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# Institutionalized Chinese children with congenital medical conditions: Placement delay, developmental issues at arrival and current wellbeing



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#### ABSTRACT

*Background:* In the US, recent years have seen a significant increase in the number of internationally adopted children, especially those from China, with congenital medical conditions. To date, there is little research on the long-term wellbeing of international adoptees with congenital medical conditions.

*Method:* We investigated the relationship between congenital conditions and post-adoption mental disorder diagnosis and treatment in 235 female youth who were adopted from China about 15 years prior. The youth provided survey data on type of congenital conditions that they had, their developmental difficulties at the time of adoption, type of mental disorders that they currently had and the type of treatments that they were currently receiving.

Results: At adoption, the adoptees with congenital medical conditions were, on average, 20 months older than those without congenital medical conditions and had more developmental difficulties. The adopted youth who had two or more congenital conditions at adoption were more than twice as likely as their peers without congenital conditions to have mental disorder diagnoses (62.5% versus 27.63%), and > 2.5 times as likely to be receiving treatments (54.17% versus 20.39%). Youth with two or more congenital medical conditions at adoption were 5.5 times as likely as their peers with no congenital conditions to currently have three or more mental disorder diagnoses (33.3% versus 5.9%), and were about 3 times as likely as their peers with no congenital conditions to be receiving medical/psychological treatments (25.0% versus 8.55%). Path analysis showed that developmental difficulties at adoption functioned as a full mediator between the number of congenital conditions at adoption and current number of current mental disorders and number of treatments.

#### 1. Introduction

In recent years, there has been a significant increase in the number of internationally adopted children from China with medical conditions (Good, 2016; Miller, Pérouse de Montclos, & Sorge, 2016). Congenital deformities such as cleft lip and/or palate are commonly observed in children adopted from China (Shay et al., 2016; Swanson et al., 2014). To date, there is little research on the wellbeing beyond children for international adoptees who arrived at their adoptive homes with congenital medical conditions (Brumble & Kampfe, 2011). A better understanding of their developmental conditions at the time of adoption and their long-term wellbeing can not only inform the institutional care of and the placement practice for institutionalized children with similar conditions, but also inform professionals and prospective adoptive families about long-term services that may benefit these adoptees. In this study we aimed to fill in the gap in the literature with data on adopted Chinese youth's congenital medical conditions at the time of adoption,

developmental problems at the time of adoption and current wellbeing. Specifically, we examined how the presence of congenital medical conditions in adopted Chinese children was correlated with their (1) developmental status at the time of adoption and (2) wellbeing about 15 years after adoption.

#### 1.1. Theoretical framework

Based on the attachment theory (Bowlby, 1951) and the theory on the long-term detriment of maternal deprivation (Rutter, 1981), the absence of a caregiver who is consistently available physically and emotionally to meet a child's developmental needs presents a major risk in the child's development. Institutional care often deprives a child of a constant and consistent caregiver. For children with congenital impairment, the social-emotional demand of having to interact with different caregivers may aggravate the vulnerability. Additionally, a child with a diagnosed or visible (e.g., cleft lip) medical conditions may need

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frequent hospital visits for treatments of checkups, which can be stressful for the child, especially when the caregiving was inconsistently provided by institutional staff members. As such, orphanage children with congenital impairment likely will be particularly vulnerable for social-emotional difficulties. For children with undiagnosed congenital medical conditions (e.g., hearing impairment), their interactions with different caregivers and peers may be extraordinarily difficult and stressful. Nonetheless, adoption functions as a highly effective form of intervention (van IJzendoorn & Juffer, 2006) because it re-creates and re-establishes a social-emotionally enriched and predictable developmental context that promotes adopted children's recovery from early deprivation, their short and long-term growth and wellbeing. Even so, severely deprived children can continue to experience difficulties years after leaving the institution for adoptive homes (Colvert et al., 2008; van der Vegt, van der Ende, Ferdinand, Verhulst, & Tiemeier, 2009; Verhulst, Althaus, & Versluis-den Bieman, 1992). These perspectives point to the need to better understand the developmental conditions of adopted children with congenital medical conditions upon their adoption and their long-term wellbeing.

#### 1.2. Literature review

Infants and young children are particularly vulnerable to the medical, physical and socio-emotional detriments of institutional care (Dozier, Zeanah, Wallin, & Shauffer, 2012; Frank, Klass, Earls, & Eisenberg, 1996; Tottenham, 2012). For children with medical conditions, it could be speculated that the institutional environment will further compromise their development as they are particularly vulnerable for many challenges (Miller et al., 2016). Evaluations of newly adopted children have provided solid evidence that institutional care often compromises the development of the children in general (Albers, Johnson, Hostetter, Iverson, & Miller, 1997; Jenista & Chapman, 1987; Miller & Hendrie, 2000). For instance, Albers et al. (1997) reported that children experienced a one-month delay for every five months of living in institutions. As such developmental problems and medical conditions are quite prevalent among international adoptees (Hostetter et al., 1991; Miller & Hendrie, 2000).

For some time now, it has been a standard practice for newly adopted children from foreign countries to receive medical screening upon arrival in the United States. In one study, medical screening within one month of adoption on 293 non-Chinese children adopted by American families from 15 different countries revealed that 57% had at least one medical condition (Hostetter et al., 1991). Among children adopted from China, Miller and Hendrie (2000) reported that about 19% (36 out of 192) had unsuspected medical conditions (e.g., malformed fingers; hearing problems), although Johnson et al. (1996) reported that at the time of adoption major medical problems in Chinese adoptees were rare and older children were more impacted by institutional care. In another study on parent report of their adopted Chinese children's medical conditions, Tan, Marfo, and Dedrick (2007) found that cleft lip and/or palate, heart conditions and other visible congenital conditions (e.g., hand deformity) were the leading special needs observed in the children. Adopted children's country of origin is often associated with the types of medical conditions (Welsh & Viana, 2012). Fetal alcohol syndrome (FAS) was common in children adopted from Eastern Europe (Landgren, Svensson, Strömland, & Grönlund, 2000), but it has not been reported among Chinese adoptees (Miller & Hendrie, 2000).

In terms of wellbeing in adolescence, international adoptees are more likely than their non-adopted peers to have poorer mental health (Askeland et al., 2017; Barroso, Barbosa-Ducharne, Coelho, Costa, & Silva, 2017) and to receive mental health services (Bramlett, Radel, & Blumberg, 2007; Graff, Siersma, Kragstrup, & Petersson, 2015; Juffer & van IJzendoorn, 2005). Recent research (e.g., Matthews, Tirella, Germann, & Miller, 2016) has shown that the wellbeing (e.g., self-esteem) of youth and young adults who were adopted internationally was

unrelated to their age, growth and development at the time of adoption. For adoptees who had experienced severe and extended deprivation in the orphanages, there continues to be problems associated with early deprivation even in early adolescence (Rutter et al., 2007). Even for adoptees whose pre-adoption experiences were relatively favorable, post-pubertal outcomes (i.e., after the process of developmental catchup has ceased) were still correlated with pre-adoption psychosocial deprivation (Tan, Rice, & Mahoney, 2015). For instance, about 16% of youth adopted from China were found to have clinical-level internalizing problems (e.g., anxiety) (China, Tan, Camras, & Kim, 2016). It should be noted, however, that there might be a lower threshold for families of adopted youth to seek psychiatric treatment or for adopted vouth to be referred for psychiatric treatment (Warren, 1992). For instance, Rogeness, Hoppe, Macedo, Fischer, and Harris (1988) reported that among children admitted into a psychiatric clinic, girls who were adopted actually had fewer anxiety symptoms compared to nonadopted girls. However, existing studies have given little attention to the role that congenital medical conditions play in internationally adopted youth's developmental conditions at placement and postadoption long-term wellbeing. The current study was aimed to add to the existing literature on the associations between congenital medical conditions, developmental difficulties at the time of adoption and current well-being with a sample of adopted Chinese youth. We directly obtained data from the adopted youth.

#### 2. Method

### 2.1. Participants

Following the approval of the institutional review board (IRB: Pro00026088), the adoptees were recruited using two methods: (1) the database of a longitudinal study with a total of 780 families that had participated in at least one wave of the study and (2) an adoptee group that the second author belonged to. The group had an active membership of about 60 youth. To qualify for the current study, the participant needed to be at least 12 years of age. For eligible families (about 600) who were in the longitudinal dataset, we first contacted the parents to inquire if they would be interested in participating. For the adoptee group, information about the study was distributed to the members directly. In total, 400 surveys were requested by the parents or the youth themselves and 264 were completed or partially completed, yielding a response rate of 66.0%.

#### 2.2. Procedures and measures

In data collection, a personalized survey link hosted by Qualtrics was sent to the adoptive parent if the eligible participant was under 18 years of age. The parent was then instructed to share the link with the child. If requested, an extra link was sent to the parent to inspect the content of the survey. For participants who were older than 18 years of age, the personalized link was sent to the parent to forward to the adoptee, or if the adoptive parent had provided an email address of the adult child, the link was sent to the adoptee directly. In addition to obtaining consent from the adoptive parents prior to sending out the personalized survey link, informed consent or assent was obtained from the adoptee at the beginning of the survey. Only youth who checked "I would like to participate" button were able to move on to the survey. We collected data for three main predictors and two outcome variables.

#### 2.3. Congenital medical condition

Congenital medical conditions are one of the reasons that some Chinese children were relinquished by their birth parents. Based on existing studies that documented specific types of medical conditions from parent reports (Rosenthal, Groze, & Aguilar, 1991; Tan et al., 2007) and direct clinical screenings on international adoptees

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