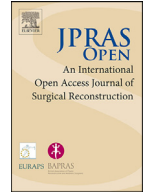




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Original Article

Disease-Related Knowledge, Stress, and Quality of Life of Parental Caregivers of Children with Cleft Lip and Palate in a Selected Hospital in Ho Chi Minh City, Vietnam

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ABSTRACT

Introduction: Cleft lip and palate (CLP) is one of the most common congenital anomalies worldwide, affecting approximately 2,000 children annually in Vietnam. Parental caregivers, particularly mothers, face considerable challenges in managing complex treatment pathways and addressing their children's multifaceted needs. This often leads to increased stress and decline in the quality of life (QoL). This study aimed to explore the relationship between disease-related knowledge, stress, and QoL among caregivers of children with CLP in Ho Chi Minh City.

Materials and Methods: A descriptive-correlational design was used with a purposive sample of 235 parental caregivers from an Odonto-Stomatology Hospital in Ho Chi Minh City, Vietnam. Data were collected using three validated instruments: the Disease-Related Knowledge Scale, Stress Scale for Parents of Children with CLP, and WHOQOL-BREF. Descriptive statistics were used to sum-

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marize the data; Pearson's correlation coefficient and multiple linear regression were used to examine the relationships between knowledge, stress, and QoL.

Results: Caregivers had moderately good disease-related knowledge ($M=3.66$, $SD=0.39$), with the highest scores in information provision ($M=3.90$, $SD=0.43$). Stress levels were moderately low ($M=3.46$, $SD=0.44$), with resource deficiencies being the most significant stressor. Although the caregivers reported good overall QoL ($M=3.97$, $SD=0.47$), psychological health scored lower ($M=3.45$, $SD=0.84$). A significant positive correlation was found between knowledge and stress ($r=0.421$, $p<0.001$), but no significant correlation was observed between knowledge and QoL ($r=-0.033$, $p=0.619$).

Conclusion: Greater disease-related knowledge correlated with increased stress, yet it did not directly improve QoL. These findings emphasize the need for comprehensive support, including education and psychosocial interventions, to reduce stress and enhance the well-being of parental caregivers.

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Introduction

Cleft lip and palate (CLP) are among the most common congenital anomalies affecting the craniofacial region, with significant implications for the physical, emotional, and social well-being of the affected children and their families. Globally, CLP occurs in approximately 1 in 700 live births, creating lifelong challenges related to feeding, speech, hearing, and facial aesthetics.¹ In Vietnam, approximately 2,000 children are born with CLP annually, and access to specialized care remains limited, especially in rural areas. This situation places substantial caregiving burdens on the parents, who must navigate complex treatment pathways and manage the multifaceted needs of their children.

Parental caregivers, particularly mothers, are often the primary caregivers for children with CLP and are tasked with understanding the condition and also ensuring proper care, managing medical appointments, and dealing with the emotional and social stressors associated with the condition.² The caregiving role is further complicated by the lack of comprehensive information and support, leading to increased stress and a potential decline in caregivers' quality of life (QoL). Caregiver stress is a key factor that influences the overall well-being of the caregiver and the child, making it essential to understand how disease-related knowledge and stress interplay to affect the caregiver's QoL.³

This study was conducted in a hospital in Ho Chi Minh City, Vietnam, to explore the relationship between disease-related knowledge, stress, and QoL among parental caregivers of children with CLP. By investigating these factors, the study aimed to provide insights that can inform the development of a parent-centered care model, addressing the informational and emotional needs of caregivers. The findings have important implications for nursing practice, as they highlight the need for comprehensive educational interventions and psychosocial support to improve the caregiving experience and outcomes for parents and children.

Materials and Methods

Study Design

This study employed a descriptive-correlational research design to explore the relationship between disease-related knowledge, stress, and QoL among parental caregivers of children with CLP in

a hospital in Ho Chi Minh City, Vietnam. The descriptive aspect allowed for the analysis of caregiver demographics, knowledge, stress levels, and QoL, whereas the correlational component examined the interactions between these variables.

Study Population

The study involved a purposive sample of 235 parental caregivers of children with CLP who received care at an Odonto-Stomatology Hospital in Ho Chi Minh City. Eligibility criteria included caregivers who were the primary decision-makers in the child's care and who had been involved in the care process for at least one year. The sample predominantly consisted of mothers, reflecting the caregiving patterns in the region. The study was conducted with parental caregivers of children with CLP, specifically those with children aged between 1 and 5 years. This age range was selected because it represents a critical period in the child's development, including early speech development, onset of surgeries, and beginning of school years, when children are more likely to face social stigma related to their cleft. The caregivers' experiences and adjustment to their child's condition were expected to vary significantly during these formative years.

Instruments

Data were collected using three validated instruments, each instrument was adapted and translated to Vietnamese to ensure clarity and cultural relevance:

Disease-Related Knowledge Scale: This scale, developed by Pongpagatip et al. (2012), assessed the caregivers' knowledge of CLP in terms of information provision, advice and treatment, multidisciplinary care, and coordination of medical visits. It used a six-point Likert scale ranging from "strongly disagree" to "strongly agree".⁴

Stress Scale for Parents with Cleft Lip and/or Palate Children: This instrument measured caregiver stress across four domains: long-term child care-related stressors, resource deficiency, family adaptation, and defect management. Responses were rated on a six-point Likert scale.

Quality of Life Scale: This scale, based on the work of Qatamin et al. (2023), evaluated the caregivers' QoL across five domains, physical health, psychological health, social relationships, environmental factors, and overall general health, using a six-point Likert scale.⁵

Data Collection Procedure

Data were collected between December 2023 and January 2024. After obtaining informed consent, caregivers were asked to complete the questionnaire during their child's routine medical visits. To ensure accuracy, a trained research assistant clarified any questions or concerns. The total time to complete the questionnaire was approximately 30 minutes.

Ethical Considerations

Ethical approval for the study was obtained from the institutional review board of the Trinity University of Asia. All participants were fully informed about the nature and purpose of the study and provided written informed consent prior to participation. Confidentiality was maintained throughout the research process, and participants were assured of their right to withdraw from the study at any time without consequence.

Data Analysis

The collected data were analyzed using descriptive and inferential statistics. Descriptive statistics, including means, standard deviations, and frequency distributions, were used to summarize the demographic characteristics of the sample and responses to the knowledge, stress, and QoL scales.

Pearson's correlation coefficient was employed to examine the relationships between disease-related knowledge, stress, and QoL. The significance level was set at $p < 0.05$. The statistical software package SPSS (Version 25.0) was used for all analyses.

Table 1
Demographic Characteristics of Parental Caregivers (n=235).

Levels	Frequency (f)	Percentage (%)
Age		
25–30 years	14	6.0
31–36 years	80	34.0
37–42 years	53	22.6
43–48 years	61	26.0
49–55 years	27	11.5
Relationship to the Child		
Father	110	46.8
Mother	125	53.2
Marital Status		
Single	1	0.4
Married	174	74.0
Divorced	60	25.5
Highest Educational Attainment		
Primary	6	2.6
Secondary	12	5.1
High School	92	39.1
College	89	37.9
Postgraduate	36	15.3

Table 2
Disease-Related Knowledge of Parental Caregivers (n=235).

Statements	Mean	SD	Descriptive Interpretation
Information provision	3.90	0.43	Slightly Agree
Advice and treatment	3.49	0.38	Slightly Agree
Information about the disease	3.74	0.34	Slightly Agree
Multidisciplinary approach to treatment	3.69	0.37	Slightly Agree
Coordination of visits to treatment	3.47	0.44	Slightly Agree
Overall Mean	3.66	0.39	Slightly Agree / Slightly Good Knowledge

Results

A total of 235 parental caregivers of children with CLP participated in the study. Most participants were aged 31–36 years (34%), with 53.2% being women and 74% married. Most caregivers had completed high school (39.1%) and were currently employed (64.7%) (Table 1).

Parents caring for children with CLP rated their knowledge about the disease as being generally good, with an average score of 3.66 ± 0.39 . Specifically, they rated their knowledge of information provision and disease information as “Slightly Good Knowledge,” with average scores of 3.90 ± 0.43 and 3.74 ± 0.34 , respectively. Similarly, the knowledge of multidisciplinary treatment methods was also rated as “Slightly Good Knowledge” with a score of 3.69 ± 0.37 . However, some aspects such as advice, treatment (3.49 ± 0.38) and coordination of examinations (3.47 ± 0.44) were rated as “Slightly Poor Knowledge” (Table 2).

The self-assessed stress level of parents caring for children with CLP is classified was “Slightly not stressful” with an average score of 3.46 ± 0.44 . Specifically, stressors related to long-term care of children and factors related to family adaptation were rated as “Slightly not stressful” with scores of 3.43 ± 0.34 and 3.37 ± 0.48 . Similarly, stressors related to resource shortages and defective management were also classified as “Slightly Stressful” with mean scores of 3.57 ± 0.58 and 3.47 ± 0.37 , respectively (Table 3).

Parents caring for children with CLP rated the overall quality of care they provide as “somewhat good,” with an average score of 3.97 ± 0.47 . They rated their general health as “good” (4.39 ± 0.50), while “slightly good” ratings were recorded for physical health (4.01 ± 0.42), environment (3.95 ± 0.40), psychological health (3.77 ± 0.49), and social relationships (3.67 ± 0.52) (Table 4).

Table 3
Stress Levels of Parental Caregivers (n=235).

Statements	Mean	SD	Descriptive Interpretation
Long Cchild care-related stressors	3.43	0.34	Sometimes
Resource deficiency-related stressors	3.57	0.58	Often
Family adaptation-related stressors	3.37	0.48	Sometimes
Defect management-related stressors	3.47	0.37	Sometimes
Overall Mean	3.46	0.44	Sometimes / Slightly not Stressful

Table 4
Quality of Life (QoL) of Parental Caregivers (n=235).

Statements	Mean	SD	Interpretation
Physical health	4.01	0.42	Slightly Agree
Psychological health	3.77	0.49	Slightly Agree
Social relationships	3.67	0.52	Slightly Agree
Environment	3.95	0.40	Slightly Agree
Overall QoL and general health	4.39	0.50	Agree
Overall mean	3.97	0.47	Slightly Agree / Slightly Good QoL

Table 5
Correlation Between Disease-Related Knowledge, Stress, and Quality of Life.

Variable	Knowledge	Stress	Quality of Life
Knowledge	1.00	0.421**	-0.033
Stress	0.421**	1.00	-0.148
Quality of Life	-0.033	-0.148	1.00

Lastly, the Pearson correlation analysis revealed a significant positive correlation between disease-related knowledge and stress ($r=0.421$, $p<0.001$), indicating that caregivers with more knowledge on CLP experienced higher levels of stress. However, no significant correlation was found between knowledge and QoL ($r=-0.033$, $p=0.619$), suggesting that increased knowledge did not directly improve caregivers' perceived QoL (Table 5).

The multiple regression analysis revealed that disease-related knowledge explained 7.4% of the variance in QoL, while stress contributed 11.3%. The positive correlation between resource-deficiency-related stressors and QoL, as shown in Table 6, highlights the impact of the free services provided by Operation Smile and the resilience of parental caregivers. Despite the significant financial burdens associated with caring for a child with CLP, including costs for travel, accommodation, and time off work, the comprehensive support offered by Operation Smile significantly improves the QoL for caregivers.

This study uses the Comprehensive Care Framework to model support for parents of children with CLP (Figure 1). Central to this model is the Parent Caregiver, representing their crucial role in caregiving. Surrounding the caregiver are several key factors that significantly influence their QoL (Figure 2).

These factors include Information Provision, which underscores the necessity of clear and accessible information regarding the child's condition and care strategies, enabling caregivers to make informed decisions. Next, Long-term child care-related stressors represent the ongoing challenges and emotional burdens that caregivers face over time as they navigate their child's needs.

Resource Deficiency-related Stressors highlight the impact of inadequate access to financial, medical, or educational resources, which can increase stress and hinder caregiving. Family Adaptation-related Stressors emphasize how a family's ability to cope with stress affects the caregiver's well-being. Lastly, Defect Management-related Stressors focus on the complexities of managing the child's medical needs, contributing to caregiver stress.

Table 6
Multiple Linear Regression between the Self-assessed Disease-related Knowledge, Stress, and Quality of Life of Parental Caregivers of Children with Cleft Lip and Palate.

Predictors Disease-related Knowledge	SE	t	β	p
Intercept	0.3609	11.317	40.843	<.001
Information provision	0.0495	-0.593	-0.0293	0.554
Advice and treatment	0.0586	-2.931	-0.1717	0.004*
Information about the disease	0.0633	-0.670	-0.0424	0.504
Multidisciplinary approach to treatment	0.0581	2.663	0.1548	0.008*
Coordination of visits to treatment	0.0484	1.032	0.0500	0.303

$R^2 = 0.074$, $R=0.272$, $F=3.65$, $p=0.003$
*** $p<.001$, ** $p<.01$ * $p<.05$

Stress				
Intercept	0.2856	10.444	29.832	< .001***
Long term child care-related stressors	0.0631	-0.731	-0.0462	0.466
Resource deficiency-related stressors	0.0753	4.137	0.3113	< .001***
Family adaptation-related stressors	0.0466	-2.519	-0.1175	0.012**
Defect management-related stressors	0.0628	1.909	0.1199	0.058*

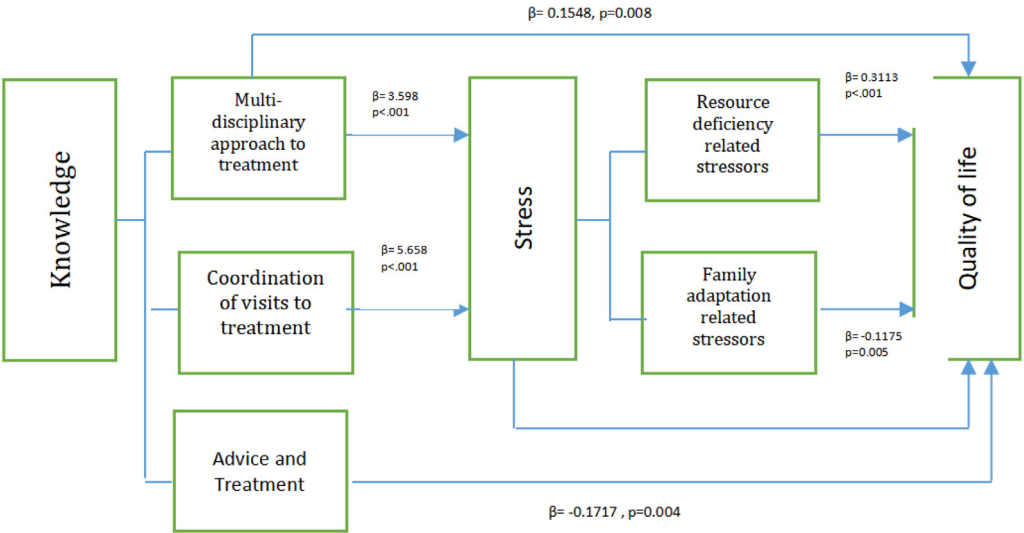


Figure 1. Parent-centered care pathway model for children with cleft lip and palate.

This model collectively provides a holistic view of the various influences on the caregiver's experience, emphasizing the interconnectedness of these factors in shaping their QoL.

Discussion

One of the significant findings of this study was the moderate level of disease-related knowledge among parental caregivers. Specifically, caregivers had the most knowledge in areas related to the multidisciplinary approach to care. This finding underscores the importance of multidisciplinary teams in providing integrated care for children with CLP. Vast knowledge in this area could be attributed to the structured interactions that caregivers have with multiple healthcare professionals, such as surgeons, speech therapists, orthodontists, and pediatricians, who together provide a comprehensive treatment plan.

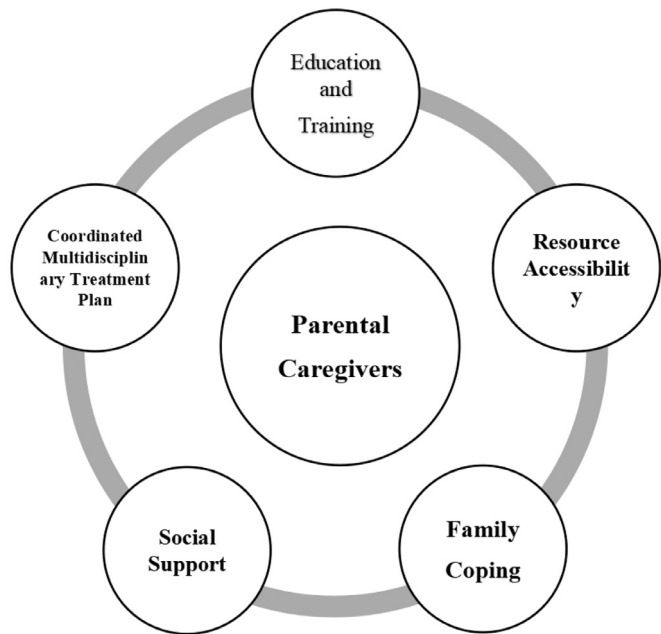


Figure 2. Parent-Centered Care Model for Children with Cleft Lip and Palate.

The study found that caregivers had lower knowledge levels in disease-specific areas related to CLP, such as its causes and long-term management. This knowledge gap is concerning, as understanding the disease etiology is crucial for informed caregiving decisions. Limited access to clear and understandable educational resources, especially for those from lower educational backgrounds or rural areas, may explain this deficit. These findings align with those of prior studies highlighting caregivers' challenges in obtaining accurate information on congenital conditions such as CLP.⁴

In Vietnam, particularly in rural areas, health literacy is often low, contributing to a knowledge gap among caregivers. Several individuals rely on informal sources such as friends, family, or the internet, which can offer inaccurate information. This highlights the need for healthcare providers to create effective educational programs tailored to the caregivers' specific needs, focusing on clear, accessible, and culturally relevant information about the disease, its causes, and long-term implications.⁶

The study found that caregivers of children with CLP experience moderate stress, primarily due to resource deficiencies. This aligns with existing literature on the financial and logistical burdens of caring for a child with a congenital condition. In Vietnam, limited and expensive healthcare resources exacerbate these challenges, forcing families to travel long distances for specialized care. Furthermore, the financial strain from repeated surgeries and treatments contributes significantly to their stress.⁷

The findings indicated that long-term caregiving and defect management stressors are significant, though less pronounced than resource deficiencies. Stressors such as managing daily health needs, navigating treatment schedules, and balancing family or work obligations are common. Particularly, mothers often bear these responsibilities, which results in chronic stress and emotional exhaustion, which can result in burnout, anxiety, or depression, ultimately reducing their capacity to provide effective care.⁸

The study found that family adaptation-related stress was less prominent than resource-related stress, likely because families develop coping strategies over time, such as seeking support from extended family or community members. However, external stressors related to healthcare access and affordability remain significant. This underscores the need for policy interventions to improve healthcare access and provide financial support for families with children with chronic conditions such as CLP.

Although caregivers reported a good QoL, their psychological health scores were low, indicating a significant emotional toll. Several of them experienced guilt, anxiety, and depression, particularly when long-term medical interventions are needed, with stigma and social isolation further worsening their psychological burden.

Although caregivers' physical health and social relationships are rated generally Slightly Good owing to their youth and supportive extended family networks, psychological health remains a challenge. This highlights the urgent need for psychosocial support services, such as counseling and support groups, to address caregiver burnout, anxiety, and depression, ultimately improving their overall well-being.

A significant finding of the study was the positive correlation between disease-related knowledge and stress among caregivers. As caregivers learned more about CLP, their stress levels tended to increase, which may appear counterintuitive as knowledge is often thought to empower individuals. However, greater awareness of the challenges and complications can heighten anxiety. This aligns with the "burden of knowledge" concept observed in other caregiving contexts, where increased knowledge leads to worries about long-term implications, financial costs, and effective management of the condition. The complexity of CLP treatment, involving multiple surgeries and therapies, can overwhelm even the well-informed caregivers.⁹

Psychological health, encompassing mental, emotional, and spiritual well-being, is crucial when managing caregiving responsibilities. This study confirms the previous findings, showing that parents of children with CLP experience significant psychological stress, particularly during the early years. Research by van Dalen et al. (2021) indicates higher levels of anxiety and depression in parents of children with CLP compared to those with healthy children, with emotional burdens and child-related demands being the key stressors. Our study similarly found elevated stress levels, highlighting the need for psychological support, especially early on in caregiving.¹⁰

The emotional strain of caregiving often leads to persistent preoccupation with the child's medical needs, which can disrupt daily functioning and sleep (Daniel et al., 2018). In our study, caregivers reported good QoL overall, but psychological health scores were significantly lower, reflecting the mental toll of caregiving. Notably, caregivers with greater disease-related knowledge reported higher stress, possibly due to anticipatory anxiety about their child's condition and treatment outcomes.¹¹

Practical stressors, such as managing medical appointments and treatment costs, were common among caregivers and exacerbated their psychological burden. As Dalen et al. (2021) pointed out, logistical and financial stressors contribute to heightened anxiety. Our study results support those findings, showing that the complexity of managing a child's care adds to emotional and psychological distress.¹⁰

Despite these challenges, caregivers can reduce stress through social support and coping strategies. Park & Lee (2022) emphasized the role of self-care and social networks in alleviating emotional strain. In line with these findings, caregivers with stronger support systems in this study reported better psychological health, underscoring the importance of integrating emotional support into caregiving interventions. Future strategies should address informational and emotional needs to help caregivers manage the psychological burdens of their role.¹²

The study did not specifically focus on whether the cleft was diagnosed prenatally. However, it is well-established in the literature that prenatal diagnosis of CLP, when possible, can affect parental adjustment. Studies show that early knowledge of the condition (prior to birth) gives parents more time to process the information, seek support, and prepare emotionally for the birth of their child, which can contribute to better psychological outcomes in the long-term.¹³ In contrast, a postnatal diagnosis can be more emotionally overwhelming for parents, who may be unprepared for the condition and its implications.¹⁴ The prenatal diagnosis could have reduced some of the emotional stressors typically reported by parents, but this aspect was not directly assessed in the present study.

The positive correlation between knowledge and stress highlights a gap in the information provided to caregivers. Although they may understand treatments, they often lack emotional support, emphasizing the need for educational programs that include coping strategies and mental health services. The study found no significant correlation between disease-related knowledge and caregivers' QoL, indicating that social support, financial stability, and healthcare access are more influential. Care-

givers with strong support networks report better QoL, underscoring the necessity for a holistic approach that includes financial assistance and mental health resources.

The finding that greater knowledge on CLP correlates with higher stress in caregivers is indeed intriguing and contrasts with the common expectation that increased knowledge reduces anxiety. This phenomenon, often referred to as the “burden of knowledge,” suggests that although understanding the medical complexities of CLP may provide caregivers with a sense of control, it may also heighten anxiety owing to the awareness of potential complications and long-term challenges. Research on parental adjustment, such as that by Namdar (2022), typically shows that knowledge helps alleviate uncertainty; however, our findings indicate that greater knowledge may instead amplify stress, particularly when caregivers are overwhelmed by the complexity of managing the child's condition. This paradoxical relationship between knowledge and stress highlights the need for interventions that provide information and also address the emotional and psychological burdens that the caregivers experience, emphasizing the importance of psychosocial support alongside medical education.¹⁵

These findings have important implications for nursing practice and healthcare policy. Nurses play a vital role in educating caregivers about CLP, and this education must be clear and supportive, including emotional support through caregiver groups or counseling. The study also emphasizes the need for policy interventions to address the financial and logistical challenges faced by caregivers in Vietnam, with several caregivers struggling to afford treatments. Furthermore, policies that provide financial assistance and improve access to multidisciplinary care centers in rural areas could alleviate these stresses.

Although the study offers valuable insights, it has limitations. As the study was conducted at a single hospital, its findings may not be generalizable. Future research should include a more diverse sample and use a mixed-methods approach to better understand the caregivers' experiences, and explore the impact of social support networks and coping strategies on effective caregiver support.

Conclusion

This study highlights the complex relationship between disease-related knowledge, stress, and QoL of parental caregivers of children with CLP. Although greater knowledge may increase the caregivers' stress, it does not necessarily improve their QoL. These findings underscore the need for a holistic approach to support the caregiver by combining education with emotional, psychological, and financial resources. By addressing the informational and emotional needs of caregivers, healthcare providers and policymakers can help improve the well-being of caregivers and children with CLP in Vietnam.

Ethical approval

Ethical approval for this study was granted by the institutional review board of Trinity University of Asia, Philippines, under reference number TUA- IERC- 015-R02. All participants were thoroughly informed about the study's nature and purpose, and provided written informed consent prior to participation. Confidentiality was upheld throughout the research process, and participants were assured of their right to withdraw from the study at any time without any negative consequences.

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Declaration of competing interest

None.

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