

# The Relationship between Adult Congenital Heart Disease (ACHD) and Psychological Disorders

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## Abstract

One of the most common cardiovascular diseases is congenital heart disease (CHD) and adult congenital heart disease (ACHD) or CHD in adult patients. The chronic effects of illness, surgery, and hospitalization in certain stages of life can have significant impacts on a patient's psychology and quality of life. This study aims to discover the relationship between CHD and psychological disorders in ACHD patients at the Integrated Heart Service Center, Dr. Soetomo General Academic Hospital. This research is a cross-sectional observational analytic study. A consecutive sampling technique was used with the correlation coefficient formula to determine the number of the minimum sample, which resulted in the minimum of 36 patients. The data was then analyzed using the Chi-square test and Fisher's Exact. The demographic data of the study were obtained from the Congenital Polyclinic Medical Records of the Integrated Heart Service Center, Dr. Soetomo General Academic Hospital and patients who fulfilled the inclusion and exclusion criteria were interviewed using the Mini International Neuropsychiatric Interview (MINI ICD-10). This study included 38 patients in total. Based on the results of interviews, it was found that 32 patients (84.2%) did not experience any psychological disorders, and 6 patients (15.8%) experienced one or more types of psychological disorders, including generalized anxiety disorder, recurrent depressive disorder, agoraphobia, obsessive compulsive disorder (OCD), and panic disorder. The results of the statistical analysis of the CHD types and psychological disorders obtained a significance value (p) of 0,228 (>0,050). With the significance value (p), it can be concluded that ACHD patients with various types of CHD do not have a significant relationship with psychological disorders at the Integrated Heart Service Center, Dr. Soetomo General Academic Hospital.

Keywords: Congenital heart disease; adult congenital heart disease; adult patients; Integrated Heart Service Center; psychological disorders.

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## 1. Introduction

Cardiovascular disease is a disease that contributes to many deaths. One of the most common cardiovascular diseases is congenital heart disease (CHD), which is the most prevalent congenital disorder. Every year, 1.35 to 1.5 million babies are born with CHD in the world<sup>[1]</sup>. In most countries, the prevalence of CHD is 8-10 out of 1000 births, with Asia having the highest prevalence, namely 9.3 out of 1000 live births<sup>[2]</sup>. In Indonesia alone, the incidence of CHD is estimated to reach 32-40 thousand per year, with patent ductus arteriosus (PDA) as the most common CHD experienced by patients<sup>[3]</sup>. The difference in the prevalence of CHD can be caused by limited access and health facilities in several countries, especially in developing countries<sup>[2]</sup>. These limited access and health facilities will further impact CHD diagnosis and treatment.

CHD diagnosis and treatment have undergone tremendous advances in the last 60 years, particularly with regard to early diagnosis and advances in cardiac surgery and interventional cardiology. These advances have extended the survival of patients with CHD like never before, even in CHD patients with the most complex lesions. More than 90% of all children born with CHD reach adulthood<sup>[1]</sup>. Although there have been significant advancements in CHD diagnosis and treatment, the interventions performed are more palliative than curative, which causes patients to often experience late complications, especially in adulthood<sup>[4]</sup>.

Adult CHD (adult congenital heart disease, also known as ACHD or the diagnosis of CHD in patients 18 years and older) prevalence has increased dramatically to overtake the prevalence of CHD in pediatrics by a ratio of 2:1. Thus, CHD can no longer be considered as a disease specific to pediatrics because most cases of CHD are incurable and

require lifelong specialized care<sup>[5]</sup>.

Children with CHD face additional challenges in terms of behavioral, emotional, and neuropsychological characteristics compared to those of healthy children. Consequently, as adults, they are at increased risk of psychological disorders, emotional distress, neurocognitive deficits, and social challenges. This condition still gets little attention when compared to the physiological problems experienced by patients<sup>[6]</sup>. As explained by Kovacs<sup>[7]</sup>, the implications of chronic disease, surgery, and hospitalization in certain stages of life can have a significant psychological impact and impacts on the quality of life (QoL) of patients. Following the diagnosis of heart disease, psychological distress is common, with approximately 20% to 50% of patients expressing difficulty adjusting to this condition. This is also related to several factors, such as trauma from being hospitalized too often, decreased adherence to treatment (non-adherence), worsening heart function requiring emergency action, high health care costs, and increased mortality<sup>[1][8]</sup>.

Based on this background, research is needed to determine the relationship between ACHD and psychological disorders in ACHD patients so that interventions from health services can be carried out not only physically and pharmacologically, but also psychologically, to control the conditions and symptoms of ACHD patients so that the patient's quality of life improves even better.

## 2. Methods

### 2.1 Study Design

This research is an observational analytic research. The population in this study were all ACHD patients who are treated at the Integrated Heart Service Center, Dr. Soetomo General Academic Hospital that fulfill the inclusive and exclusive criteria using the non-probability sampling/consecutive sampling technique until the sample size was sufficient. We used data from the medical records of CHD patients at the Integrated Heart Service Center, Dr. Soetomo General Academic Hospital with the age of 18 years and above. All medical records containing patients' age, gender, type of CHD, and type of treatment were collected and recorded. The Mini International Neuropsychiatric Interview (MINI ICD-10) was then used to screen patients for psychological disorders. This research was carried out from September 2021 to September 2022.

### 2.2 Statistical Analysis

The data was analyzed using a data processing software, namely IBM SPSS version 25. Two types of analysis were carried out: univariate and bivariate analysis. The frequency of age, type of CHD, type of treatment, and psychological disorders of ACHD patients was determined using a univariate analysis, meanwhile a bivariate analysis was also carried out through the Chi-square test and Fisher's Exact to find out whether there is a relationship between ACHD and psychological disorders.

### 2.3 Ethical Acceptance

Dr. Soetomo Hospital's Health Research Ethics Committee approved this study on December 14<sup>th</sup>, 2021, with the certificate number 0334/KEPK/XII/2021.

## 3. Results and Discussion

We report a 1-year observational analytic study on the relationship between ACHD and psychological disorders at the Integrated Heart Service Center, Dr. Soetomo General Academic Hospital. This study provides an overview of the patient characteristics (age and gender), type of CHD diagnosis distribution, types of treatments performed on patients, as well as psychological disorders likely experienced by patients. The data in this study are taken from primary and secondary data. Primary data was in the form of interview results related to indications of psychological disorders in patients using the MINI ICD-10 questionnaire, while secondary data was in the form of medical records of ACHD patients at the Integrated Heart Service Center, Dr. Soetomo General Academic Hospital. The quantity of patients the researchers had attempted to contact were 202 patients (from 5 January to 9 March 2022) with 86 patients unresponsive, 68 patients not having WhatsApp, 6 patients not willing to be research subjects, 2 patients who died, 1 patient was mentally disabled, and 1 patient with an incorrect diagnosis (arrhythmia). Therefore, the size of the population used in the study was 38 medical records of the subjects who had been interviewed, from a minimum sample size of 36 subjects. This number is quite different from a study conducted at the Department of Cardiology and Angiology at Hannover Medical School, Germany

which used 150 subjects and research by Anggrahini & Sensussiana which only used and observed 1 subject<sup>[9]</sup> <sup>[10]</sup>. The number of subjects may vary based on the type of questionnaire/interview conducted, the type of research conducted, and the length of time the research was conducted.

**Table 1.** The Characteristic of Patients in ACHD patients at the Integrated Heart Service Center, Dr. Soetomo General Academic Hospital

	Category	Total, n (%)
<b>Age</b>	18—40 years	31 (81,6%)
	40—60 years	5 (13,2%)
	>60 years	2 (5,3%)
<b>Gender</b>	Female	29 (76,3%)
	Male	9 (23,7%)

Based on Table 1, most ACHD patients were aged 18-40 years (81.6%) with a total of 31 patients. Age 18-40 years is a productive age, where patients can experience more pressure which could possibly interfere with school/work activities. This is related to research conducted on residents of the Kebon Kalapa subdistrict, Bogor in 2011 which stated that the age group 35-44 years had the highest frequency of psychological disorders<sup>[11]</sup>. On the other hand, in this study, the least age of ACHD patients was found at >60 years (5.3%) in 2 patients. There were also patients aged 40-60 years (13.2%) with a total of 5 patients.

In addition, in this study it was found that there were more women who had ACHD (76.3%), namely 29 patients. This is probably caused by the nature of women who tend to be more emotional and more diligent (which could mean diligent health control so that a diagnosis can be made). Psychological disorders are also generally more common in women, at an older age, and at a lower economic level<sup>[11]</sup>. On the other hand, men who experienced ACHD in this study had a percentage of 23.7% with a total of 9 patients.

**Table 2.** Frequency Distribution of CHD Types in Adult Patients at the Integrated Heart Service Center, Dr. Soetomo General Academic Hospital

Type of CHD	Frequency	Percentage
Atrial Septal Defect (ASD)	26	68,4%
Coarctation of Aorta (CoA)	1	2,6%
Patent Ductus Arteriosus (PDA)	2	5,3%
Pulmonary Stenosis (PS)	1	2,6%
Tetralogy of Fallot (ToF)	2	5,3%
Ventricular Septal Defect (VSD)	6	15,8%
<b>Total</b>	<b>38</b>	<b>100%</b>

It is displayed in Table 2 that the type of CHD that was most often found in adult patients was Atrial Septal Defect (ASD) (68.4%) with a total of 26 patients. According to another study, the third most common type of CHD is ASD<sup>[12]</sup>. On the other hand, in this study, the types of CHD that are rarely found in adult patients are Coarctation of Aorta (CoA) (2.6%) and Pulmonary Stenosis (2.6%) with a total of 1 patient. Several other types of CHD can also be experienced by adult patients such as Ventricular Septal Defect (VSD) (15.8%) with a total of 6 patients, as well as Patent Ductus Arteriosus (PDA) (5.3%) and Tetralogy of Fallot (ToF) with a total of 2 patients.

Based on another study, the prevalence of mild lesions such as ASD, VSD, and PDA increased during the study period<sup>[12]</sup>. This reflects an increase in detection of CHD cases, especially those with CHD types of mild lesions. This could be caused by advances in technology so that many pregnant women are more careful to avoid risk factors for CHD such as alcohol consumption and smoking. The study also stated that ASD has the most striking increase in prevalence estimates among other mild lesions, but the type of CHD with the highest prevalence is VSD.

**Table 3.** Frequency distribution of treatment in ACHD patients at the Integrated Heart Service Center, Dr. Soetomo General Academic Hospital

Treatment	Frequency	Percentage
None	2	5,3%
Medical therapy	16	42,1%
Non-surgical intervention with medication	8	21,1%
Non-surgical intervention without medication	1	2,6%
Medical surgical intervention	11	28,9%
Surgical intervention without medication	0	0%
<b>Total</b>	<b>38</b>	<b>100%</b>

Adult and pediatric cardiologists must receive formal training in ACHD cases in order to acquire the knowledge and experience required to provide patients with the best possible care<sup>[13]</sup>. Based on Table 3, the action that was mostly performed in this study was medical therapy (42.1%) with a total of 16 patients. This can be caused by the greater prevalence of mild lesions, resulting in a simple therapy only in the form of drugs instead of operation. Meanwhile, the lowest action performed was surgical intervention (including surgery) without medical treatment (0%). This is related to research conducted at the Hasan Sadikin Hospital Inpatient Installation in 2018, which implies that oral drug therapy and surgery are the most frequently given therapies<sup>[14]</sup>. There were also medical surgical interventions (28.9%) performed by 11 patients, non-surgical medical interventions (21.1%) in 8 patients, no action was performed (5.3%) in 2 patients, and non-surgical interventions without medication (2.6%) with a total of 1 patient.

**Table 4.** Frequency Distribution of Psychological Disorders in ACHD Patients at Integrated Heart Service Center, Dr. Soetomo General Academic Hospital

Psychological disorder	Frequency	Percentage
None	32	84,2%
Generalized Anxiety Disorder	2	5,3%
Recurrent Depressive Disorder, Agoraphobia, Obsessive Compulsive Disorder, and Generalized Anxiety Disorder	1	2,6%
Panic Disorder	2	5,3%
Agoraphobia with Panic Disorder	1	2,6%
<b>Total</b>	<b>38</b>	<b>100%</b>

Due to the diversity of this disease burden, some ACHD patients may be more vulnerable to emotional distress, including symptoms of depression, anxiety and other psychological disorders<sup>[15]</sup>. As shown in Table 4, 32 patients did not experience psychological disorders (84.2%). There were also patients who had generalized anxiety disorder (7.9%) with a total of 3 patients and panic disorder (5.3%) with a total of 2 patients. These results are related to research conducted at Hannover Medical School, Germany which stated that major depression and generalized anxiety disorder were more common in ACHD than the control group<sup>[9]</sup>. In this study, there were more patients who had no indication of experiencing psychological disorders because the patients were adults and had understood and adapted to their condition. These patients have accepted this congenital disease and they only wish to be able to undergo surgery when necessary. Only 1 patient (2.6%) had recurrent depressive disorder, agoraphobia, obsessive compulsive disorder, and agoraphobia with panic disorder.

**Table 5.** Relationship Analysis of Psychological Disorders in Various Clinical Diagnoses of CHD

	Psychological Disorder(s)				Total	P Value
	Yes		No			
	Frequency	Percentage	Frequency	Percentage	Frequency	Percentage
<b>Atrial Septal Defect (ASD)</b>	3	7,9%	23	60,5%	26	68,4%
<b>Coarctation of Aorta (CoA)</b>	0	0%	1	2,6%	1	2,6%
<b>Patent Ductus Arteriosus (PDA)</b>	1	2,6%	1	2,6%	2	5,3%
<b>Pulmonary Stenosis (PS)</b>	1	2,6%	0	0	1	2,6%
<b>Tetralogy of Fallot (ToF)</b>	0	0%	2	5,3%	2	5,3%
<b>Ventricular Septal Defect (VSD)</b>	1	2,6%	5	13,2%	6	15,8%
<b>Total</b>	6	15,8%	32	84,2%	38	100%

The findings of this study revealed that there was no significant relationship between the type of CHD and general psychological disorders ( $p$  value = 0.228 ( $> 0.050$ )). Overall, it is reasonable to state that no significant relationship exists between the type of CHD and psychological disorders at the Integrated Heart Service Center, Dr. Soetomo General Academic Hospital. The findings of this study are consistent with another research at Dr. Soetomo General Academic Hospital which showed that there was no statistically significant link between chronic disease and psychological disorders in adult patients<sup>[16]</sup>. The CHD population is predisposed to developing a variety of comorbidities as they age, including psychological issues<sup>[17]</sup>.

There are several other factors that were not examined in this study, including family support. The majority of parents reported that their child's CHD brought their family closer despite facing significant financial obligations. This is evidenced by situations when parents are busy and emotionally stressed by treatment procedures and hospitalization of children with CHD, extended family members try to fill the role of parents for other siblings at home. Parents also report receiving a lot of family support when caring for their child with CHD<sup>[18]</sup>.

Despite their own challenges, parents try to overcome their fears and provide a safe environment for their children diagnosed with CHD<sup>[18]</sup>. Because of their child's perceived vulnerability, parents may be overprotective of them and more permissive in their parenting style. It was found that there was no discernible difference in anxiety levels between parents of children with diagnosed CHD and healthy children<sup>[19]</sup>.

Another factor that can affect the patient's mental health is religion. Patients who stated their religious beliefs had higher levels of resilience, physical QoL, and environmental QoL. Patients who fully comprehend their illness have higher environmental QoL scores. As psychosocial health: family, religion, understanding of one's illness, as well as social

adjustment and self-perceived health status, are far more important than medical variables<sup>[20]</sup>.

The limitation of this study is that there are a lot of patient telephone number data in the medical record that is no longer active/has changed numbers, making it difficult to contact patients for the interview. Consequently, the number of subjects in this study was small and each psychological disorder cannot be linked to ACHD, but rather as a unit. Another factor that might have influenced the results of this study was that there were data errors in writing in the medical record.

The limitations of this study are also the variables of family support, chronic illness, and religion which can affect the patient's psychological condition. As mentioned in another research, when comparing those with a psychological disorder to those without, demographic differences were discovered<sup>[21]</sup>. In addition, a comprehensive approach to patient history that includes factors other than cardiac clinical history, such as socioeconomic status and socio-cultural factors, will undoubtedly improve the model's predictive outcomes<sup>[17]</sup>. All of this information was not written in the patient's medical record so it was not examined in this study so that it could be a suggestion for improvement in further research.

#### 4. Conclusion

In this study, most ACHD patients at the Integrated Heart Service Center, Dr. Soetomo General Academic Hospital were found in the age range of 18-40 years (81.6%) and the least in the age range > 60 years (5.3%), most of them are female (76.3%) and less in males (23.7%). The type of CHD diagnosis that most patients experience at the Integrated Heart Service Center, Dr. Soetomo General Academic Hospital has an Atrial Septal Defect (ASD) (68.4%) and the least type of Coarctation of Aorta (CoA) (2.6%) and Pulmonary Stenosis (PS) (2.6%). The most common therapy for ACHD patients at the Integrated Heart Service Center, Dr. Soetomo General Academic Hospital is medical (medicine) only (42.1%) and the least is surgical intervention without medication (0%). Many patients do not experience psychological disorders (84.2%). The most common psychological disorders: generalized anxiety disorder (5.3%) and panic disorder (5.3%), and the least: recurrent depressive disorder, agoraphobia, and obsessive-compulsive disorder (2.6%). It is concluded that ACHD patients with various types of CHD do not have a significant relationship with psychological disorders at the Integrated Heart Service Center, Dr. Soetomo General Academic Hospital.

For the Integrated Heart Service Center, Dr. Soetomo General Academic Hospital, it is suggested to improve the existing collaboration with the Department of Psychiatry to monitor and maintain the mental health of patients. During the interview in this research, many patients also complained that they received uncertainty regarding the surgery schedule. Therefore, the researchers suggest that the Integrated Heart Service Center, Dr. Soetomo General Academic Hospital should increase the number of medical personnel or open a new Integrated Heart Service Center branch.

For future researchers who conduct similar research, it is advisable to conduct research with a longer period of time, a larger number of subjects, and more variables so that more valid or accurate results can be obtained.

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