The mental health and quality of life of adult patients with congenital heart disease

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ABSTRACT

Background: The quality of life (QoL) of adults with congenital heart disease (CHD) has gained significant interest. In addition to medical problems, many patients with CHD face psychosocial, educational, and behavioral challenges. However, few studies have examined the relationship between disease severity and QoL in adults with CHD.

Methods: Eighty-five patients (50 men, 35 women) aged 20–52 years (median, 26.5 years) were enrolled. Patients underwent a QoL, Beck Depression Inventory (BDI), and Beck Anxiety Inventory (BAI) survey. The scores were compared with those of age- and gender-matched population data according to the degree of underlying CHD. Disease severity was classified in relation to initial diagnosis, illness course, and current functional status (New York Heart Association [NYHA] class, ability index, CHD functional index, ventricular ejection fraction, and peak VO_2).

Results: There was no significant correlation between disease severity and current functional status assessed by BDI and BAI. Patients who stated that they were religious had better scores for resilience ($p = 0.031$), physical QoL ($p = 0.008$), and environmental QoL ($p = 0.025$). Environmental QoL scores were higher in patients who fully understood their disease ($p = 0.004$). Current NYHA functional class was associated with scores for psychological resilience.

Conclusions: CHD severity had a detrimental impact on resilience only when measured in terms of poor functional status. The initial diagnosis and course of the illness influence QoL and perceived health. Good psychosocial adaptation could be the result of close family relationships and involvement, making mental adjustment easier.

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1. Introduction

Advances in surgery and intensive care have increased the life expectancy of children with congenital heart disease (CHD). Over 90% of infants born with congenital heart defects now reach adulthood [1]. Today, there are more adults than children and adolescents living with CHD [2]. Therefore, it is important to assess the long-term results of treatment in these patients, not only in medical terms but also in terms of health-related quality of life (QoL) and subjective health status [3]. Potential challenges faced by patients with CHD include heart-focused anxiety, concerns about mortality, treatment decision-making, surgical preparation, adjustment to implanted cardiac devices, difficult child-to-adult transitions, and adherence concerns [4]. Therefore, satisfaction with medical consultations may increase if physicians assess general wellbeing as well as functional status [5].

Guidelines for the care of adult patients with CHD advocate for the treatment of psychosocial difficulties, including depression, anxiety, and social limitations [6]. Few studies have attempted to examine the relationship between disease severity and QoL in adults with CHD [3,7,8]. A potential relationship between disease severity and QoL may be inferred from a series of studies that have applied the same instrument in populations of patients with different heart defects [9–11]. In these studies, QoL was measured in terms of either subjective health status [7,9–11] or the emotional response to health problems [3], or in terms of external life conditions, interpersonal relationships, and internal psychological states [8]. However, there are few such data available for adult CHD patients from South Korea.

The objective of this study was to evaluate the psychosocial adjustment of adult CHD patients by examining the prevalence of mood and anxiety disorders among such patients recruited from inpatient and outpatient clinics. The study also aimed to analyze QoL and the specific psychosocial problems encountered in daily life by patients with various heart conditions.

2. Methods

2.1. Study population

Adult CHD patients who visited the outpatient clinic or had been admitted to the Seoul National University Children's Hospital for congenital heart disease were asked to

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participate in the study. A questionnaire package was provided to 127 patients. Each questionnaire package contained a QoL survey, a Beck Depression Inventory (BDI), a Beck Anxiety Inventory (BAI), and an additional questionnaire assessing more specific aspects of daily life. The inclusion criteria were as follows: (1) structural congenital heart disease, as confirmed by echocardiogram, cardiac catheterization, or surgery; (2) ability to read and complete the consent form and questionnaires; and (3) age ≥20 years. Patients were excluded if they were visiting the outpatient clinic for the first time or if they were judged to have learning disabilities during the clinical interview.

Informed consent was obtained from each patient. The study protocol conformed to the ethical guidelines of the 1975 Declaration of Helsinki and was approved by the institution's human research committee.

2.2. Variables and measurements

2.2.1. Disease severity

Various components of CHD severity were measured: initial diagnosis, illness course, and current functional status [12–15]. To determine the need for specialized care, Task Force 1 of the 32nd Bethesda Conference of the American College of Cardiology categorized CHD defects into 3 classes: mild, moderate, and severe [16], based on the initial diagnosis or specific types of operations. The disease severity index was developed to reflect the course of the illness [12]. Disease severity was classified as low (≤1 cardiovascular procedure), moderate (>1 cardiovascular procedure), or high (cyanosis or single ventricle physiology). To assess the current functional status, 3 classification methods were used: the New York Heart Association (NYHA) functional class [17], the ability index [13], and the CHD functional index [14]. Peak VO$_2$ was measured by cardiopulmonary exercise test as a fourth indicator of functional status. Peak VO$_2$ is well established as one of the best indicators of exercise capacity [18]. Left ventricular ejection fraction measured by transthoracic echocardiography, a well-established measure of cardiac function, was used as a fifth indicator.

2.2.2. QoL

Although the amount of QoL research has grown exponentially, major conceptual and methodological challenges have also emerged. There is still no consensus regarding the conceptualization, operational definition, and measurement of QoL [19]. The short version of the World Health Organization (WHO) QoL assessment (WHOQOL-BREF) was used to evaluate the pertinent aspects of QoL in our subjects [20]. The output of the WHOQOL-BREF is a QoL profile, and it is possible to derive 4 domain scores. Two additional items are examined separately: Question 1 asks about an individual's overall perception of their QoL, and Question 2 asks about an individual's overall perception of their health. The 4 domain scores indicate perceptions of QoL in the domains of physical health, psychological health, social relationships, and environmental health. Cronbach's alpha (an estimate of internal consistency) for the WHOQOL-BREF was 0.93 for the present study.

Table 1
Demographic and clinical characteristics of 85 adult CHD patients.

Sex	
Men	50 (58.8%)
Women	35 (41.2%)
Median age (±SD)	26.5 ± 5.9 years
Employment status	
Student	33 (38.8%)
Full-time worker	39 (45.9%)
Part-time worker	7 (8.2%)
Other	6 (7.1%)
No response	0
Marital status	
Married	9 (10.6%)
Unmarried	70 (82.4%)
No response	6 (7.1%)
Children	
None	74 (91.7%)
One	2 (2.4%)
Two	4 (4.7%)
Three or more	1 (1.2%)
No response	0
Final education level	
Postgraduate	5 (5.9%)
University	67 (78.8%)
High school	9 (10.6%)
Middle school	4 (4.7%)
No response	4 (4.7%)
Insight into illness	
Fully known	47 (55.3%)
Partially known	34 (40.0%)
Unknown	4 (4.7%)
No response	4 (4.7%)
Religion	
Yes	33 (38.8%)
No	47 (55.3%)
No response	5 (5.9%)
Domicile	
Living with family	73 (85.9%)
Living alone	7 (8.2%)
No response	5 (5.9%)

Table 2
Classification systems for adult CHD patients.

Classification system	Prevalence
Initial diagnosis (n = 85)	
Task Force 1 of the 32nd Bethesda Conference of the American College of cardiology [1]	
Mild (e.g. ASD, VSD, PDA, isolated valve disease)	17 (20.0%)
Moderate (e.g. TOF, CoA, AVSD, TGA)	31 (36.5%)
Severe (e.g. Functional single ventricle, DORV, Eisenmenger)	37 (43.5%)
Illness course (n = 85)	
Disease severity index [2]	
Low: maximum 1 cardiovascular operation or 1 catheterization procedure	16 (18.8%)
Moderate: more than 1 cardiovascular operation or 1 catheterization procedure	45 (52.9%)
High: persistent cyanosis, <92% oxygen saturation at rest, or single ventricle physiology	24 (28.2%)
NYHA functional class [3] (n = 85)	
Class I: No limitations of physical activities. Ordinary activity does not cause undue angina pain, dyspnea, fatigue, or palpitations.	39 (45.9%)
Class II: Slight limitations of physical activities. Comfortable at rest, but ordinary activity results in angina pain, dyspnea, fatigue, or palpitations	46 (54.1%)
Class III: Marked limitations of physical activities. Comfortable at rest, less than ordinary activity causes angina pain, dyspnea, fatigue, or palpitations	0
Class IV: Unable to carry on any physical activities without discomfort. Symptoms of cardiac insufficiency or angina syndrome may be present even at rest.	0
Ability index [4] (n = 85)	
Class 1: normal life (full time work or school, pregnancy poses no health risk)	48 (56.5%)
Class 2: able to work (intermittent symptoms, interference with life, pregnancy possible)	37 (43.5%)
Class 3: unable to work (limitation of all activities, pregnancy poses health risk)	0
Class 4: extreme limitation (dependent, almost housebound)	0
Congenital heart disease functional index [4] (n = 85)	
Class 1: no surgery, good clinical status, medical follow up not strictly necessary	4 (4.7%)
Class 2: with or without surgery, functionally perfect, postoperative normalization of clinical condition, medical checkup every 3 to 5 years, competitive sports permitted	10 (11.8%)
Class 3: with or without surgery, functionally good, medical restrictions, medical checkup every 1 to 2 years, recreational sports permitted	66 (77.6%)
Class 4: with or without surgery, moderate functional status, functioning at own pace, medical checkup every year	5 (5.9%)
Class 5: with or without palliative surgery, bad functional status, cyanosis, medical checkup every 6 to 12 months	0
Ventricular ejection fraction (n = 83)	
Decreased: <50%	15 (17.6%)
Normal: ≥50%	68 (80%)
Peak VO$_2$ [6] (n = 65)	
Mild to moderate aerobic impairment < 20 mL/kg/min	6 (9.3%)
Deconditioned 20–30 mL/kg/min	26 (40%)
Optimal: ≥30 mL/kg/min	33 (50.7%)