A causal model for health-related quality of life among Thai adolescents with congenital heart disease

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Abstract

**Purpose** – The objective of this study was to examine the causal relationships among sex, social support, disease severity, symptoms, physical activity, general health perception and health-related quality of life (HRQOL) in Thai adolescents with congenital heart disease (CHD).

**Design/methodology/approach** – A cross-sectional study was conducted using convenience sampling to recruit 200 Thai adolescents with CHD aged between 13 and 18 years from four tertiary university hospitals in Bangkok. Interview method and self-administered questionnaires were used for data collection held between November 2018 and February 2019. Data were analyzed using path analysis to test the hypothesized model of the relationships.

**Findings** – The causal model of HRQOL revealed a good fit with the data. This model of relationship could explain 48% of the variances in HRQOL. Only direct effects of disease severity, symptoms and social support on HRQOL were found while indirect effects were not.

**Originality/value** – Due to the lack of study focusing on factors influencing HRQOL in Thai adolescents with CHD, this empirical study provides the evidence in Thai literature. The modifiable influencing factors for HRQOL found in this study can be manipulated through psycho-educational intervention given to the adolescents and significant others, especially parents, to help increase quality of life in adolescents with CHD.

**Keywords** Adolescent, Congenital heart disease, Health-related quality of life, Disease severity, Social support, Symptoms

**Paper type** Research paper

Introduction

Congenital heart disease (CHD) is a defect in the structure of the heart that is present at birth. CHD is a significant cause of death among children worldwide. Problems found from the defect range from simple to complex. Some problems can be self-healing and a child grows out of it, while others can be managed with medicine. Some require either surgery in the first few hours of life or several surgeries throughout their lives. Due to advancements in medical technology and treatment, improved survival rates for CHD have been evident and these...
children grow up well past childhood into adulthood. However, remaining signs and symptoms, residual defects and the treatment itself, which is usually prolonged, would interfere with their daily lives and consequently could affect their quality of life [1].

The defects of CHD can restrict an individual’s ability to achieve developmental tasks during adolescence, a crucial period of profound hormonal and neurological changes wherein even typical adolescents often manifest behavioral problems [1]. According to the underlying pathophysiology, even regular day-to-day activities that healthy adolescents normally undertake become off-limits for some adolescents with CHD [2]. Impaired physical ability and prolonged illness as well as dissatisfactory body image (like small stature, surgical scar, blue-tinted lips and nail beds) can have particularly detrimental psychological effects on these adolescents [2]. In addition, the fear of easily getting infections that may lead to complications like pneumonia or infective endocarditis may cause social isolation. Adolescents with CHD are also absent from school more than others due to frequent medical appointments and repeated hospitalization, consequently leading to school functioning impairment [3]. Furthermore, CHD itself could be associated with a higher rate of depression and loneliness, making them less likely to attend school or interact with peers [4].

Given this concern, the health-related quality of life (HRQOL) for adolescents with CHD can be defined as an individual adolescent’s perception of well-being related to how satisfied he or she is with life as a whole [5]. HRQOL has received increasing attention as an important health outcome. Despite several existing studies on this matter, gaps in knowledge remain. First, past study results were inconclusive, possibly due to conceptual and methodological differences among those studies [6]. Second, several previous studies did not explicitly indicate the use of a conceptual/theoretical framework for guiding the test of hypotheses based on the tenets of the theory [7, 8]. Next, the investigation of both direct and indirect effects of the factors on HRQOL in adolescents with CHD is scarce; most studies focused only on the direct effects of the predictive factors [7, 8]. Lastly, no studies concerning HRQOL of Thai adolescents with CHD and the influencing factors have been carried out. As a result, the generalizability of previous findings obtained in various countries, where environmental characteristics that could influence variance in HRQOL, may be limited to Thai adolescents with CHD.

To bridge the gaps in knowledge, it is necessary to examine the pattern of causal relationships among influencing factors and HRQOL in the Thai population. Thus, the current study was conducted using the conceptual model of HRQOL [5] to examine HRQOL as well as its direct and indirect influencing factors among Thai adolescents with CHD. In this conceptual model, the decisive health outcomes include biological function, symptoms, functional status, general health perceptions and HRQOL; the reciprocal relationships among these patient outcomes are assumed. The study factors under the model constructs were selected based on previous studies. The modifiable factors and personal characteristics useful for targeting interventions specifically for adolescents with CHD were selected for investigation in this study. It was hypothesized that the selected factors including sex [8], social support [9], disease severity [3], symptoms [10], physical activity [11] and general health perception [12] would have direct and indirect effects on the HRQOL, as proposed in Figure 1. An understanding of the pattern of relationships among factors influencing HRQOL could be beneficial for developing a holistic intervention to improve HRQOL for adolescents with CHD.

Methods
Population and sampling
The study used a cross-sectional design with path analysis involving Thai adolescents with CHD who received outpatient healthcare services at four tertiary hospitals located in
Bangkok from November 2018 to February 2019. Convenience sampling was used with the following inclusion criteria: (1) between 13 and 18 years of age, (2) diagnosed with CHD and any type of defect and (3) being able to read and communicate in Thai. The exclusion criteria included the presence of medical comorbidities such as psychiatric problems, Down’s syndrome, diabetes mellitus, asthma and neurological problems.

According to a rule of thumb for sample size needed for path analysis, the sample size should not be less than 200 [13]. The final sample size in this study with 16 estimated parameters was 200 participants.

Research instruments
The original research instruments and the Thai versions were used to collect data with permission. The reliability of each instrument was tested with 25 adolescents with CHD.

The Personal and Clinical Information Form developed by the researchers consists of the respondents’ personal and clinical information (including age, sex, diagnosis, treatments of CHD, vital signs and oxygen saturation), all of which were obtained from their medical records.

The Thai Quality of Life in Children (ThQLC), a child self-report form [14], was used to measure HRQOL. The ThQLC is usually used to assess HRQOL in children with chronic illness aged between 6 and 15 years. However, its use can be extended to children up to 18 years of age (Boon-ysidhi V, personal communication via e-mail, February 13, 2018). This 23-item questionnaire with a five-point rating scale ranging from 0 (not at all problematic) to 4 (extremely problematic) is a multi-dimensional scale composed of five domains of physical functioning, psychological functioning, social functioning, school functioning and outlook on life in general. The scores for each item are reversed as follows: 0 = 100, 1 = 75, 2 = 50, 3 = 25 and 4 = 0. The summation of item scores divided by the number of items answered gives the total scores for HRQOL. Higher scores indicate better HRQOL. Cronbach’s alpha coefficient of the THQOL in this study was 0.85.

The Social Support Questionnaire for Children (SSQC) – Thai version with back-translation [15] was used to measure social support provided by parents, relatives, teachers,

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**Figure 1.** Hypothesized model of HRQOL among adolescents with CHD
siblings and peers. The SSQC consists of 50 items with a four-point rating scale ranging from 0 (never or rarely true) to 3 (always true). Higher scores indicate greater perceived social support. Cronbach’s alpha coefficient of the SSQC in this study was .96.

The Disease Severity Index [16] was used to measure disease severity, which is scored as 1 – low severity (having one cardiovascular surgery or catheterization procedure to date, or none), 2 – moderate severity (having more than one cardiovascular surgery or catheterization procedure to date) and 3 – high severity (having persistent cyanosis, < 92% oxygen saturation at rest or single ventricle physiology).

The Cardiac Symptom Survey (CSS) [17] was originally used to evaluate the symptoms experienced in the last seven days by adult patients with post-operative coronary artery bypass grafting. The CSS is composed of ten symptoms including angina, shortness of breath, fatigue, depression, sleeping difficulty, incisional pain, swelling in the legs, palpitations, anxiety and poor appetite. In total, two components of the scale, consisting of evaluation of symptoms and symptom interference, are evaluated for each symptom. For the purposes of this study, however, only the evaluation of symptoms was evaluated. Each subcomponent is rated on a 0–10 point scale ranging from (0) none to (10) all the time, for frequency; and (0) none to (10) extremely severe, for severity. Furthermore, one item asking about incisional pain was deleted because it did not apply to those who had never undergone surgery. The scores for the two subcomponents (frequency and severity) were totaled and divided by two; thus, the total scores ranged from 0 to 90. Higher scores indicate a greater perception of symptoms. In this study, the CSS was validated by five experts in cardiology for use in adolescents; the content validity index (CVI) was .82, while Cronbach’s alpha coefficient was 0.75.

The Modified Thai Adolescent’s Physical Activity Questionnaire (MTAPAQ) [18] measures eight groups of physical activity with a total of 37 items. Respondents are asked to recall the number of days that they performed each activity (frequency) and the length of time (duration) each day they were involved in each activity over the previous seven days. Energy expenditure of a specific physical activity is expressed as metabolic equivalent of task (MET), which is defined as the ratio for the rate of energy expended during a specific physical activity to a reference metabolic rate (or the rate of energy expended at rest). The volume of total physical activity is calculated using the formula: MET-hours = MET x frequency x duration in hours. Higher calculated values indicate higher volumes of physical activity. The test–retest reliability of MTAPAQ in this study was .83.

Self-assessed health (SAH) was used to measure a person’s perception of his or her general health at a given point in time [19]. The SAH is a single item asking, “In general, how would you rate your health today,” using a five-point rating scale from 1 (very bad) to 5 (very good). Higher scores indicate better health status. Similar to other studies, this study did not examine the reliability of the SAH as it has found to be reliable when respondents rate the same assessment within a period where their health was unlikely to change [20].

Data collection
A staff nurse in each setting introduced the research study to eligible adolescents and their families. Those who were interested would be referred to the researcher in order to obtain more information concerning the study objectives and procedures. Adolescents and their parents who agreed to participate in the study signed assent forms and consent forms. Subsequently, the adolescents completed the initial SSQC, SAH and ThQLC in a designated area. Afterward, they were interviewed by the first researcher using the CSS and MTAPAQ. The adolescents’ personal information was collected from their medical records.
Data analysis
Descriptive statistics were employed to describe the demographic characteristics of the sample and the study variables. Path analysis was performed as a method for examining the direct and indirect effects of the study variables. As the skewness and kurtosis of all study variables were less than two and seven, the maximum likelihood was obtained to check the parameter estimation method. The goodness of fit criteria were used for evaluating the model fit, including (1) nonsignificant chi-square ($\chi^2$); (2) the relative or norm chi-square ($\chi^2/df$) less than two; (3) goodness of fit index (GFI) and adjusted goodness of fit index (AGFI) values greater than 0.9 and (4) the root mean square error of approximation (RMSEA) value less than 0.05.

Ethical considerations
This study was approved by the institutional review boards of the respective hospitals included in the study (COA No. Si672/2018, IRB NO.61156, COA No. MURA2018/706 and COA No.1102/2018).

Results
Characteristics of the study sample
The participants in the study comprised 200 adolescents with CHD. As shown in Table 1, 52% were male with a mean age of 15.08 years (SD = 1.83). Cyanotic and noncyanotic groups were found equally. One-third of the adolescents (33%) had problems of the left to right shunt (including ventricular septal defect, atrial septal defect and patent ductus arteriosus) and 17% of obstructions like pulmonary stenosis or coarctation of the aorta. Defects with decreased and increased pulmonary blood flow were found at 34% and 16%, respectively. Approximately 83% of the adolescents had previously undergone heart surgery, while 41% had received no treatment in the past year.

| Characteristics                        | $n$ (%) | $M$ (SD) |
|----------------------------------------|---------|----------|
| **Gender**                             |         |          |
| Male                                   | 104 (52)|          |
| Female                                 | 96 (48) |          |
| Age (years)                            |         | 15.08 (1.83) |
| **Diagnostic group**                   |         |          |
| Acyanotic CHD                          | 100 (50)|          |
| Left to right shunt                    | 66 (33) |          |
| Obstruction                            | 34 (17) |          |
| Cyanotic CHD                           | 100 (50)|          |
| Decreased PBF                          | 68 (34) |          |
| Increased PBF                          | 32 (16) |          |
| **Number of heart surgeries**          |         | 1.38 (1.09) |
| None                                   | 35 (17.5)|         |
| One                                    | 94 (47) |          |
| More than one                          | 71 (35.5)|         |
| **Current treatment (within the last year)** |         |          |
| Medication                             | 113 (56.5)|        |
| Cardiac catheterization                | 39 (19.5)|        |
| Surgery                                | 24 (12) |          |
| No treatment                           | 82 (41) |          |

**Note(s):** PBF – pulmonary blood flow

Table 1. Characteristics of the study sample ($N = 200$)
Description of the study variables
In Table 2, descriptive statistics for the study variables are displayed. When considering the five domains of HRQOL (not shown in the table), the domain of outlook on life in general obtained the highest scores, while physical function got the lowest scores. The most received support came from parents, followed by relatives, peers, teachers and siblings, respectively. In total, 60% of the adolescents had low severity of the disease. Regarding the symptoms, fatigue was the most frequently reported symptom (38.5%) in the last seven days, followed by palpitations (34%), shortness of breath (20.5%), chest pain (19%) and depressed feeling (12.5%). The mean energy expenditure of total physical activity was 159.20 (SD = 60.95) MET-hr. Most of the adolescents (83%) rated their general health as good or very good.

Model testing
The estimated model revealed a good fit model ($\chi^2 = 6.11$, df = 5, $p$-value = 0.30, $\chi^2$/df = 1.22, GFI = 0.99, AGFI = 0.95, RMSEA = 0.034), which could explain 48% of the variance in HRQOL. In Figure 2 and Table 3, only direct effects of three factors on HRQOL were found; these factors included disease severity, symptoms and social support.

| Variables                        | Possible range | Actual range | M (SD)     | Skewness | Kurtosis |
|----------------------------------|----------------|--------------|------------|----------|----------|
| HRQOL                            | 0–100          | 56.52–100    | 85.70 (9.94) | −0.672   | −0.206   |
| Social support                   | 0–150          | 33–150       | 93.33 (7.00) | −0.128   | −0.770   |
| Disease severity                 | 1–3            | 1–3          | 1.35 (0.74)  | 0.954    | −0.517   |
| Symptoms                         | 0–90           | 0–29         | 4.95 (0.65)  | 1.354    | 1.342    |
| Physical activity (MET-hour/week)| 67.48–44.91    | 159.20 (60.95)| 0.854    | 0.307    |
| General health perception        | 1–5            | 2–5          | 4.12 (0.68)  | −0.243   | −0.482   |

Table 2. Descriptive statistics for the study variables ($N = 200$)

Figure 2. The final model of HRQOL among adolescents with CHD

Note(s): $\chi^2 = 6.11$, df = 5, $p$-value = 0.30, $\chi^2$/df = 1.22, GFI = 0.99, AGFI = 0.95, RMSEA = 0.034; * $p < 0.01$; ns not statistically significant
Discussion

Though there were no normative scores from healthy adolescents for comparison, the HRQOL scores of adolescents with CHD in this study appeared to be noteworthy (that is, 85.70 out of 100 points). First, the finding could be explained using an adaptation process or so-called “response shift”, which explains that patients with a chronic illness tend to adapt to their disease by changing internal standards, values or reconceptualization, resulting in changes in the meaning of their self-evaluation of quality of life. Consequently, they can maintain good HRQOL despite any physical or functional impairments [21]. The adolescents in this study had been growing up with the disease since the beginning of their lives; they had learned to develop coping strategies and practiced adaptation throughout their lives. Second, the adolescents did not have comorbidities which might lessen HRQOL. Lastly, they were patients undergoing regular follow-up visits at tertiary hospitals with pediatric cardiology clinics staffed by specialists providing modern medical care and holistic nursing care. However, in the meanwhile, the latter two reasons could be a source of potential selection bias for this study.

The causal model of HRQOL in adolescents with CHD, proposed in Figure 1, fitted with the empirical data, but only partially supported the model. In total, three out of six factors (disease severity, symptoms, and social support) could explain HRQOL in adolescents with CHD.

As expected, disease severity had a negatively direct effect on HRQOL in adolescents with CHD. The complexities of cardiac condition and the treatments received would limit the energy exertion of adolescents to engage in daily-life and social activities, particularly activities that required stamina like judo, karate and basketball due to the relative fragility caused by the severity of the disease. Moreover, patients with complex heart disease usually have frequent medical appointments that cause increased absences from school, resulting in low HRQOL in terms of academic achievement [3].

The symptoms experienced in the previous seven days showed the strongest direct and negative effects on HRQOL. Reported clinical symptoms such as fatigue, palpitation, shortness of breath, chest pain and depressed feeling had a noticeable impact on perceived HRQOL as the daily lives of these adolescents were affected by the impairment (leading to some restrictions on physical, social, and school performance) [2, 3, 10]. The study findings were consistent with previous studies that indicated both physical (such as chest pain, dyspnea and fatigue) and psychological symptoms (such as anxiety and depression) had a significantly negative and direct effect on HRQOL among adolescents with CHD [7, 10]. In addition, symptoms did not have an indirect effect on HRQOL through general health perception; we found only a direct effect from symptoms on general health perception. The

| Causal variables       | Physical activity | General health perception | HRQOL |
|------------------------|-------------------|----------------------------|-------|
|                        | DE    | IE    | TE    | DE    | IE    | TE    | DE    | IE    | TE    |
| Sex                    | 0.03  | 0     | 0.03  | 0.11* | 0     | 0.11* | 0.05  | 0.01  | 0.06  |
| Disease severity       | – – – | –     | –     | –     | –     | –     | –20*  | 0     | –20*  |
| Symptoms               | – – – | –     | –     | –28*  | 0     | –28*  | –55*  | 0.01  | –56*  |
| General health perception | – – – | –     | –     | –     | –     | –     | 0.06  | 0     | 0.06  |
| Physical activity      | – – – | –     | –     | –     | –     | –     | 0.02  | 0     | 0.02  |
| Social support         | 0.01  | 0.01  | 0     | 0.16* | 0     | 0.16* | –     | –     | –     |

\[ R^2 = 0.09 \]
\[ R^2 = 0.00 \]
\[ R^2 = 0.48 \]

**Note(s):** HRQOL = health-related quality of life; DE = direct effect; IE = indirect effect; TE = total effect; ns = not statistically significant and \( ^* p < 0.01 \)
result sounds logical because people who report fewer symptoms would likely view their overall health as good and vice versa. However, the perception of good health did not affect HRQOL in this study. The reason may be due to the measurement used. The SAH contains only one item, which is too broad to elicit the overall health perceived; the one-item scale could not provide comprehensive information for the various domains of health. Thus, it would be a limitation of this study. Further literature review and study are likely needed to explore a more appropriate measurement of general health perception or health status for use in Thai adolescents with CHD.

The direct effect of social support on HRQOL found in this study was consistent with a previous study reporting that adolescents and young adults with CHD with more support showed better quality of life in all dimensions compared to those with less support [9]. The perception of social support and trust in support availability helps adolescents to meet the human need for security, resulting in a reduction of exposure to stress. Social support also helps to mitigate the negative impacts of stressors. However, social support does not have an indirect effect on HRQOL through physical activity. It should be noted that more than half (60%) of adolescents had low severity of the disease. Thus, it is possible that adolescents with CHD might have less need for support from others in their daily physical activities. This is likely why social support revealed an insignificant effect on physical activity. The influence of physical activity on HRQOL did not exist either. In this regard, the limitation of the tool used for measuring physical activity should be of concern. The MTAPAQ requires the respondents to recall the physical activity they performed during the previous seven days, potentially yielding inaccuracy in the calculated values for MET-hr.

In this study, differences in sex did not show a direct effect on HRQOL. The unexpected finding found is difficult to explain as a previous study strongly supported a contradictory result by reporting that female adolescents with CHD had lower quality of life. It also reported more frequent physical and psychological symptoms of the diseases [8]. An additional analysis of our data (data not displayed) did not show any significant differences regarding disease severity and symptoms between male and female adolescents ($\chi^2 = 4.92, p = 0.085$ and $\chi^2 = 41.41, p = 0.324$). Thus, it is possible that the homogeneity of the study sample in terms of disease severity and symptoms was a reason why sex did not directly influence HRQOL.

Differences in sex did not have an indirect effect on HRQOL through general health perception and physical activity. However, a significant effect of gender difference on general health perception was found; the finding was consistent with a previous study. Though this study did not investigate whether women or men perceived better health status, a previous study revealed that women tended to report more symptoms and functional limitations due to a heart defect [8]. With regards to the finding that the physical capability to carry out daily-life activities and social activities was not affected by sex, the limitation of the MTAPAQ might have been a reason, as mentioned earlier.

**Conclusions**

This study is the first study in Thailand that examined the factors that influence HRQOL among adolescents with CHD using path analysis. The influencing factors found in the study include disease severity, symptoms and social support. Thus, an intervention program focusing on disease/symptom management should be implemented to reduce the severity and prevent complications. As smartphones are used nationwide, the use of m-health applications in such a program may be an appropriate and interesting channel to provide health information specifically to adolescents with CHD. In this study, adolescents received the most support from their parents. This indicates the importance of involving parents in the psycho-educational program. The parents of teen children with CHD should be educated, trained, coached and empowered to act as sources of support.
Using a questionnaire for the measurement of HRQOL may limit holistic understanding of HRQOL among adolescents with CHD. A qualitative study is suggested for further study to examine more comprehensive aspects of HRQOL. In addition, the adolescents in this study could be considered good patients as they visited the clinics regularly. As such, it could be assumed that their parents possessed positive attitudes and sufficient knowledge to provide for the benefit and well-being of their children. Such characteristics may be relevant to their socioeconomic conditions as well. However, our assumption is beyond the scope of this study. Thus, the inclusion of socioeconomic variables in the model of relationships is suggested for future studies.

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