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Caregiver burden and associated factors among primary caregivers of children with congenital disorders: a comparative cross-sectional study in Hunan Province, China

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Abstract

Background Congenital disorders are a significant public health concern and a leading cause of infant mortality and morbidity, causing a substantial burden to the family caregivers. Various psychosocial factors have been shown to be associated with caregiver burden across different populations, yet their associations are less studied among caregivers of children with congenital disorders. Thus, this study aimed to describe caregiver burden and psychosocial characteristics of caregivers of children with congenital disorders compared with healthy children's caregivers and to explore factors associated with caregiver burden of children with congenital disorders.

Methods A comparative cross-sectional study was conducted in three cities that represent high, medium, and low socioeconomic development in Hunan Province from January to December 2021. 194 caregivers of children with congenital disorders and 194 caregivers of healthy children were matched based on the family residence and the age. Sociodemographic information, caregiver burden, depressive symptoms, anxiety symptoms, perceived discrimination, social support, and family resilience were collected by a series of standardized scales and researcher-designed questionnaires. Multiple linear regression analysis was applied to identify factors associated with caregiver burden of children with congenital disorders.

Results Compared with healthy children's caregivers, caregivers of children with congenital disorders were more likely to have moderate-to-severe (19.6% vs. 14.9%) and severe (3.6% vs. 0.5%) burden, depressive symptoms (20.1% vs. 10.8%), and anxiety symptoms (23.7% vs. 11.9%). In addition, the following factors were independently associated with higher levels of caregiver burden among caregivers of children with congenital disorders: having resigned from

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work for childcare (β = 7.795, *p* = 0.002), anxiety symptoms (β = 11.285, *p* = 0.001), perceived discrimination (β = 4.645, *p* < 0.001), and low levels of family resilience (β=-0.196, *p* = 0.043).

Conclusions This study showed that caregivers of children with congenital disorders had a higher caregiver burden than healthy children's caregivers, which was associated with multiple psychosocial factors. The findings provide helpful guidance for future intervention programs to address caregiver burden by improving psychosocial factors such as strengthening family resilience, decreasing anxiety symptoms, and developing anti-discrimination activities.

Clinical trial number Not applicable.

Keywords Congenital disorders, Caregivers, Burden, Children

Background

Congenital disorders, defined as structural, functional, or metabolic anomalies that occur before birth, are a prevalent and significant public health concern affecting at least five million births annually around the world [1]. Congenital disorders are a leading cause of infant mortality and life-long disability [2]. According to the recent estimates by the World Health Organization [3], congenital disorders cause an annual 240,000 deaths among newborns within 28 days of birth and a further 170,000 deaths of children aged between 1 month and 5 years globally. The most common severe congenital disorders are heart defects, neural tube defects, and Down syndrome, 90% of which are concentrated in low- and middle-income countries [3]. China has a high burden of congenital disorders, with a prevalence rate of around 5.6%, and 900,000 newborns are diagnosed with congenital disorders each year [4].

Due to high dependency and cognitive deficiency, children with congenital disorders (CWCD) mainly rely on family caregivers to provide care and help with daily activities, medication management, appointment keeping, and economic and emotional support [5]. Therefore, parents or other primary caregivers play a crucial role in their disease treatment, rehabilitation, and management. However, long-term caregiving requires caregivers to contribute tremendous time, energy, and effort [5]. Additionally, some caregivers, especially moms, may experience a sense of guilt for having a child with congenital disorders [6]. All these factors may cause significant caregiver burden. Caregiver burden refers to the negative effects of caregiving activities or experiences on caregivers' physical health, emotional health, financial status, and social life [7, 8]. A large body of evidence has consistently shown that caregivers with higher levels of caregiver burden are at increased risk of psychological distress, such as perceived stress, depression, and anxiety [9, 10]. The caregiver burden and psychological distress may further impair the quality of care provided by the caregivers, leading to poor health outcomes for the care recipients [9, 10].

Previous studies have identified a wide range of influencing factors of caregiver burden among various populations, among which modifiable psychosocial factors, such as depression, anxiety, discrimination, social support, and resilience, have been widely explored and reported [8, 11]. Extensive studies consistently show that depression and anxiety are prevalent among caregivers and are closely related to caregiver burden [7]. For instance, Hu et al. investigated 117 caregivers of stroke patients and found 43.9% of them had anxiety symptoms, and 53.9% had varying degrees of depressive symptoms, which were positively correlated with caregiver burden [12]. Caregivers of individuals with stigmatized diseases, such as schizophrenia and intellectual disabilities, may experience stigma by association due to providing care to these individuals, which may increase their caregiver burden [13, 14]. Liu's research on Chinese parents of children with mental illness showed that over a third of parents may avoid inviting friends into their home due to fear of stigma, which may limit parents from using effective coping patterns or seeking support, leading to increased caregiver burden [15].

While psychological distress and discrimination are well-established risk factors of caregiver burden, some other psychosocial factors, such as social support and resilience, have been shown to be protective factors that buffer against the negative impacts of caregiver burden. Social support is one of the most important positive psychosocial factors that contribute to decreased caregiver burden and improved well-being among caregivers [16]. The positive role of social support in alleviating caregiver burden has been consistently observed among caregivers of cancer patients [17], caregivers of older adults with chronic illness [18], and caregivers of dementia patients [19]. In addition, family as a social system can provide a supportive environment to improve resilience and reduce caregiver burden. Family resilience refers to the ability of families to adapt to stress and recover from adversity when experiencing risk and distress [20, 21]. A study on caregivers of early-stage breast cancer survivors showed that higher family resilience was associated with lower burden and that caregivers in families providing a supportive environment experienced a lower degree of burden [22].

Despite extensive studies on caregiver burden, most of them focused on caregivers of patients with certain diseases, such as stroke [23], dementia [24], and schizophrenia [25], and there is little literature on caregivers of CWCD. In addition, previous studies only investigated caregivers of people with diseases using cross-sectional study designs without a comparison group, which may limit the comparability of their findings [5, 7]. Furthermore, most previous studies examined the association between caregiver burden and each of the above-mentioned psychosocial factors individually, and studies investigating all these factors are limited. To fill these research gaps, this study used a comparative cross-sectional design, taking Hunan Province as the research site, to determine the caregiver burden among caregivers of CWCD compared with healthy children's caregivers. In addition, we explored a range of psychosocial factors, including depression, anxiety, perceived discrimination, social support, and family resilience, to identify factors associated with caregiver burden of children with congenital disorders.

Methods

Study design and settings

This was a comparative cross-sectional study conducted in Hunan Province, a populous province with a high prevalence of congenital disorders. A systematic review and meta-analysis reported that the perinatal prevalence of congenital disorders in Hunan between 2000 and 2021 ranged from 138.18 to 190.28 per 10,000, with an average of 164.23 per 10,000, ranking fourth in Mainland China [26]. Hunan province includes 14 regions, which are categorized into three economic development levels based on Gross Domestic Product (GDP) per capita in 2019. Given that regional economic development may influence household income and access to healthcare services, this study adopted a multistage stratified cluster random sampling method. First, Changsha, Yueyang, and Huaihua were chosen at random to represent high, medium, and low-level cities, respectively. Second, one urban district and one to two counties were chosen randomly from each city. Three districts (Kaifu in Changsha, Yueyanglou in Yueyang, and Hecheng in Huaihua) and five counties (Changsha and Liuyang in Changsha, Pingjiang in Yueyang, and Xupu and Zhijiang in Huaihua) were chosen as the study sites. In each district or county, families of CWCD registered in the Hunan Birth Defect Surveillance System were included in the sample lists, and caregivers of healthy children were matched based on the family residence and children's age.

Hunan Birth Defect Surveillance System tracked all perinatal infants (including dead fetuses, stillbirths, or live births between 28 weeks of gestation and 7 days after delivery) in 52 hospitals that joined the hospital-based birth defect surveillance. The birth defect registration card and the quarterly table with the number of perinatal births were filled out by gynecologists, pediatricians, or neonatologists. They were reported quarterly both on paper and online. Congenital disorders were diagnosed according to the Chinese Birth Defects Monitoring Scheme and were classified into 23 types according to the WHO International Classification of Diseases (Tenth Revision, ICD-10). The data were audited by maternal and child health hospitals and health administrative departments at each level. Surveillance hospitals were spot-checked quarterly at the district and county levels, semi-annually at the city level, and annually at the provincial level.

Sample

Based on the Hunan Birth Defect Surveillance System, CWCD and their caregivers who met the following inclusion criteria were included in the study.

Study group

The inclusion criteria for caregivers of CWCD were: (a) living in the study sites continuously for at least 6 months; (b) being registered in the Hunan Birth Defect Surveillance System; (c) living with CWCD who were born between January 1, 2016, and December 31, 2021, and were alive during the investigation; (d) being the primary caregiver, defined as taking care of children for the longest average daily time within the family; and (e) being at least 18 years of age. Exclusion criteria were: (a) being unable to be contacted or lost to follow-up through the local maternal and child health department and public health department; (b) receiving payment for care; (c) having a severe physical or mental illness; (d) caring for children with other illness during the investigation, and (e) refusing the investigation after being fully informed.

Comparison group

Group matching was used to enroll caregivers of healthy children who were matched by age and place of residence. Inclusion criteria were: (a) living in the same communities (townships) with the study group continuously for at least 6 months; (b) living with healthy children at the same age with CWCD in the study group; (c) being the primary caregiver; and (d) being at least 18 years of age. Exclusion criteria were the same as the study group. To minimize recall bias of caregivers, children in this study were under 6 years old.

The sample size was computed utilizing PASS 15.0 software with the following parameters: a bilateral alpha of 0.05, a power of 0.90, and a 1:1 ratio. According to the preliminary results of our pre-experiment, the mean and standard deviation of ZBI scores were 26.58 ± 12.596 in the study group and 20.28 ± 18.454 in the comparison group. The minimum sample size required was 134 caregivers of CWCD and 134 caregivers of healthy children. Considering a 25% dropout rate, 179 caregivers would be enrolled in each group. Finally, the sample size was expanded to 194 caregivers of CWCD, including 109 (56.2%) in Changsha, 40 (20.6%) in Yueyang, and 45 (23.2%) in Huaihua, and 194 caregivers of healthy children, including 120 (61.9%) in Changsha, 35 (18.0%) in Yueyang, and 39 (20.1%) in Huaihua.

Study procedure

This study was conducted from January to December 2021. First, families of CWCD were selected from the Hunan Birth Defect Surveillance System and included in the sample lists according to the registered residence. Then, these lists were sent to maternal and child care hospitals in each district (county). The local maternal health professionals or child health professionals verified whether children were still receiving childcare services in their jurisdictions. During initial contact with the families, the professionals determined the primary caregivers and explained the aim of the study. Next, the primary caregivers were contacted by the investigators to sign informed consent and complete electronic questionnaires or telephone interviews.

The comparison group was selected using the group matching method based on family residence and children's age to ensure comparability between two groups. This procedure controlled for the potential confounding influence of geographic and age-related factors at the group level. Caregivers of healthy children were recruited from the community health service centers and township hospitals offering routine child health services in the same neighborhoods as the study group. The investigators approached the primary caregivers of healthy children on-site and explained the study's purpose and significance. After providing written informed consent, caregivers completed the questionnaires via either online or telephone interviews.

Measures

Sociodemographic information

The sociodemographic information of caregivers and their families was collected by a researcher-developed questionnaire. The children's sociodemographic information, including the date of birth, gender, and diagnosis of congenital disorders was abstracted from the Hunan Birth Defect Surveillance System. Congenital disorders were divided into ten categories in this study: (1) cardiovascular system defects, (2) polydactyly and syndactyl, (3) inherited metabolic disorders, (4) cleft lip and palate, (5) genitourinary defects, (6) external ear defects, (7) appendicular skeletal abnormalities, (8) chromosomal anomalies, (9) digestive tract atresia, (10) others [27].

Caregiver burden

Caregiver burden was assessed by the Chinese version of the Zarit Burden Interview (ZBI) [28]. The ZBI is the most frequently used scale of caregiver burden worldwide [29]. It consists of 22 items that reflect the negative impacts of caregiving on the caregiver's physicality, emotions, social life, finances, and relationship with the care recipients [30]. Each item is rated on a 5-point Likert-type scale ranging from 0 to 4. The total score ranges from 0 to 88 points, with a higher score suggesting a heavier burden. Based on the total score, participants were further categorized into three groups: less than moderate burden (0–40), moderate to severe burden (41–60), and severe burden (61–88) [31]. In this study, the Chinese version of ZBI showed good reliability with a Cronbach's α coefficient of 0.922.

Depressive symptoms

Depressive symptoms were assessed using the 9-item Patient Health Questionnaire (PHQ-9) [32]. Each item is rated on a 4-point Likert-type scale ranging from 0 to 3. The total score ranges from 0 to 27 points, with a higher score indicating more severe depressive symptoms and a score of 10 or above suggesting significant depressive symptoms. The PHQ-9 has shown good reliability and validity among the Chinese population [33]. In this study, the PHQ-9 showed good reliability with a Cronbach's α coefficient of 0.908.

Anxiety symptoms

Anxiety symptoms were assessed by the 7-item Generalized Anxiety Disorder Questionnaire (GAD-7) [34]. Each item is rated on a 4-point Likert-type scale ranging from 0 to 3. The total score ranges from 0 to 21 points, with a higher score indicating more severe anxiety symptoms and a score of 10 or above suggesting significant anxiety symptoms. The GAD-7 has shown good reliability and validity among the Chinese population [35]. In this study, the GAD-7 showed good reliability with a Cronbach's α coefficient of 0.919.

Perceived discrimination

Perceived discrimination was assessed using the Chinese version of the Multidimensional Scale of Perceived Discrimination (MSPD), which was originally compiled by Fernando et al. [36]. It is a universal scale for measuring perceived discrimination among different stigmatized groups. It consists of 20 items, covering four dimensions: blatant group discrimination (BGD), subtle group discrimination (SGD), blatant individual discrimination (BID), and subtle individual discrimination (SID). Each item is rated on a 5-point Likert-type scale, and the total score is the average of 20 items, ranging from 1 to 5. A higher score indicates more severe perceived discrimination. We obtained the approval for translation and cross-cultural adaptation from the original developer of MSPD. The English version of MSPD was translated into Chinese by three social medicine professionals who were proficient in both Chinese and English, and this version was translated back into English by a bilingual professor in public health. Then, the back-translated version was compared with the original English versions, and the items with semantic differences and inconsistencies were discussed and modified. All item adjustments and modifications were acknowledged by the original developer. Finally, we formed the Chinese version of MSPD. In this study, the Chinese version of MSPD showed good reliability with a Cronbach's α coefficient of 0.977.

Social support

Social support was assessed using the Social Support Rating Scale (SSRS) [37]. It consists of 10 items, covering three dimensions: objective support, subjective support, and support utilization. The total score ranges from 12 to 66 points, with a higher score indicating better social support. In the current study, the SSRS showed acceptable reliability with a Cronbach's α coefficient of 0.686.

Family resilience

Family resilience was assessed using the Family Resilience Questionnaire (FRQ) designed by Bu and Liu [38]. It consists of 20 items, covering four subscales: perseverance, harmony, openness, and support. Each item is rated on a 5-point Likert-type scale, ranging from 1 to 5. The total score ranges from 20 to 100, and a higher score indicates stronger family resilience. In this study, the FRQ showed good reliability with a Cronbach's α coefficient of 0.966.

Data analysis

Statistical analyses were performed using SPSS 26.0. The data analysis followed two main stages aligned with our study objectives. First, descriptive statistics, chi-square tests, Fisher's exact tests, and u-tests were utilized to describe and compare sample characteristics between the study and comparison groups. This between-group comparison allowed us to identify distinct characteristics and challenges faced by caregivers of CWCD compared to those of healthy children.

Second, we conducted a within-group analysis to identify factors associated with caregiver burden specifically among caregivers of CWCD. The caregivers of CWCD were further categorized into two groups based on ZBI score: less than moderate burden (0–40) and moderate or above burden (41–88). Univariate analysis was used to compare the sociodemographic and psychosocial characteristics between these two burden-level groups. The variables with $p < 0.1$ in the univariate analysis were included in the subsequent multiple linear regression analysis to identify factors independently associated with caregiver burden.

Ethical considerations

The study was approved by the Institutional Review Board (IRB) of Xiangya School of Public Health at Central South University (XYGW-2021-01). The aim and content of this study were explained, and written informed consent was obtained. If participants were in poor physical or psychological condition, the investigation would be paused, and medical help would be provided if necessary. Moreover, personal information was kept strictly confidential and handled under the privacy protection regulations.

Results

Characteristics of children and families

The characteristics of children and families in both the study and comparison groups are presented in Table 1. Compared to the comparison group, the study group had more males (66.0% vs. 53.1%, $P = 0.010$) and more co-caregivers, but were less likely to have two or more co-caregivers (25.8% vs. 62.4%, $P < 0.001$). There were no statistical differences between the two groups in other variables. In the study group, the top four most common diagnoses were polydactyly and syndactyl (21.6%), cardiovascular system defects (16.5%), inherited metabolic disorders (11.9%), and cleft lip and palate (11.3%).

Sociodemographic characteristics of caregivers

Table 2 shows the sociodemographic characteristics of caregivers in the study and comparison groups. Compared to the comparison group, the study group had lower education (college and above: 41.8% vs. 57.7%, $P < 0.001$) and were more likely to resign for childcare (64.4% vs. 45.9%, $P < 0.001$). There were no significant differences in other variables between the two groups.

Caregiver burden and psychosocial characteristics of caregivers

Table 3 shows the caregiver burden and psychosocial characteristics of caregivers in the study and comparison groups. Compared to the comparison group, the study group was more likely to have moderate and above levels of caregiver burden (23.2% vs. 15.4%, $P = 0.042$), depressive symptoms (20.1% vs. 10.8% $P = 0.011$), and anxiety symptoms (23.7% vs. 11.9%, $P = 0.002$). No significant difference was observed in perceived discrimination, social support, or family resilience between the two groups.

Factors associated with caregiver burden among caregivers of CWCD

The variables with $p < 0.1$ in the univariate analysis included annual household income, age of caregivers,

Table 1 Sample characteristics of children and families in the study and comparison groups

Variable	**Study group (*n* = 194)**	**Comparison group (*n* = 194)**	***χ*2/z**	***p***
	***n* (%)**	***n* (%)**		
Age (Yr)			1.018[a]	0.309
≤ 1	34(17.5)	55(28.3)		
～2	59(30.4)	44(22.7)		
～3	48(24.7)	41(21.1)		
～4	35(18.0)	30(15.5)		
～5	18(9.3)	24(12.4)		
Gender			6.687	**0.010**
Male	128(66.0)	103(53.1)		
Female	66(34.0)	91(46.9)		
Type of congenital disorders diagnosed			—	—
Polydactyly and syndactyl	42(21.6)	—		
Cardiovascular system defects	32(16.5)	—	—	—
Inherited metabolic disorders	23(11.9)	—	—	—
Cleft lip and palate	22(11.3)	—	—	—
Appendicular skeletal abnormalities	18(9.3)	—		
Genitourinary defects	16(8.2)	—	—	—
External ear defects	14(7.2)	—	—	—
Digestive tract atresia	6(3.1)	—		
Chromosomal anomalies	4(2.1)	—	—	—
Other	17(8.8)	—	—	—
Family residence			0.259	0.611
Urban	94(48.5)	89(45.9)		
Rural	100(51.5)	105(54.1)		
Annual household income (Yuan)			1.586[a]	0.113
≤ 50,000	62(32.0)	49(25.3)		
～100000	64(33.0)	59(30.4)		
～150000	25(12.9)	41(21.1)		
> 150,000	43(22.2)	45(23.2)		
The number of children to be raised			1.306[a]	0.191
One	64(33.0)	53(27.3)		
Two	115(59.3)	122(62.9)		
Three or above	15(7.7)	19(9.8)		
The number of co-caregivers			6.065[a]	**< 0.001**
Zero	11(5.7)	18(9.3)		
One	133(68.6)	55(28.4)		
Two or above	50(25.8)	121(62.4)		

[a] u test; Bold values represent statistical significance at $p < 0.05$

having resigned for childcare, depressive symptoms, anxiety symptoms, social support, perceived discrimination, and family resilience, which were included in the subsequent multivariate analysis. Table 4 showed that the following factors were positively associated with caregiver burden: having resigned from work for childcare (β = 7.795, $p = 0.002$), anxiety symptoms (β = 11.285, $p = 0.001$), and perceived discrimination (β = 4.645, $p < 0.001$). In contrast, family resilience was negatively associated with caregiver burden (β=-0.196, $p = 0.043$).

Discussion

Summary of the findings

To the best of our knowledge, this is the first study to examine caregiver burden and its psychosocial correlates among caregivers of CWCD using a comparative cross-sectional study design in Hunan, China. Our major findings were that every one out of five CWCD caregivers experienced moderate and above burden (23.2%), depressive symptoms (20.1%), and anxiety symptoms (23.7%), which were much higher than that of healthy children's caregivers. In addition, having resigned due to childcare, anxiety symptoms, perceived discrimination, and lower family resilience were associated with higher levels of caregiver burden among caregivers of CWCD.

Table 2 Sociodemographic characteristics of caregivers in the study and comparison groups

Variable	Study group ($n = 194$)	Comparison group ($n = 194$)	χ2/z	*p*
	***n* (%)**	***n* (%)**		
Role			3.243	0.198
Mother	165(85.1)	175(90.2)		
Father	21(10.8)	16(8.2)		
Grandfather/grandmother	8(4.1)	3(1.5)		
Gender			0.467	0.494
Male	21(10.8)	17(8.8)		
Female	173(89.2)	177(91.2)		
Race			0.033	0.856
Han	177(91.2)	178(91.8)		
Minority	17(8.8)	16(8.2)		
Age (Yr)			0.311[a]	0.756
≤ 25	14(7.2)	16(8.2)		
26–35	132(68.0)	125(64.4)		
36–45	41(21.1)	46(23.7)		
≥ 46	7(3.6)	7(3.6)		
Education level			3.568[a]	**< 0.001**
Junior high school or lower	66(34.0)	37(19.1)		
High school/ secondary specialized school	47(24.2)	45(23.2)		
College or higher	81(41.8)	112(57.7)		
Having resigned for childcare			13.504	**< 0.001**
Yes	125(64.4)	89(45.9)		
No	69(35.6)	105(54.1)		

[a] u test; Bold values represent statistical significance at $p < 0.05$

Table 3 Caregiver burden and psychosocial characteristics of caregivers in the study and comparison groups

Variable	Study group ($n = 194$) ***n* (%)/Median (IQR)**	Comparison group ($n = 194$) ***n* (%)/Median (IQR)**	χ2/z	*p*
Caregiver burden			2.031[a]	**0.042**
Less than moderate burden	149(76.8)	164(84.5)		
Moderate to severe burden	38(19.6)	29(14.9)		
Severe burden	7(3.6)	1(0.5)		
Depression symptoms			6.388	**0.011**
Without (PHQ-9 < 10)	155(79.9)	173(89.2)		
With (PHQ-9 ≥ 10)	39(20.1)	21(10.8)		
Anxiety symptoms			9.325	**0.002**
Without (GAD-7 < 10)	148(76.3)	171(88.1)		
With (GAD-7 ≥ 10)	46(23.7)	23(11.9)		
Perceived discrimination	2.23(1.24, 2.95)	2.05(1.34, 2.65)	1.148[a]	0.251
Social support	43.50(37.00, 51.00)	45.00(38.00, 52.00)	1.395[a]	0.163
Family resilience	80.00(70.00, 88.00)	78.00(70.00, 87.00)	1.102[a]	0.270

[a] u test; PHQ-9: The 9-item Patient Health Questionnaire; GAD-7: The 7-item Generalized Anxiety Disorder Questionnaire; Bold values represent statistical significance at $p < 0.05$

Table 4 Multivariate analysis of the factors associated with the burden of caregivers of CWCD

Variable	b	S.E	t	*P*	95%CI	
					LL	UL
Having resigned for childcare	7.795	2.443	3.204	**0.002**	2.994	12.596
Anxiety symptoms	11.285	3.447	3.274	**0.001**	4.484	18.087
Perceived discrimination	4.645	1.210	3.840	**< 0.001**	2.258	7.032
Family resilience	-0.196	0.096	-2.034	**0.043**	-0.386	-0.006

Bold values represent statistical significance at $p < 0.05$

Comparison of caregiver profiles

Our study showed that caregivers of CWCD had lower levels of education than healthy children's caregivers. Previous studies have also suggested that lower education levels may increase the risk of fetal congenital disorders [39, 40]. In this study, 85.1% of primary caregivers of CWCD were mothers. Lower education levels among pregnant women may lead to a lack of awareness about the importance of prenatal examinations, potentially resulting in missing the best opportunities to screen for fetal diseases. This highlights the need for enhanced maternal health education, particularly for individuals with lower education levels.

Additionally, caregivers of CWCD were more likely to resign from work to provide child care and had fewer co-caregivers compared to the comparison group. 64.4% of caregivers of CWCD had resigned due to caregiving responsibilities. This finding was similar to a previous study on parents of highly impaired children showing that 65% reported absenteeism in the past six months due to caregiving [41]. CWCD require more assistance in health-related activities, which can make it challenging for caregivers to maintain full-time employment. Furthermore, the study observed that although over 60% of CWCD caregivers had one co-caregiver, only 25.8% of the primary caregivers had two or more co-caregivers, compared to 62.4% of healthy children's caregivers. This disparity indicates that CWCD have limited family members involved in caregiving tasks. Therefore, we advocate for increased outside social support for these families. Communities can provide daycare services, volunteer organizations can offer family visits, and patient organizations can share caregiving experiences.

Caregiver burden

Our study showed that 23.2% of caregivers of CWCD reported a moderate or above level of burden, which was higher than that of healthy children's caregivers. Caring for CWCD imposes a greater burden on caregivers. The burden experienced by CWCD caregivers in our study was comparable to that of caregivers of cancer patients in India [42] and that of caregivers of children and adolescents with mental health issues in Lagos, Nigeria [43]. While previous research has predominantly focused on caregiver burden related to mental disorders [44], cancer [42], and stroke [45], there has been less emphasis on the caregiver burden of CWCD, indicating the need for more research in this area in the future.

Psychosocial factors

Our study showed that caregivers of CWCD were more likely to have depression and anxiety symptoms than caregivers of healthy children. Caregiving may exacerbate the caregiver's psychological distress due to concerns about the patient's prognosis or fears that the care is insufficient. If the health status of a patient does not improve as expected, caregivers may experience increased psychological distress due to worries about the patient's future quality of life. These findings suggest that the caregiver's emotional state warrants special attention, and social workers should provide psychological support for them. In addition, we did not detect any significant difference in perceived discrimination between the two groups of caregivers. One possible explanation may be that both groups consist of preschool children with limited social interaction and are less exposed to potential social discrimination.

Factors associated with caregiver burden

This study observed that the following factors were associated with higher caregiver burden among CWCD caregivers: having resigned from work due to caregiving, anxiety symptoms, perceived discrimination, and lower levels of family resilience. Previous studies suggested that employment may have a protective effect on caregivers [46]. Employment enables them to escape family responsibilities temporarily, have a stable income, and obtain support from work and colleagues, which can enhance their self-esteem and sense of achievement [47, 48]. In contrast, resignation and shifting focus entirely to children and families may diminish the caregivers' financial stability and social support, leading to increased caregiver burden. This study revealed that caregivers with anxiety symptoms experienced a higher caregiver burden, which is consistent with previous studies on caregivers of patients with various chronic diseases [7, 11]. Preschool CWCD highly depend on caregivers. Anxiety symptoms may impair caregiving capacity, so caregivers require additional efforts to provide high-quality care, which can increase caregiver burden [11].

Moreover, our study showed that higher perceived discrimination of caregivers was associated with greater caregiver burden. On the one hand, caregivers who experience discrimination tend to feel stressed and distressed [49], leading to more negative emotional responses and a higher caregiver burden. On the other hand, caregivers who fear discrimination often avoid social activities [50], conceal children's illnesses, and are reluctant to seek help [51], which, in turn, prevents effective coping with negative emotions, leading to increased caregiver burden. These findings suggest that community-level anti-discrimination education and campaigns are needed, especially regarding visible structural malformations or cognitive impairment. Finally, the finding that lower levels of family resilience were associated with higher levels of caregiver burden was also supported by previous studies on caregivers of children with epilepsy [52] and caregivers of breast cancer patients [53]. These findings suggest that caregiver burden may be lessened by effective family communication, a positive outlook on the disease and treatment, actively seeking support, and tackling challenges together [20].

Limitations

This study has several limitations. First, CWCD who died during and before the survey were not included, and the severity of congenital disorders was not detailedly distinguished. These may lead to bias in assessing the caregiving burden. Second, the study focused on the primary caregivers, which may ignore the burden of other family members and the whole family. Future research should explore the caregiver burden on the entire family and compare primary and secondary caregivers' burden and psychosocial characteristics. Third, the small sample size may introduce potential bias and limit the generalizability of our findings to the wider population. Future large-sample studies are needed to increase the statistical power and draw more reliable conclusions. Fourth, this was a cross-sectional survey, and causal relationships between caregiver burden and associated factors were not established, nor could the dynamic changes of these variables be explored over time. Future longitudinal studies are needed to examine the impact of psychosocial factors on caregiver burden over time.

Conclusions

Our study showed that caregivers of CWCD had significantly higher caregiver burden and psychological distress than healthy children's caregivers. Multiple psychosocial factors were associated with the caregiver burden of CWCD caregivers. Our findings suggest that the caregiver burden of CWCD caregivers is a critical issue that deserves more research and political attention. Community and organizations should provide more care assistance to caregivers of CWCD, with a special focus on their emotional health and providing psychosocial support, which will help maintain long-term caregiving capacity. In addition, anti-discrimination activities at the community level may be feasible measures to create a supportive social environment for caregivers. Furthermore, carrying out family-based training programs for improving caregiving skills and involving other family members in the caregiving process may also help alleviate caregiver burden.

Abbreviations

BGD	Blatant Group Discrimination
BID	Blatant Individual Discrimination
CWCD	Children with Congenital Disorders
FRQ	The Family Resilience Questionnaire
GAD-7	The 7-item Generalized Anxiety Disorder Questionnaire
MSPD	The Multidimensional Scale of Perceived Discrimination
PHQ-9	The 9-item Patient Health Questionnaire
SGD	Subtle Group Discrimination
SID	Subtle Individual Discrimination
SSRS	The Social Support Rating Scale
ZBI	The Zarit Burden Interview

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Author contributions

Yi YU and Long YANG: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Visualization, Writing – original draft, Writing – review & editing. Yanlin LIU: Investigation, Validation. Junqun FANG and Hua WANG: Funding acquisition, Resources, Project administration. Dan LUO: Conceptualization, Funding acquisition, Resources, Project administration, Supervision, Validation, Writing – original draft, Writing – review & editing.

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Data availability

The datasets generated and analysed during the current study are not publicly available due to privacy and ethical restrictions of the participants, but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study was approved by the Institutional Review Board (IRB) of Xiangya School of Public Health at Central South University (XYGW-2021-01). The aim and content of this study were explained, and written informed consent was obtained. All procedures were performed in accordance with the principles of the Helsinki Declaration.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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