



Psychosocial adjustment and quality of life of adolescents and adults with congenital heart disease

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The incidence of people living with congenital heart disease (CHD) has been increasing every year owing to remarkable advances in surgical and catheter intervention techniques and devices, and improved knowledge of critical care for patients with CHD. However, these patients continue to face physical, psychosocial, and environmental challenges, and a number of studies have shown higher rates of depression and anxiety disorders than the general population. To improve psychosocial functioning and quality of life for adults with CHD, health care providers are recommended to inform CHD patients of an accurate diagnosis, and overall treatment process, beginning in adolescence to facilitate a smooth transition from adolescence to adulthood. Active cooperation with psychiatrists, psychologists, social workers, chaplains, and family members is highly recommended to help CHD patients feel normal and optimistic and to promote good social interactions, close family relationships, and a strong sense of coherence.

Key words: Heart disease, Depression, Anxiety, Quality of life

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Received: 5 April, 2014

Accepted: 16 May, 2014

Introduction

The incidence of adults living with congenital heart disease (CHD) has been increasing every year due to remarkable advances in surgical and catheter interventional techniques and devices, and knowledge of critical care for patients with CHD¹⁻³. However, the definition of a successful outcome of CHD treatment may vary. While clinicians traditionally considered a decrease in morbidity and mortality after treatment of CHD to be a successful outcome, patients may have a more stringent criterion for success.

Like other patients with chronic illness, adults with repaired or unrepaired CHD continue to face physical, psychosocial, and environmental challenges after successful treatment through surgical or catheter interventional treatment^{4,5}. Although the assessment and measures for the improvement of quality of life (QoL) in adults with CHD are still unclear, clinicians should be more attentive to the importance of improving QoL, including psychosocial adjustment, for adolescents and adults with repaired or unrepaired CHD.

Changing profile of adults with CHD

Since the first surgical patent ductus arteriosus ligation in 1938 performed by Dr. Gross and the first open heart repair for a child with Tetralogy of Fallot in 1954 performed by Dr. Lillehei, most varieties of CHDs have been treated successfully by surgery or a catheter

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intervention¹⁾. The noticeable improvement of treatment for CHD and survival of patients with CHD over the last half century has given rise to a continuously increasing number of adults with CHD. Since the development of successful neonatal repair of complex lesions in the 1970s, an estimated 85%–90% of patients survive into adulthood compared with the 20% survival rate 50 years ago^{4,6)}. Considering the overall 1% prevalence of CHD in the live birth neonates and recent surgical mortality rates of less than 5% in the most developed countries, about 1 in 150 young adults would be expected to have a form of repaired or unrepaired CHD in the next decade in the developed countries^{3,6)}.

Although there is a lack of reliable data on the number of adults with CHD in South Korea, the pattern of increasing numbers of adults with CHD is comparable to most developed countries, because of the increase in number of surgeries for CHD since the late 1970s and the establishment of the Korean Heart Foundation⁷⁾. Information from the database of the Korean Heart Foundation indicates that about 50,000 adults with CHD are estimated to currently live in South Korea, and more than 4,000 patients enter into adulthood annually (Fig. 1).

The need for attention to the psychosocial function of adolescents and adults with CHD

Like other patients with chronic medical conditions, most adolescents and adults with repaired or unrepaired CHD continue to face life-long QoL challenges after successful surgical or catheter interventional treatment. Thus far, a widely accepted definition of QoL has not been established, and current definitions continue to vary from country to country. However, physical, psychosocial,

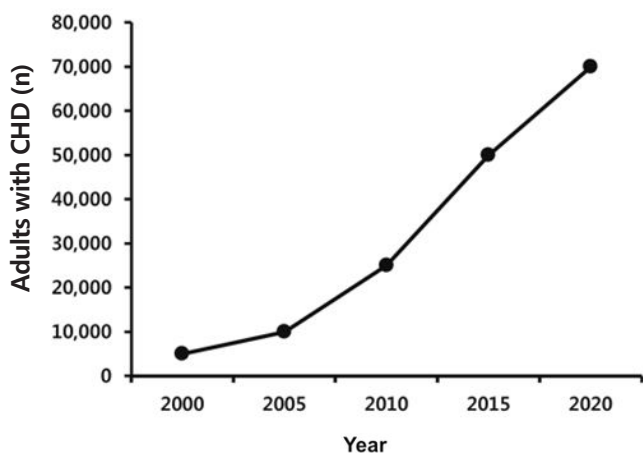


Fig. 1. Adult congenital heart disease population in South Korea. From the database of the Korean Heart Foundation, we estimated that about 50,000 adults with congenital heart disease (CHD) live in South Korea and more than 4,000 patients newly enter adulthood every year. At the current rate, we will have about 70,000 by the year 2020.

and environmental aspects of life are very important and reasonable domains to assess the QoL of adults patients with CHD⁴⁾.

In many studies, QoL was excellent and similar to an age- and gender-matched standard population in patients with simple CHDs such as atrial septal defect, ventricular septal defect, and coarctation of aorta^{4,8)}. However, many other patients with complex CHDs with or without arrhythmia, such as complete atrioventricular septal defect, Tetralogy of Fallot, and a single ventricle, showed a decrease in physical activities, which also affected physical functioning capacity, emotional well-being, and subsequently limited the patients' ability to conduct activities of daily living^{4,8-10)}.

Accumulation of medical costs due to repeated procedures and operations is a significant burden to adults with complex CHD and a life-long concern that contributes to psychosocial problems. When the cost of treatment for 55 years of Tetralogy of Fallot was measured in United Kingdom, the overall medical cost was estimated to be approximately 65,310 pounds (about 116,000,000 KRW; Korean Won, the currency of South Korea)¹¹⁾. Total medical costs may increase for adults with CHD as medical care improves in every developed country.

Adolescents and adults with CHD are prone to feel different from generally healthy people because of their various degrees of physical limitations and visible marks, such as surgical wounds. Although this feeling may be influenced by patients' environment, health care system, and personality, it is evident that patients struggle constantly to perceive themselves as normal compared to other healthy people¹²⁾.

These distinct findings demonstrate that various degrees of decreased physical activity, life-long medical cost burden, and the feeling of being different from healthy people inevitably affect the psychosocial aspects of QoL, possibly contributing to depression and anxiety in adults with CHD. These impairments of psychosocial functions could affect the QoL of adolescents and adults with CHD when they are under great stress, such as adolescent developmental crisis, job-hunting, pregnancy, etc.¹³⁾. With this in mind, the focus of this review is the means by which psychosocial adjustment can be used to improve the QoL of adolescents and adults with CHD.

Assessment of psychosocial function of adolescents and adults with CHD

Because knowledge about the psychosocial functioning of adolescents and adults with CHD is quite limited, there is no internationally standardized methodology to evaluate psychosocial adjustment in this group. Several measures that have been used for evaluation include TNO-AZL Questionnaire for Adult's Health-

Table 1. Beck depression inventory

	Score	Inventory
1	0	I do not feel sad
	1	I feel sad
	2	I am sad all the time and I can't snap out of it
2	3	I am so sad and unhappy that I can't stand it
	0	I am not particularly discouraged about the future
	1	I feel discouraged about the future
3	2	I feel I have nothing to look forward to
	3	I feel the future is hopeless and that things cannot improve
	0	I do not feel like a failure
4	1	I feel I have failed more than the average person
	2	As I look back on my life, all I can see is a lot of failures
	3	I feel I am a complete failure as a person
5	0	I get as much satisfaction out of things as I used to
	1	I don't enjoy things the way I used to
	2	I don't get real satisfaction out of anything anymore
6	3	I am dissatisfied or bored with everything
	0	I don't feel particularly guilty
	1	I feel guilty a good part of the time
7	2	I feel quite guilty most of the time
	3	I feel guilty all of the time
	0	I don't feel I am being punished
8	1	I feel I may be punished
	2	I expect to be punished
	3	I feel I am being punished
9	0	I don't feel disappointed in myself
	1	I am disappointed in myself
	2	I am disgusted with myself
10	3	I hate myself
	0	I don't feel I am any worse than anybody else
	1	I am critical of myself for my weaknesses or mistakes
11	2	I blame myself all the time for my faults
	3	I blame myself for everything bad that happens
	0	I don't have any thoughts of killing myself
12	1	I have thoughts of killing myself, but I would not carry them out
	2	I would like to kill myself
	3	I would kill myself if I had the chance
13	0	I don't cry any more than usual
	1	I cry more now than I used to
	2	I cry all the time now
14	3	I used to be able to cry, but now I can't cry even though I want to
	0	I am no more irritated by things than I ever was
	1	I am slightly more irritated now than usual
15	2	I am quite annoyed or irritated a good deal of the time
	3	I feel irritated all the time

Table 1. Beck depression inventory (Continue)

	Score	Inventory
12	0	I have not lost interest in other people
	1	I am less interested in other people than I used to be
	2	I have lost most of my interest in other people
13	3	I have lost all of my interest in other people
	0	I make decisions about as well as I ever could
	1	I put off making decisions more than I used to
14	2	I have greater difficulty in making decisions more than I used to
	3	I can't make decisions at all anymore
	0	I don't feel that I look any worse than I used to
15	1	I am worried that I am looking old or unattractive
	2	I feel there are permanent changes in my appearance that make me look unattractive
	3	I believe that I look ugly
16	0	I can work about as well as before
	1	It takes an extra effort to get started at doing something
	2	It takes an extra effort to get started at doing something
17	3	I can't do any work at all
	0	I can sleep as well as usual
	1	I don't sleep as well as I used to
18	2	I wake up 1-2 hours earlier than usual and find it hard to get back to sleep
	3	I wake up several hours earlier than I used to and cannot get back to sleep
	0	I don't get more tired than usual
19	1	I get tired more easily than I used to
	2	I get tired from doing almost anything
	3	I am too tired to do anything
20	0	My appetite is no worse than usual
	1	My appetite is not as good as it used to be
	2	My appetite is not as good as it used to be
21	3	I have no appetite at all anymore
	0	I haven't lost much weight, if any, lately
	1	I have lost more than five pounds
22	2	I have lost more than ten pounds
	3	I have lost more than fifteen pounds
	0	I have not noticed any recent change in my interest in sex
23	1	I am less interested in sex than I used to be
	2	I have almost no interest in sex
	3	I have lost interest in sex completely
24	0	I am no more worried about my health than usual
	1	I am worried about physical problems like aches, pains, upset stomach, or constipation
	2	I am very worried about physical problems and it's hard to think of much else
25	3	I am so worried about my physical problems that I cannot think of anything else

related Quality of Life¹⁴, Short Form-36⁹, World Health Organization Quality of Life^{15,16}, the Linear Analogue Scale¹⁷, and the Satisfaction With Life Scale¹⁷. However, these measures provide only a broad evaluation of overall QoL of the patient, and cannot be used for precise screening of mental health concerns, including depressive or anxiety disorders in adults with CHD.

In this context, the Beck Depression Inventory (BDI) and the Beck Anxiety Inventory (BAI) can be good tools to screen for depressive or anxiety disorders in adults with CHD. The BDI is a 21-item self-administered questionnaire used to assess the severity of subjective depressive symptoms (Table 1)^{16,18}. Each item is scored from 0 to 3 points (the total possible score ranges from 0 to 63; 0–9 indicates minimal depression with emotional changes that are considered normal; 10–18 indicates mild depression; 19–29 indicates moderate depression; and 30–63 indicates severe depression)¹⁸. The BAI is also a 21-item self-report questionnaire, and is used to assess the subjective feelings expressed as well-known symptoms of anxiety during the previous one week (Table 2)¹⁹. Each question has the same set of four possible answers and patients indicate how much they have been bothered by that symptom during the past week including the day of the survey (final scores are interpreted as 0–7, minimal level of anxiety; 8–15, mild anxiety; 16–25, moderate anxiety; and 26–63, severe anxiety)^{16,20}. Women with anxiety disorders tend to score four

points higher than men with anxiety disorders²⁰. In the clinical setting, patients with a higher than moderate degree of depression or anxiety on each inventory are recommended for referral to a psychologist for further evaluation and treatment.

Psychosocial adjustment of adolescents and adults with CHD

Although the exact prevalence of depression and anxiety in adolescents and adults with CHD is unknown, a number of studies have shown diverse ranges of depression and anxiety disorders. In assessing psychosocial adjustment, it is important to keep in mind that the prevalence of depression and anxiety varies significantly in adults with CHD, which may be influenced by international differences in economic, medical, and social environments.

The reported prevalence of depression in adolescents and adults with CHD ranges from 9% to 33%, according to every evaluating scale^{16,21-26}. A recent population study evaluating the prevalence of major psychological disorders from 6,022 healthy people (age range, 18–74 years) used the World Health Organization Composite International Diagnostic Interview in South Korea. Results indicated that the prevalence of depressive disorders identified by the criteria of the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV) were 7.5% throughout life and 3.5% in the past year²⁷. A recent survey to identify the frequency of depressive disorders in adults with CHD (age range, 20–52 years) using the BDI in the Seoul National University Children’s Hospital (SNUCH) found that 18% of patients showed mild depression, 8% showed moderate depression, and 1% showed severe depression. These data suggested that over 9% of adult patients with CHD should be referred to a psychologist¹⁶. In a German study of 1,274 adults with CHD by EuroQol-5D, the authors found that 30% of the patients showed problems in the anxiety/depression dimensions²⁴. Additional studies measuring the frequency of depressive disorders using different evaluation scales are presented in Table 3.

The reported prevalence of anxiety in adolescents and adults with CHD was generally higher than that of depression, and ranged from 6.4% to 27% according to each evaluation scale^{16,26}. From a Korean general population study, the life-time and 1-year prevalence of anxiety disorders as identified by the criteria in DSM-IV were 8.7% and 6.8%, respectively²⁷. Meanwhile, we found that 31% of CHD patients showed mild, 16% showed moderate, and 2% showed severe depression from SNUCH data by BAI, which suggests that more than 18% (more than moderate anxiety by BAI) of adult patients with CHD should be referred to a psychologist to be evaluated and properly treated¹⁶.

Table 2. Beck Anxiety Inventory

	Not at all	Mildly*	Moderately†	Severely‡
Numbness or tingling	0	1	2	3
Feeling hot	0	1	2	3
Wobbliness in legs	0	1	2	3
Unable to relax	0	1	2	3
Fear of worst happening	0	1	2	3
Dizzy or lightheaded	0	1	2	3
Heart pounding/racing	0	1	2	3
Unsteady	0	1	2	3
Terrified or afraid	0	1	2	3
Nervous	0	1	2	3
Feeling of choking	0	1	2	3
Hands trembling	0	1	2	3
Shaky/unsteady	0	1	2	3
Fear of losing control	0	1	2	3
Difficulty in breathing	0	1	2	3
Fear of dying	0	1	2	3
Scared	0	1	2	3
Indigestion	0	1	2	3
Faint/lightheaded	0	1	2	3
Face flushed	0	1	2	3
Hot/cold sweats	0	1	2	3

*But it didn’t bother me much. †It wasn’t pleasant at times. ‡It bothered me a lot.

Findings from various studies of anxiety disorder prevalence using different evaluating scales are also presented in Table 3.

Factors affecting psychosocial functioning of adolescents and adults with CHD

A number of studies have suggested major risk factors affecting psychosocial functioning in adolescents and adults with repaired or unrepaired CHD. A common assumption is that patients with severe CHD, such as functional single ventricle or Eisenmenger syndrome, would have greater psychosocial dysfunction. Freitas et al.²⁵⁾, reported from a cohort study that females, patients with severe CHD, patients with surgical repair, cyanotic patients, and the patients with severe-to-moderate form of residual lesions showed worse psychosocial adjustment. On the contrary, many other studies have shown that original CHD severity, present heart status, and present New York Heart Association functional class were not predictors of the impairment of psychosocial function of adults with CHD^{16,17,26,28-30)}. In one study, patients showed greater psychological resilience in response to the severity of their initial CHD, and each patient's disease severity had a harmful effect only when it was evaluated in view of poor functional status¹⁶⁾. Another study found that adults with CHD who developed heart failure were particularly vulnerable to disorders of psychosocial functioning³¹⁾.

A perceived financial burden was reported to be significantly related to anxiety, depression, and somatic symptoms, and lower perceived social support was significantly related to anxiety and depression in the CHD patients^{25,32)}. Kovacs et al.²⁸⁾ suggested that significant predictors of depressive mood were loneliness, perceived health status, and fear of negative evaluation, and predictors of patients' anxiety were loneliness and fear of negative evaluation. In this study, CHD severity and poor functional class did not predict patients' depressive mood or levels of anxiety²⁸⁾. Early exposure to stress from CHD and medical treatments from

infancy, separation from parents during hospitalizations, and brain damage during treatments have also been known to provoke abnormal emotional adjustment and depression²¹⁾.

Perception of self-image is also an important factor affecting psychosocial functioning of adults with CHD. An unfavorable self-image can lead patients to view themselves as defective, which subsequently can be associated with self-doubt and insecurity. As a result, this unfavorable perception of self-image strongly affects depressive moods and anxiety³⁰⁾. In addition to perception of self-image, cognitive perceptions are also believed to have a great influence on CHD patients' lives. The more negative perceptions patients had, the higher psychological distress was evident. Negative perception can be more strongly associated with higher distress and poorer psychosocial adjustment than the severity of CHD, which could develop from adolescence³³⁾.

Solutions to improve psychosocial function and QoL of adolescents and adults with CHD

A successful, smooth transition from adolescence to adulthood is very important for improving psychosocial functioning and QoL of CHD patients, whether they were repaired or not. To facilitate a successful transition, two important goals have been suggested: to prevent loss of follow-up care and to foster and encourage patients' self-care behaviors³⁴⁾. An accurate knowledge of CHD by patients has been associated with improved psychological functioning and the patients' QoL^{4,29,35)}. Although clear insight about their CHD is known to reduce patients' confusion and improve healthy behaviors for dealing with a chronic heart condition²⁹⁾, only 30% of child and adolescent patients indicated good insight into their CHD, and 77% of patients did not know the medical diagnosis of their own CHD, which meant that children and adolescents appeared to be less concerned about their CHD³⁶⁾. Therefore, it is necessary for health care providers to better inform CHD patients of the accurate diagnosis of their own disorder and overall treatment

Table 3. Depression or anxiety disorders in adolescents and adults with congenital heart disease

Study	No.	Age (yr)	Depression (%)	Scale	Anxiety (%)	Scale
Cho ²⁷⁾ (control)	6,022	18-74	3.5	CIDI	6.8	CIDI
Bang et al. ¹⁶⁾	85	20-52	9.0	BDI	18.0	BAI
Horner et al. ²²⁾	29	26-56	14.0	Interview	17.2	Interview
Bromberg et al. ²³⁾	22	19-60	27.3	Interview, BSI	9.1	Interview, BSI
Berghammer et al. ²⁴⁾	1,274	15-87	30.0*	EQ-5D	30.0*	EQ-5D
Freitas et al. ²⁵⁾	110	12-26	11.8	ASR/YSR	6.4	ASR/YSR
Wang et al. ²⁶⁾	119	12-20	9.0	HADS	27.0	HADS
Kovacs et al. ²⁸⁾	280	Mean, 32	33.0	BDI	26.0	STAI-T

CIDI, composite international diagnostic interview; BDI, Beck Depression Inventory; BAI, Beck Anxiety Inventory; EQ-5D, EuroQol-5D; ASR/YSR, Adult Self-Report/Youth Self-Report; HADS, Hospital Anxiety and Depression Scale; STAI-T, the State-Trait Anxiety Inventory-Trait Version.

*Patients showed 30% in the anxiety/depression dimensions in total.

process during adolescence. One recent multicenter study in the United States, conducted to confirm the validity and reliability of the Pediatric Cardiac Quality of Life Inventory, supported the above-mentioned concept of monitoring CHD patients from childhood³⁷.

Even patients with successfully repaired CHD had diverse psychosocial dysfunctions and significantly poorer QoL. However, little has been determined about effective psychological interventions for patients with CHD^{6,38}. Although use of tricyclic antidepressants and selective serotonin receptor inhibitors for the treatment of secondary depression with diverse causes has been widely accepted³⁹, specialized services devoted to individual patients' conditions may be preferable, because they could provide multidisciplinary and comprehensive patient care⁴⁰. It is important to recognize that treating psychosocial disorders, including depression and anxiety, in CHD patients may require specialized multidisciplinary management to alleviate symptoms from diverse psychosocial dysfunction and to improve QoL⁴⁰. Therefore, the primary health care provider for CHD patients is encouraged to cooperate actively with psychiatrists, psychologists, social workers, chaplains, and family members to improve psychosocial functioning.

Because feeling different from healthy people is a significant concern in the CHD patients' daily lives as mentioned above, helping CHD patients feel normal is another important intervention when managing patients' suffering¹². Wang et al.²⁶ suggested that a feeling of optimism was the most important factor in reducing CHD patients' depression and anxiety and that good social support and a strong sense of coherence were important for psychosocial stability. In our study, good psychosocial adaptation of CHD patients appeared to be the result of close family relationships and involvement making mental adjustment easier¹⁶.

Conclusions

The number of adolescents and adults living with CHD has been increasing every year and they continue to face physical, psychosocial, and environmental challenges. Although the exact prevalence of depression and anxiety in adolescents and adults with CHD is unknown, a number of studies have shown higher rates of depression and anxiety disorders than the general population. To improve psychosocial functioning and the QoL for adolescents and adults with CHD, health care providers should inform CHD patients of their accurate diagnosis and overall treatment process from adolescence. Active cooperation with psychiatrists, psychologists, social workers, chaplains, and family members is recommended to help CHD patients feel normal and optimistic, and to encourage good social relationships, close family relationships, and a strong sense of coherence.

Conflict of interest

No potential conflict of interest relevant to this article was reported.

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