Original article

Factors associated with stress in parents of children with congenital anomalies

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Abstract

Objective: To assess the stress levels and associated factors in parents of children with congenital anomalies.

Methods: A cross-sectional survey was conducted with parents of children aged 1 month to 12 years with congenital anomalies who visited Nopparat Rajathanee Hospital between April 2023 and March 2024. Parents who were unable to read or write in Thai were excluded. Stress levels were measured using the Thai version of the Parenting Stress Index - Fourth Edition - Short Form (PSI-4-SF). Data were analyzed using descriptive statistics and odds ratios.

Results: Thirty parents were included in the study. Among them, 6.7% reported high stress levels, and 23.3% reported significant stress levels. Higher PSI-4-SF scores were more common among parents with lower education, those living without a partner, those unemployed, and those lacking support, as well as parents of older children, those diagnosed after birth, and those with longer hospital stays. However, no statistically significant risk factors were identified.

Conclusion: Parents of children with anomalies experience higher stress levels compared to parents of unaffected children. Early identification and intervention targeting modifiable factors, particularly within the first year of the child's life, may help alleviate stress and improve outcomes for parents and families.

Keywords: congenital anomalies, parents, stress

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นิพนธ์ต้นฉบับ

ปัจจัยที่มีผลต่อความเครียดของผู้ปกครองของเด็กที่มีความผิดปกติแต่กำเนิด

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บทคัดย่อ

วัตถุประสงค์ : เพื่อประเมินระดับความเครียดและปัจจัยที่เกี่ยวข้องของผู้ปกครองเด็กที่มีความผิดปกติแต่กำเนิด

วิธีการ : การศึกษาแบบภาคตัดขวางในผู้ปกครองของเด็กอายุ 1 เดือนถึง 12 ปีที่มีความพิการแต่กำเนิดและเข้ารับการรักษาที่โรงพยาบาลนพรัตนราชธานีระหว่างเดือนเมษายน พ.ศ. 2566 ถึง มีนาคม พ.ศ. 2567 โดยผู้ปกครองต้องสามารถอ่านและเขียนภาษาไทยได้ วัดระดับความเครียดด้วยเครื่องมือ parenting stress index - fourth edition - short form (PSI-4-SF) ฉบับภาษาไทย นำเสนอข้อมูลพื้นฐานและระดับความเครียดด้วยสถิติเชิงพรรณนา วิเคราะห์ความสัมพันธ์ระหว่างปัจจัยต่าง ๆ และความเครียดด้วย odds ratio

ผล : กลุ่มตัวอย่าง 30 คน ร้อยละ 6.7 มีความเครียดสูงกว่าระดับปกติ และร้อยละ 23.3 มีความเครียดระดับรุนแรง กลุ่มที่มีแนวโน้มระดับความเครียดสูงถึงรุนแรง ได้แก่ ผู้ปกครองที่มีการศึกษาต่ำ อาศัยอยู่โดยไม่มีคู่ชีวิต ว่างงาน และขาดแหล่งสนับสนุน รวมถึงผู้ปกครองของเด็กที่อายุมากกว่า 1 ปี ได้รับการวินิจฉัยครั้งแรกหลังคลอด และรักษาตัวในโรงพยาบาลเป็นระยะเวลานาน อย่างไรก็ตาม ไม่พบปัจจัยเสี่ยงของความเครียดระดับสูงถึงรุนแรงที่มีนัยสำคัญทางสถิติ

สรุป : ผู้ปกครองเด็กที่มีความพิการแต่กำเนิดมีความเครียดสูงกว่าผู้ปกครองเด็กทั่วไป ควรมีการคัดกรองและให้การดูแลโดยเน้นปัจจัยที่สามารถปรับเปลี่ยนได้ โดยเฉพาะในช่วงขวบปีแรกของเด็ก เพื่อช่วยลดความเครียดของผู้ปกครองและครอบครัว

คำสำคัญ : ความเครียด, ความผิดปกติแต่กำเนิด, ผู้ปกครอง

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Previous knowledge: Parents of children with congenital anomalies are more vulnerable to higher stress levels compared to parents of unaffected children.

New knowledge: Nearly one-third of parents of children with congenital anomalies experience high to significant stress. This is more common among parents with lower education, living without a partner, unemployed, and lacking support, as well as parents of children with older age, diagnosed after birth, and with longer hospital stays.

Application: The findings highlight the need for early identification and interventions for parents of children with such conditions, focusing on possible modifiable risk factors.

Introduction

A child's birth, while considered as a fundamental process in human life, can be profoundly disrupted by the unexpected occurrence of congenital anomalies. These anomalies, define as structural or functional abnormalities during intrauterine development, affect approximately 3 - 5% of live births.[1] They may be diagnosed prenatally or manifest at birth or later in life.

Congenital anomalies can affect various systems, including cardiovascular, craniofacial, neurological, and gastrointestinal systems. Parents of children with these conditions experience distinct emotional challenges. Parents of children with congenital heart defects reported high levels of psychological distress, particularly during the first year of life.[2] Repeated surgical operations could also be a significant predictor for psychological impact on these families.[3] Cleft lip and palate demonstrates unique stressors for parents, particularly concerning feeding difficulties.[4] Neural tube defects tend to cause higher levels of stress in mothers compared to fathers.[5] Gastrointestinal anomalies pose specific challenges related to feeding, nutrition, and growth. A large case-control study found that mothers of children with congenital diaphragmatic hernia had an increased risk of depression compared to controls.[6] Furthermore, post-traumatic stress disorder (PTSD) has been found in parents of children with anomalies.[7] However, it is also noted that anxiety and stress tend to decrease over time as families adjust to their child's condition.[8]

Previous studies have identified factors contributing to parental stress, including severity and treatment of the anomalies. Parents of children with more severe or complex anomalies tend to report higher stress levels due to the uncertainty surrounding long-term outcomes and potential disabilities.[8,9] Intensive medical care, frequent hospitalizations, and ongoing therapies can further exacerbate this stress.[10,11] Additionally, parental characteristics such as age, socioeconomic status, and the availability of social support can modify the stress experiences.[6,12]

These stressors are well-documented in western countries, which may differ contextually from other regions, particularly Southeast Asia, in terms of sociocultural influence on illness beliefs, parenting norms, and relationships with service providers. This study aims to explore parental stress related to congenital anomalies and identify associated factors within the Thai context.

Methods

A cross-sectional study was conducted with parents of children with congenital anomalies who visited Nopparat Rajathanee Hospital between April 2023 and March 2024. The study was approved

by the Research and Ethics Committee of Nopparat Rajathanee Hospital on February 20, 2023.

Population and sample

Participants included mothers, fathers, or legal guardians of children aged 1 month to 12 years, who had a confirmed diagnosis of any congenital anomaly.[1] Eligible participants were required to be fluent in Thai and provide informed consent to complete the questionnaire. All potential participants from both the outpatient and inpatient departments at the hospital were recruited for the study.

Parental stress

Parental stress was assessed using the Parenting Stress Index - Fourth Edition - Short Form (PSI-4-SF). The Thai version of PSI-4-SF has been validated and tested for reliability with parents of children aged 1 month to 12 years.[13] Three domains across 36 items were identified from the original version: parental distress (items 1 - 12), parent-child dysfunctional interaction (items 13 - 24) and difficult child (items 25 - 36). Total scores of 54 - 109, 110 - 113, and above 113 indicated normal stress, high stress, and significant stress, respectively. Defensive responding was assessed by the sum of items 1, 2, 3, 7, 8, 9 and 11. A score of 10 or lower may suggest that respondents are minimizing the problems/stress or not fully engaging in the parenting roles. Alternatively, this could reflect a high level of competence in managing the parent-child relations and responsibilities.

Independent variables

The independent variables included the parental and child socio-demographics, the chlid's anomalies and consequences, and parental perceptions regarding anomalies and treatments. The supporting system experience in caring for the child, awareness of treatment plans, percentage of the child's life spent in hospital, sufficiency of received information, expectations for the child after treatment, and the child's daily functioning were based solely on participants' responses.

Statistical analysis

Descriptive statistics were presented as frequencies and percentages for categorical variables, and as means with standard deviations (SD) for continuous variables, as the data followed a normal distribution. Odds ratio was used to examine relationships between independent variables and stress. The statistical significance was accepted for p-value less than .05.

Results

The study included 30 parents, with an average age of 30.9 years (SD = 6.2), ranging from 19 to 46 years old. A majority of them were mothers (76.7%), had attained mandatory secondary education or less (70.0%), lived with a partner (83.3%), were employed (60.0%), and had no underlying diseases (76.7%) or family psychiatric issues (83.3%). Some parents (6.7%) reported receiving insufficient information about treatment plans from healthcare providers.

Three of the four (76.7%) children were boys. Their mean age was 26 months (SD = 16.5), ranging from 1 month to 8 years. Anomalies included hydrocephalus, gastrointestinal tract atresia, cleft lip/palate, and hypospadias. Slightly more than half (53.3%) of the affected children were expected to fully recover without complications after treatment.

None of the participants responded defensively to the PSI-4-SF. All domain scores followed a normal distribution, with a mean total score of 101.7 (SD = 9.8) Average scores for the domains of parental distress, parent-child dysfunctional interaction, and difficult child were

37.2 (SD = 10.3), 31.1 (SD = 11.6), and 33.4 (SD = 10.8), respectively.

High to significant levels of stress were reported by 6.7% and 23.3% of parents, respectively. Parents with lower educational attainment, those living without a partner, unemployed parents or housewives, parents with more than one child, those lacking a supporting system, and those perceiving insufficient information from healthcare providers were more likely to report high to significant stress. Additionally, parents of children over one year old, diagnosed after birth, and those with longer hospital stays were also more likely to report high to significant stress. However, no statistical significant factors were identified. Due to the small sample size, multivariate analysis was not performed. (Table 1)

The mean score of the parental distress domain was slightly higher than that of the parent-child dysfunctional interaction and difficult child domains. The contribution of each domain to the total PSI-4-SF score was proportionally comparable between the normal stress and higher stress groups. (Table 2)

Table 1 Factor associated with parental stress (n = 30)

	Total	Stress level		Odds ratio	95% CI
		Normal (n = 21)	High to significant stress (n = 9)		
Parents factors					
Sex					
Male	7 (23.3%)	5 (16.7%)	2 (6.7%)	1	-
Female	23 (76.7%)	16 (53.3%)	7 (23.3%)	1.1	0.2 - 7.1
Age (year)					
≤35	23 (76.7%)	15 (50.0%)	8 (26.7%)	1	-
>35	7 (23.3%)	6 (20.0%)	1 (3.3%)	0.3	0.0 - 3.1
Relationship with the child					
Father or mother	28 (93.3%)	20 (66.7%)	8 (26.7%)	1	-
Others	2 (6.7%)	1 (3.3%)	1 (3.3%)	2.5	0.1 - 45.0
Highest level of education					
Secondary or below	21 (70.0%)	13 (43.3%)	8 (26.7%)	1	-
Vocational/Bachelor's degree	9 (30.0%)	8 (26.7%)	1 (3.3%)	0.2	0.0 - 1.9
Living status					
Couple	25 (83.3%)	18 (60.0%)	7 (23.3%)	1	-
Single	5 (16.7%)	3 (10.0%)	2 (6.7%)	1.70	0.2 - 12.6
Occupation					
Employed	18 (60.0%)	14 (46.7%)	4 (13.3%)	1	-
Housewife/unemployed	12 (40.0%)	7 (23.3%)	5 (16.7%)	2.5	0.5 - 12.4
Underlying disease					
Yes	7 (23.3%)	6 (20.0%)	1 (3.3%)	1	-
No	23 (76.7%)	15 (50.0%)	8 (26.7%)	3.2	0.3 - 31.4
Family psychiatric problems					
Yes	5 (16.7%)	2 (6.7%)	3 (10.0%)	1	-
No	25 (83.3%)	19 (63.3%)	6 (20.0%)	0.2	0.0 - 1.6

Table 1 Factor associated with parental stress (n = 30) (continued)

	Total	Stress level		Odds ratio	95% CI
		Normal (n = 21)	High to significant stress (n = 9)		
Parents factors (continued)					
Financial status*					
In debt	14 (46.7%)	8 (26.7%)	6 (20.0%)	1	-
No debt	12 (40.0%)	9 (30.0%)	3 (10.0%)	0.4	0.1 - 2.4
Supporting system*					
Yes	23 (76.7%)	17 (56.7%)	6 (20.0%)	1	-
No	6 (20.0%)	3 (10.0%)	3 (10.0%)	2.8	0.5 - 18.0
Number of children*					
1	14 (46.7%)	12 (40.0%)	2 (6.7%)	1	-
> 1	15 (50.0%)	8 (26.7%)	7 (23.3%)	5.3	0.9 - 32.0
Experience in take care of anomaly child					
Yes	9 (30.0%)	5 (16.7%)	4 (13.3%)	1	-
No	21 (70.0%)	16 (53.3%)	5 (16.7%)	0.4	0.1 - 2.0
Awareness of treatment plans					
Yes	20 (66.7%)	20 (66.7%)	8 (26.7%)	1	-
No	10 (33.3%)	1 (3.3%)	1 (3.3%)	2.5	0.1 - 45.0
Sufficiency of information from health providers					
Yes	28 (93.3%)	9 (30.0%)	7 (23.3%)	1	-
No	2 (6.7%)	11 (36.7%)	2 (6.67%)	0.2	0.0 - 1.4
Expectations for the child after treatment*					
As if no anomaly before	16 (53.3%)	14 (46.7%)	6 (20.0%)	1	-
Living without help	13 (43.3%)	7 (23.3%)	3 (10.0%)	1	0.2 - 5.2
Child factors					
Sex					
Male	23 (76.7%)	16 (53.3%)	7 (23.3%)	1	-
Female	7 (23.3%)	5 (16.7%)	2 (6.7%)	0.9	0.1 - 5.9
Age (month)					
< 12	13 (43.3%)	7 (23.3%)	6 (20.0%)	1	-
> 12	17 (56.7%)	14 (46.7%)	3 (10.0%)	0.3	0.1 - 1.3
Category of anomaly					
Nervous system	3 (10.0%)	1 (3.3%)	2 (6.7%)	-	-
Orofacial anomaly	3 (10.0%)	3 (10.0%)	0 (0.0%)		
Genitourinary system	6 (20.0%)	4 (13.3%)	2 (6.7%)		
Gastrointestinal system	9 (30.0%)	7 (23.3%)	2 (6.7%)		
Limb's anomaly	1 (3.3%)	1 (3.3%)	0 (0.0%)		
Abdominal wall defect	3 (10.0%)	1 (3.3%)	2 (6.7%)		
Cardiac anomaly	1 (3.3%)	1 (3.3%)	0 (0.0%)		
Multiple abnormalities	3 (10.0%)	2 (6.7%)	1 (3.3%)		
Prenatal Diagnosis					
Yes	10 (33.3%)	8 (26.7%)	2 (6.7%)	1	-
No	20 (66.7%)	13 (43.3%)	7 (23.3%)	2.2	0.4 - 13.1

Table 1 Factor associated with parental stress (n = 30) (continued)

	Total	Stress level		Odds ratio	95% CI
		Normal (n = 21)	High to significant stress (n = 9)		
Child factors (continued)					
Percentage of life spent in hospital					
0 - 25	17 (56.7%)	13 (43.3%)	4 (13.3%)	1	-
> 25	13 (43.3%)	8 (26.7%)	5 (16.7%)	2.0	0.3 - 5.2
Surgical correction of anomaly					
Yes	21 (70.0%)	17 (56.7%)	4 (13.3%)	1	-
No	9 (30.0%)	4 (13.3%)	5 (16.7%)	2.0	0.4 - 9.9
Previous life-threatening events					
Yes	7 (23.3%)	5 (16.7%)	2 (6.7%)	1	-
No	23 (76.7%)	16 (53.3%)	7 (23.3%)	1.1	0.2 - 7.1
Daily functioning					
Full	23 (76.7%)	17 (56.7%)	6 (20.0%)	1	-
Partial	7 (23.3%)	4 (13.3%)	3 (10.0%)	2.1	0.4 - 12.4

* Some participants did not answer the question

Table 2 The average scores of total stress and each domain

	Stress level	
	Normal (n = 21) Mean (SD)	High to significant (n = 9) Mean (SD)
Parental distress	32.5 (7.3)	48.2 (7.5)
Parent-child dysfunctional interaction	25.5 (6.3)	44.2 (10.6)
Difficult child	28.8 (7.6)	44.2 (9.6)
Total stress	**86.8 (29.9)**	**136.7 (32.0)**

SD = standard deviation

Discussion

According to the result from the PSI-4-SF, we found that 30% of parents exhibited high to significant levels of stress. In the normal population, 15% of parents (85^{th} - 100^{th} percentile) was categorized as having high to significant stress levels.[13] Studies from Jordan and Portugal also reported abnormally high levels of psychological distress in this parents group.[14,15] A French study founded that PTSD rates were as high as 59% in parents of children with congenital esophageal atresia.[16] However, a Swedish study found the stress levels of parents of children with congenital diaphragmatic hernia were similar to those of parents of children without congenital conditions.[17] Our finding that the parental distress domain scored higher than parent-child dysfunctional interaction and difficult child domains suggests that the participants' own feelings of inadequacy or personal difficulties may be the largest contributor to their overall stress, compared to the perceived quality of their relationship with their child or the child's characteristics. However, this pattern was observed in both normal stress group and high to significant stress group. Comparison with parents of unaffected children may warrant further investigation.

The stress may result from a combination of parental and child-related factors. While many studies found that mothers experienced higher stress than fathers when dealing with congenital malformation and surgical newborn,[8,15,17,18] our study did not observe any significant difference between fathers and mothers. The difference in stress between parental genders may vary across socioeconomic and cultural backgrounds. Other parental factors that tended to increase likelihood of high to significant stress include living without a partner and being unemployed or a housewife. Single parents generally bear both in paternal and maternal responsibilities. An unemployed parent may experience financial stress but an advantage is that they have more time to care for their children. Some participants reported receiving insufficient information, and one third indicated that they were unaware of their child's treatment plan. Improving two-way communication and involving a third party may help bridge the gap between healthcare providers and families.

Our finding that parents of children with a prenatal diagnosis were more likely to report high to significant stress levels than parents of children diagnosed after birth, although not statistically significant, is consistent with previous studies.[8,19] Knowing the diagnosis may cause earlier psychological distress for parents, however, this may be alleviated by repeated consultations.[19] Furthermore, the severity of child's illness, impairment of daily functioning, and prolonged hospital stays likely contributed to stress, as seen in previous study.[19] Typically, congenital anomalies are diagnosed within the first year of life. As children grow older, however, parents often adjust to their circumstance,[20,21] which is reflected in the decreased parental stress observed in our data.

Aside from the limited statistical power due to rarity of the conditions, the lack of significant risk factors for parental stress may suggest that all parents and families of children with anomalies are vulnerable to certain levels of stress. Early identification and supportive interventions could help alleviate this situation.[22] Additionally, the study's generalizability could be limited due to its tertiary setting and the exclusion of potential participants with language barriers. Future research should involve larger, more representative samples and explore additional factors, such as coping strategies.

Conclusion

This study highlights the elevated stress levels experienced by parents of children with congenital anomalies in Thailand and identifies potential risk factors. Interventions targeting modifiable factors may help alleviate family stress. However, larger studies are needed to confirm these findings and guide clinical practice.

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Author contributions

Siripuk Sawetchaikul : data collection, data analysis, writing of the manuscript ; Paweena Wongborpid : revision of the manuscript ; Kanokluck Songking : revision of the manuscript.

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