

The correlation between disease awareness, disposition, and caregiving competency among parents of children with congenital heart disease in selected communities in Vietnam

Dang Van Sang¹, Joanna Sanchez De Guzman²

Tran Thi My¹, Nguyen Nhat Tuan Trung³

¹ Tam Duc Heart Hospital

² Trinity University of Asia

³ University of Medicine and Pharmacy at Ho Chi Minh City

Correspondence to

Dr. Dang Van Sang
Tam Duc Heart Hospital
Email: sangdangopsmile@gmail.com

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ABSTRACT

Objectives: To investigate the relationship between disease awareness, caregiving disposition, and competency among parents of children with congenital heart disease.

Methodology: A correlational descriptive study was conducted involving 275 parents of children with congenital heart disease across three regions: the Mekong Delta, Central Highlands, and Central Coastal areas.

Results: Parents of children with congenital heart diseases demonstrated a high level of disease awareness, with a mean score of 3.82. Their attitude towards the condition was notably positive, scoring an average of 4.65, and their caregiving competency was similarly strong, with a mean score of 4.36. While no significant correlation was found between disease awareness and both disposition or caregiving competency, a significant positive correlation was identified between attitude and caregiving competency, reflected by a high correlation coefficient and a p-value of less than 0.001. Furthermore, the study revealed that the linear regression model had an r^2 value of 0.386, indicating that 38.6% of the variability in caregiving ability could be explained by factors, such as acceptance of the condition, recognition of parental role, and support and collaboration with other parents of children with congenital heart disease.

Conclusions: Disposition and caregiving competency play a critical role in determining the health outcomes and quality of care for children with congenital heart disease. As such, it is essential to design and implement specialized training programs tailored for parents, aimed at strengthening their caregiving skills and improving the overall well-being of their children.

Keywords: Disease awareness, disposition, caregiving competency, congenital heart disease, parents.

INTRODUCTION

Congenital heart disease (CHD) is one of the most frequently diagnosed

congenital disorders, afflicting approximately 0.8% to 1.2% of live births worldwide (W Wu, 2020). CHD management is chronic, requiring ongoing hospitalizations, surgeries, and lifelong follow-up (Ruben Willems et al., 2019). This places significant demands on families, often leading to challenges such as maintaining care routines and managing financial and social constraints (Cardoso Vaz Jéssica & Marten Milbrath Viviane, 2018). Previous studies have shown that parents of children with CHD may struggle with disease management due to limited disease awareness and challenges in planning and implementing care strategies (Berto J. Bouma, 2017; Devyani Chowdhury, 2021). These difficulties can compromise the quality of care provided, potentially leading to poorer health outcomes for the child (Alina Morawska, 2015). Therefore, understanding how parental awareness, psychology, and caregiving competency are interconnected is crucial for developing targeted interventions. This study aims to explore the correlations between disease awareness, attitudes, and caregiving abilities of parents with children suffering from congenital heart disease in order to enhance these factors and support families in effectively managing their child's condition..

METHODS

Population

Parents of children aged 0-18 with congenital heart diseases living in selected areas of Vietnam: Mekong Delta (Dong Thap, Ca Mau), Central Highlands (Lam Dong, Dak Lak), and Central Coast (Phu Yen, Ninh Thuan).

Inclusion Criteria: Participants must be able to read and write and must agree to participate.

Exclusion Criteria:

- Parents of children with additional illnesses other than congenital heart diseases.
- Parents unable to complete the study due to illness, personal reasons, or unwillingness to participate.

Settings

Research period: from October 25, 2023 to July 17, 2024

Research location: conducted in three regions of Vietnam: Mekong Delta (Dong Thap, Ca Mau), Central Highlands (Lam Dong, Dak Lak) and Central Coast (Phu Yen, Ninh Thuan).

Design

A correlational descriptive study was used.

Sample size

The sample size was determined using G Power software, version 3.1.9.2. With an effect size (ρ) of 0.20, a power of 80%, and a margin of error of 5%, the estimated sample size was 275.

Data collection

The questionnaire was developed based on relevant studies and content-validated by five cardiovascular disease experts (Cardoso Vaz Jéssica & Marten Milbrath Viviane, 2018; Kunnara Maneekunwong, 2022; Osama Hafiz Elshazali & Farah, 2020). It was pilot-tested with 25 respondents who met the inclusion criteria but were not part of the final study. The questionnaire showed good internal consistency, with a Cronbach's alpha of 0.805.

Data were collected directly using a self-administered questionnaire with a 5-point Likert scale, including:

- + Part A of the questionnaire deals with study characteristics
- + Part B of the questionnaire pertains to the disease awareness on congenital heart disease
- + Part C of the questionnaire pertains to the disposition among parents of children with congenital heart disease
- + Part D of the questionnaire pertains to the caregiving competency among parents in caring for their children with congenital heart disease.

Data Analysis

The data were processed and analyzed using Jamovi 2.5, with techniques including frequency, percentage, mean, and Pearson's correlation coefficient analysis.

Research Ethics

The study was conducted after approval from Trinity University of Asia and subsequently with the specific community where the research was carried

out. Participants' personal information and data obtained from the research were kept confidential and used only for research purposes.

RESULTS

Characteristics of the study subjects

Table 1. Characteristics of the Study Population (n=275)

| Demographic | Frequency | Percentage (%) |
|---------------------------------------|-----------|----------------|
| Sex | | |
| Female | 180 | 65.5% |
| Male | 95 | 34.5% |
| Others | 0 | 0% |
| Highest educational attainment | | |
| Primary level | 57 | 20.7% |
| Secondary level | 179 | 65.1% |
| College level | 36 | 13.1% |
| Postgraduate level | 0 | 0% |
| None | 3 | 1.1% |
| Occupational status | | |
| Employed | 193 | 70.2% |
| Unemployed | 81 | 29.5% |
| Student | 0 | 0% |
| Retired | 1 | 0.4% |
| Area of Residence | | |
| Urban | 226 | 82.2% |
| Rural | 49 | 17.8% |
| Civil Status | | |
| Single | 14 | 5.1% |
| Married | 255 | 92.7% |
| Divorced | 4 | 1.5% |
| Widow | 2 | 0.7% |
| Socioeconomic Status | | |
| Poor level (<65 USD) | 55 | 20.0% |
| Near-poor level (~65 USD – ~85 USD) | 98 | 35.6% |
| Average level (~65 USD – ~130 USD) | 82 | 29.8% |
| Above average level (>130 USD) | 40 | 14.5% |

The study involved 275 participants with the following key characteristics:

The age range of parents in the study spans from 19 to 68 years, with a mean age of 38 years. The children's ages range from 1 to 17 years, with a mean age of 6.5 years.

Majority were female (65.5%), with males making up 34.5%.

Most participants had secondary education (65.1%), while primary education was held by 20.7%, and university education by 13.1%.

The majority were employed (70.2%), and 29.5% were unemployed. A significant majority lived in urban areas (82.2%).

Most were married (92.7%), with a small proportion being single (5.1%).

The largest group had a medium socioeconomic status (35.6%), followed by upper-medium (29.8%) and low (20.0%).

Most were mothers (59.6%), followed by fathers (32.0%).

Table 2. Characteristics of congenital heart disease in children (n=275)

| Demographic | Frequency | Percentage (%) |
|---|-----------|----------------|
| Relationship with child | | |
| Father | 88 | 32.0% |
| Mother | 164 | 59.6% |
| Others | 23 | 8.4% |
| Child's initial diagnosis | | |
| Hypoplastic left-heart syndrome | 1 | 1.8% |
| Univentricular physiology | 9 | 3.3% |
| Tetralogy of Fallot | 34 | 12.4% |
| Double-outlet right ventricle | 20 | 7.3% |
| Double-inlet left ventricle | 12 | 4.4% |
| Truncus arteriosus | 0 | 0% |
| Transposition of the great arteries (TGA) | 0 | 0% |
| Congenitally-corrected TGA | 3 | 1.1% |
| Coarctation of the aorta | 35 | 12.7% |

| Demographic | Frequency | Percentage (%) |
|--|-----------|----------------|
| Atrioventricular septal defect | 19 | 6.9% |
| Atrial septal defect, type 1 | 4 | 1.5% |
| Ebstein malformation | 10 | 3.6% |
| Pulmonary valve abnormality | 14 | 5.1% |
| Aortic valve abnormality | 1 | 0.4% |
| Aortic abnormality | 3 | 1.1% |
| Left ventricle outflow tract obstruction | 3 | 1.1% |
| Atrial septal defect, type 2 | 7 | 2.5% |
| Ventricular septal defect | 75 | 27.3% |
| Mitral valve abnormality | 20 | 7.3% |
| Pulmonary vein abnormality | 1 | 0.4% |
| Other | 0 | 0% |

The most common initial diagnoses were Ventricular septal defect at 27.3%, Coarctation of the aorta at 12.7% and Tetralogy of Fallot at 12.4%.

Disease awareness among parents of children with congenital heart disease

Table 3. Disease Awareness Among Parents of Children with Congenital Heart Disease

| Dimension | Mean | Interpretation |
|-----------------------|-------------|---|
| A. Disease | 3.83 | Strongly Agree/ High awareness |
| B. Symptoms | 3.90 | Strongly Agree/ High awareness |
| C. Treatment | 3.84 | Strongly Agree/ High awareness |
| D. Prevention | 4.01 | Strongly Agree/ High awareness |
| E. Complications | 3.50 | Neither Agree Nor Disagree / Moderate Awareness |
| Overall Rating | 3.82 | Agree/High awareness |

Legend:
4.51 – 5.00 – Strongly Agree / Very High Awareness
3.51 – 4.50 – Agree / High Awareness
2.51 – 3.50 – Neither Agree Nor Disagree / Moderate Awareness
1.51 – 2.50 – Disagree / Low Awareness
1.00 – 1.50 – Strongly Disagree / Very Low Awareness

The average scores for various aspects of congenital heart disease awareness were as follows: Disease (3.83), Symptoms (3.90), Treatment (3.84), Prevention (4.01), and Complications (3.50). Overall, general awareness was high, with a mean score of 3.82, indicating strong agreement with a high level of awareness.

Disposition Among Parents of Children with Congenital Heart Disease

Table 4. Disposition Among Parents of Children with Congenital Heart Disease

| Dimension | Mean | Interpretation |
|--------------------------------|-------------|---|
| A. Acceptance of the Condition | 4.59 | Strongly Agree / Very Good disposition |
| B. Acknowledgement of Role | 4.66 | Strongly Agree / Very Good disposition |
| C. Support and Collaboration | 4.71 | Strongly Agree / Very Good disposition |
| Overall Rating | 4.65 | Strongly Agree / Very Good disposition |

Legend:

4.51 – 5.00 – Strongly Agree / Very Good disposition
3.51 – 4.50 – Agree / Good disposition
2.51 – 3.50 – Neither Agree Nor Disagree / Fair disposition
1.51 – 2.50 – Disagree / Poor disposition
1.00 – 1.50 – Strongly Disagree / Very Poor disposition

The mean scores for different aspects of parental attitudes towards congenital heart disease were: Acceptance of the condition (4.59), Role perception (4.66) and Support and cooperation (4.71). Overall, the general attitude was very positive with a mean score of 4.65, indicating strong consensus and very good attitudes towards caring for children with congenital heart disease.

Caregiving Competency Among Parents of Children with Congenital Heart Disease

Table 5. Caregiving Competency Among Parents of Children with Congenital Heart Disease

| Dimension | Mean | Interpretation |
|-----------------------|------|------------------------|
| A. Care after surgery | 4.46 | Often/ Good competency |
| B. Nutritional care | 4.37 | Often/ Good competency |

| | | |
|--|-------------|-------------------------------|
| C. Compliance to medication | 4.63 | Always/ Very Good competency |
| D. Physical Activity | 4.09 | Often/ Good competency |
| E. Oral Care | 4.11 | Often/ Good competency |
| F. Caring in emergency situation | 4.52 | Always/ Very Good competency |
| Overall Rating | 4.36 | Often/ Good competency |
| Legend: | | |
| 4.51 – 5.00 – Always/ Very Good competency | | |
| 3.51 – 4.50 – Often/ Good competency | | |
| 2.51 – 3.50 – Sometimes/ Fair competency | | |
| 1.51 – 2.50 – Seldom/ Poor competency | | |
| 1.00 – 1.50 – Never/ Very Poor competency | | |

The average scores for various aspects of caregiving are as follows: Post-operative Care (4.46), Nutritional Care (4.37), Medication Adherence (4.63), Physical Activity (4.09), Oral Care (4.11), and Emergency Care (4.52). Overall, caregiving competency is rated as good with a mean score of 4.36, indicating that parents frequently exhibit good caregiving skills.

Linear relationship between the assessed disease awareness, disposition and caregiving competency among parents of children with congenital heart disease

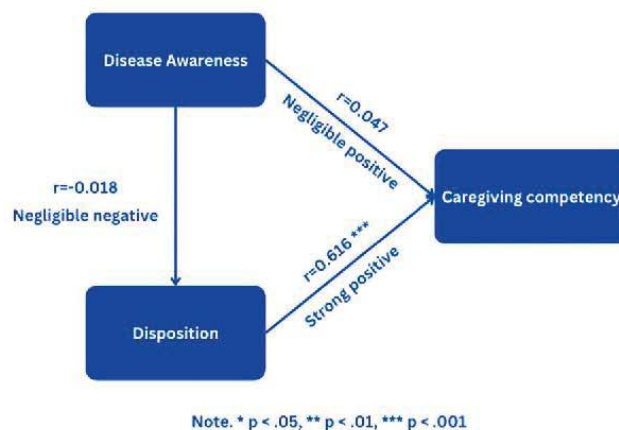


Figure 1. Linear relationship between the assessed disease awareness, disposition and caregiving competency among parents of children with congenital heart disease

The study found a statistically significant correlation between attitudes and caregiving ability, suggesting that positive attitudes may be associated with better caregiving ability. Other factors such as illness awareness did not show a significant effect on attitudes or caregiving ability.

The predictive relationship between the assessed disposition and caregiving competency among parents of children with congenital heart disease

Table 6. The predictive relationship between the assessed disposition and caregiving competency among parents of children with congenital heart disease

| Variables | Caregiving Competency | | |
|--------------------------------|-----------------------|----------------------------------|---------|
| | Coefficients | 95% Confidence Interval – 95% CI | p-value |
| Intercept | 0.2459 | | |
| A. Acceptance of the Condition | 0.0696 | -0.0336 ; 1.695 | 0.139 |
| B. Acknowledgement of Role | 0.0615 | 0.1413 ; 0.383 | < .001 |
| C. Support and Collaboration | 0.310 | 0.1724 ; 0.447 | < .001 |
| | R² | 0.386 | |

The findings showed that both acknowledgement of Role and Support and Collaboration were significantly positively associated with caregiving

competency, as indicated by confidence intervals that did not include zero, confirming statistical significance. In contrast, Acceptance of the Condition

had a positive coefficient, its confidence interval includes zero, suggesting the relationship was not statistically significant. The model explains 38.6% of the variance in caregiving competency, highlighting the strong predictive power of the key dispositions. The resulting predictive equation was:

$$\text{Caregiving Competency} = 0.2459 + (0.0696 * \text{Acceptance of the Condition}) + (0.0615 * \text{Acknowledgement of Role}) + (0.310 * \text{Support and Collaboration}).$$

Intercept (0.2459): Baseline caregiving competency.

Acceptance of the Condition: Increases caregiving competency by 0.0696 units per one-unit increase but is not statistically significant ($p = 0.139$).

Acknowledgement of Role: Increases caregiving competency by 0.0615 units per one-unit increase and is statistically significant ($p < 0.001$).

Support and Collaboration: Increases caregiving competency by 0.310 units per one-unit increase and is statistically significant ($p < 0.001$).

These results highlighted the importance of support and collaboration in improving caregiving competency, while suggesting further research on other influential factors.

DISCUSSION

The study highlights several key characteristics of the participants. The majority are female (65.5%) and married (92.7%), with mothers comprising 59.6% and fathers 32.0% of the respondents. In terms of education, 65.1% have completed secondary education, reflecting a similar trend in developing countries (Osama Hafiz Elshazali & Farah, 2020). Regarding employment, 70.2% are employed, which is higher compared to previous studies that reported lower employment rates (Kunnara Maneekunwong, 2022; Osama Hafiz Elshazali & Farah, 2020). Most participants live in urban areas (82.2%), consistent with the increasing trend of urbanization. Socioeconomic status is categorized as follows: 20.0% are classified as "poor," 35.6% as "near-poor," 29.8% as "middle," and 14.5% as "above average," differing from other

studies that reported higher percentages in lower socioeconomic categories (Kunnara Maneekunwong, 2022; Osama Hafiz Elshazali & Farah, 2020).

The study found that awareness of congenital heart disease (CHD) prevention is high, with an average score of 4.01, reflecting effective public health initiatives. In contrast, awareness of complications is lower, with a score of 3.50, indicating a need for better education on severe CHD outcomes such as arrhythmias and heart failure. Similarly, Elshazali et al. (2020) and Maneekunwong et al. (2022) emphasize that educational campaigns have improved general knowledge but often fail to address the complexities of CHD complications (Kunnara Maneekunwong, 2022; Osama Hafiz Elshazali & Farah, 2020). Therefore, enhancing education on CHD complications is crucial for better disease management and achieving improved outcomes.

The study shows that "Support and Cooperation" has the highest average score of 4.71. On the other hand, "Acceptance of the Condition" has the lowest score of 4.59. This is consistent with findings from Chowdhury et al. (2021) and other studies indicating that acceptance of illness can be a gradual process (Devyani Chowdhury, 2021; Kunnara Maneekunwong, 2022; Osama Hafiz Elshazali & Farah, 2020). Overall, enhancing informational and psychological support for parents could further improve their coping and acceptance of their child's condition.

The study indicates high competency in "Medication Adherence," with an average score of 4.63, reflecting strict adherence to medication regimens for controlling congenital heart disease (CHD). This is crucial for effective treatment and preventing complications, consistent with findings by Bouma (Berto J. Bouma, 2017) and Maneekunwong (Kunnara Maneekunwong, 2022). However, "Physical Activity" also scored 4.63, suggesting a need for improved management of physical activity in CHD care. This contrasts with the higher emphasis found in other studies in 2023, which highlighted the importance of balanced physical activity (Macarena Lorente, 2023). This study underscores the need for a comprehensive care approach that also addresses physical activity and emergency care.

The study reveals a statistically significant correlation between attitude and caregiving ability, indicating that a positive attitude may be related to better caregiving. This highlights the need for support programs focused on emotional management and communication skills for caregivers. Further research could enhance understanding of these dynamics and improve intervention strategies (Kunnara Maneekunwong, 2022; Lorente et al., 2023).

CONCLUSION AND RECOMMENDATIONS

There is a no significant linear relationship between disease awareness and disposition among parents of children with congenital heart disease, nor between disease awareness and caregiving competency. However, a significant linear relationship exists between disposition and caregiving competency. This highlights the need to focus on enhancing caregiving attitudes as a critical factor in improving care quality.

There is no significant linear relationship between disease awareness and disposition among parents of children with congenital heart disease (CHD), nor between disease awareness and caregiving competency. However, a significant linear relationship exists between disposition and caregiving competency. This highlights the need to focus on enhancing caregiving attitudes as a critical factor in improving care quality.

A comprehensive training program has been developed to improve the quality of life for children with congenital heart disease (CHD) through education on complications, early detection, and physical activity. Raising awareness among parents and caregivers is crucial, with a focus on early diagnosis, treatment options, and regular medical follow-ups. Social and psychological support, along with improved access to pediatric cardiology services, are essential, as is expanding outreach through educational initiatives and community partnerships.

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