: $r = -0.025$, $p = .785$; Dutch: $r = 0.074$, $p = .476$).

At Step 1 of the multiple regression model, 15% of the variance in parenting stress was explained by caregiver factors, child factors and COVID-19 worries, F (5212) = 7.37, p < .001. Younger caregivers ($\beta = -.34$, $p <$[0.001 and caregivers with more COVID-19 worries ($\beta = .24$, $p <$[0.001 reported more parenting stress. Other demographic factors did not make a significant independent contribution to the variance in parenting stress.

At Step 2, factor Country explained significant variance (15.9%) in parenting stress ($\beta = .56$, $p <$[0.001 over and above the other factors, indicating that Chinese caregivers reported higher parenting stress compared to Dutch caregivers when controlling for the other demographic variables ($M_{\text{Chinese}} = 43.36$, $M_{\text{Dutch}} = 32.92$, $t = -7.56$, $p < .001$). The parenting stress levels in Dutch caregivers was similar to those previously reported in Dutch caregivers raising an autistic child using the same measurement ($M = 32.38$) (Clifford et al., 2022). The association between informants' age and parenting stress lost significance after adding Country to the regression model.

In Step 3, adding interaction terms to the model did not add explained variance in parenting stress, but the association between parental COVID-19 worries and parenting stress did vary significantly per country ($\beta = -.50$, $p =$[0.023. In both groups of caregivers, there is a small positive association between COVID-19 worries and parenting stress, but this association is significantly stronger in the Dutch sample (see Fig. 1).

3. Discussion

The one-factor model of the parenting stress scale was confirmed in China and the Netherlands. Chinese caregivers of autistic children reported significantly higher parenting stress levels than Dutch caregivers. Younger caregivers and caregivers with more COVID-19 worries reported more parenting stress in both countries. Family SES and children's age were not associated with parenting stress.

Consistent with previous studies that reported higher parenting stress in Eastern Asian caregivers compared to Western European caregivers (DeLambo et al., 2011; Giannotti et al., 2021), our findings reveal that Chinese caregivers of autistic children experienced higher levels of parenting stress compared to Dutch caregivers. At least three cultural and contextual factors may account for this finding. First, the focus on family relationships and obligations in Asian culture may promote self-sacrificing behavior and the social isolation of caregivers, negatively affecting their mental health (Grace et al., 2018). In Western European cultures (e.g., Dutch culture), caregivers may try to seek more external support to help their child live independently (Chun et al., 2006), thereby lowering their parenting stress. Secondly, the Chinese care and support system for autistic individuals may be limited due to restricted access and affordability (de Leeuw et al., 2020; Durkin et al., 2015), lack of experienced and qualified practicing clinicians (Reardon et al., 2017) and low confidence in available interventions (Cauce et al., 2002). External resources, such as formal support services, are an important protective factor against parenting stress (Liao et al., 2022; Zeng et al., 2020). Additionally, China does not have a well-developed social security or welfare system (Huang et al., 2013). Very few families can afford treatment and support for their children with autism on a regular basis. Thirdly, Chinese caregivers may also be burdened with concerns such as loss of face (mianzi) due to their autistic child's social and behavioral difficulties. 'Mianzi' (or 'lian' in mandarin Chinese) refers to a person's desire to maintain their social image (Mak & Kwok, 2010; Yabuuchi, 2004).

COVID-19 worries and parenting stress were associated in both countries. The fact that Chinese caregivers reported more parenting stress, but fewer COVID-19 worries than the Dutch caregivers, suggests that the group difference in parenting stress cannot be attributed to generally higher stress levels in all domains.

Consistent with previous findings, younger caregivers reported more parenting stress in both countries (Cheung & Yeung, 2021). It is possible that younger caregivers are in general more inexperienced in life and may exhibit lower levels of confidence in their parenting ability. The "wear and tear" hypothesis suggested that as a child with Autism Spectrum Disorder (ASD) reaches adolescence, the persistent nature of parenting stress may gradually accumulate over time, leading to an elevated sense of burden in caregiving, heightened levels of intrapersonal distress, and increased maladaptive coping strategies appear (Cadman et al., 2012; Rezendes & Scarpa, 2011). Notably, a large proportion of the caregivers in our study were with children in pre-school and early school ages and most of them were newly diagnosed with autism (50% of Dutch participants and 95% of Chinese participants). Therefore, our findings may reflect that the acute/sub-acute responses of caregivers which could be influenced by their age/maturity. These findings underscore the importance of providing targeted support and resources, such as the utilization of adaptive coping strategies (e.g. cognitive reframing; seeking social support), to younger caregivers who may be facing unique challenges in their caregiving journey.

We found no associations between family SES, children's age and parenting stress, possibly due to a lack of variance in SES. Although the age of a child with autism is a variable that has typically been found to affect parenting stress in a American/ European context (Rivard et al., 2014; Smith et al., 2021), there are some inconsistent findings in an Asian context (DeLambo et al., 2011; Jiar & Xi, 2012). Because autistic children generally tend to be more highly dependent on their caregivers' support compared to their non-autistic peers, the age of the children may not influence their caregivers' stress as much (McStay et al., 2014).

The higher levels of parenting stress in Chinese compared to Dutch caregivers emphasizes the necessity of supporting caregivers of children with autism through tailored interventions that take caregivers' cultural and contextual backgrounds into account. Interventions aimed at stress management and coping skills, reducing self-blame and worries associated with perceptions of competence and parental role burden may be particularly beneficial for (younger) Chinese caregivers (Chanet al., 2018; Hu et al., 2019; Lai et al., 2015). Social support services, including individualized and appropriate educational services, should be contextually adapted, physically available (both in major cities and remote areas), and low-cost access for Chinse families with autism, especially those with

lower SES, to reduce the barriers to help-seeking (Divan et al., 2021; pp. 4, 1340; Huang et al., 2013). More knowledge of autism and developing trusting relationships with families is also required to reduce social stigma in the Chinese population (Huang et al., 2019).

Some local governments in China have provided respite care services and enhanced communication between families with autism (Chan et al., 2018; Yu et al., 2016). As a result, they observed considerable improvements in parental mental health (Wang & Hu, 2014). Moreover, the positive association between COVID-19 worries and parenting stress in both countries suggests that caregivers of autistic children may need professional help to reduce parenting stress in particularly stressful situations such as the COVID-19 pandemic. To address the specific challenges posed by the pandemic, various forms of support are necessary, including online support resources, access to child mental health care and information, and empathy from healthcare professionals and other support networks. These measures can be particularly effective in helping caregivers cope with the increased stress and challenges brought about by the pandemic.

Our current research has some limitations, the heterogeneity of our sample in terms of child age, caregivers' age and educational background may limit comparability. Second, low SES caregivers may have limited access to the internet or are difficult to reach for research, and this may particularly be true in China (the proportion of individuals using the internet nationwide is 70% in China and 91% in the Netherlands; World Bank, 2020). Third, we did not collect data about children's severity of autistic traits or co-occurring behavioral problems. This limitation means we can't rule out the possibility that the higher level of parenting stress found in Chinese caregivers is explained by greater symptom severity in their children (Ilias et al., 2018; Ingersoll & Hambrick, 2011; Liu et al., 2021; McStay et al., 2014).

Our results suggest that culture and context play an explanatory role in parenting stress levels of caregivers of autistic children, with Chinese caregivers reporting higher stress levels than Dutch caregivers. Younger caregivers of autistic children in particularly stressful situations such as the present COVID-19 pandemic may need professional help to reduce parenting stress. The needs of Asian caregivers with autistic children require more careful examination to inform the development of culture-specific support to help buffer parenting stress.

Ethics approval and consent to participate

All parents provided informed consent before joining the study. Preregistration of this study can be found at Open Science Framework (https://osf.io/p8zyd/). The data collection has been reviewed and approved by the ethics committee of the Vrije Universiteit Amsterdam (VCWE 2020–041R1) and Nankai University (NKUIRB2020059).

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data Availability

Data will be made available on request.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.rasd.2023.102224.

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