UNIVERSITY OF GÄVLE

FACULTY OF HEALTH AND OCCUPATIONAL STUDIES
Department of Caring Sciences

NURSING DEPARTMENT,
MEDICINE AND HEALTH COLLEGE
Lishui University, China

Life Experience of Adults with Congenital Heart Disease: A Descriptive Review

Wang Yani (Nicole)
Xu Qiyao (Sophia)

2023

Student thesis, Bachelor degree, 15 credits
Nursing
Degree Thesis in Nursing
Supervisor: Wang Yu (Beth)
Examiner: Mikaela. Willmer

Abstract

Background: The life expectancy of adults with congenital heart disease has significantly increased due to the enormous progress of medical technology. Consequently, adults with congenital heart disease constitute a relatively new and growing patient population. However, as they age, the development of their illness to varying degrees has brought about various impacts on their lives.

Aim: The aim of the study was to describe the life experience of adults with congenital heart disease.

Methods: It was a descriptive literature review and was undertaken in May 2022 using PubMed and Cinahl databases with the search terms of " adults " " congenital heart disease or congenital heart defect " " life experiences or feelings or coping " to retrieved English articles from 2012 to 2022. Through multiple screening procedures, 12 articles were finally included and analyzed the data using the thematic synthesis method developed by Thomas and Harden.

Results: Three themes relating to life experience of adults with CHD were identified : (1) Personal perceptions of physical and mental activity; (2) Support from family; and, (3) Experience of social life.

Conclusions: The uncertainty in illness permeated all aspect of their experiences, affecting their emotions and psychological well-being, daily activities, and future outlook. To progressively attain cohabitation with disorders, they attempted to create constructive coping mechanisms. In order to improve the quality of life and even survival rate of adults with CHD, ACHD professional teams, multidisciplinary teams, governments, and social institutions must pay close attention to the problems and needs that adults with CHD faced in their lives.

Keywords: Adults, Congenital heart disease, Life experience, Literature review

摘要

背景：由于医疗技术的巨大进步，先天性心脏病患者的预期寿命得到显著提高。因此，成人先天性心脏病患者构成了一个相对较新且不断增长的患者群体。然而，随着年龄的增长，疾病不同程度发展对他们的生活造成了多方面的影响。

目的：本研究的目的是探讨成人先天性心脏病患者的生活经历。

方法：本研究属于描述性文献综述。于 2022 年 5 月使用 PubMed 和 Cinahl 数据库以“成人”“先天性心脏病或先天性心脏缺陷”“生活经历或感受或应对”为检索词，检索了 2012 年至 2022 年的英文文章。通过多次筛选，纳入 12 篇文章。并使用 Thomas 和 Harden 开发的主题综合法对数据进行分析。

结果：本研究提取了与成人先天性心脏病患者生活经历相关的三个主题：(1) 个人对身心活动的感知；(2) 来自家庭的支持；和，(3) 社会生活的体验。

结论：疾病带来的不确定性是贯穿 ACHD 生活经历的主题，这影响着他们的情绪和心理状态，约束着他们的日常活动并影响着他们对未来的构想，他们尝试制定积极的应对策略，以慢慢达到与疾病共存的状态。ACHD 患者这些生活经历中的问题和需求需要 ACHD 专业团队、多学科团队、政府以及社会机构引起高度重视，并能够提出有针对性的有效解决举措，从而提高 ACHD 患者的生活质量，甚至提高生存率。

关键词：成人，先天性心脏病，生活经历，文献综述

Table of Contents

1 Introduction

1. 1 Background

Congenital heart disease (CHD) is the most common cause of major congenital anomalies, with 13. 3 million patients worldwide in 2019, representing a major global health problem (Roth et al., 2019). In the past decades, the mortality of the whole spectrum of CHD has been considerably reduced due to the enormous progress of medical technology (such as imaging techniques, biomarkers and refinement of percutaneous and surgical interventions), improved nursing organization and clinical research, and continuous innovation in diagnosis and monitoring (Bouma and Mulder, 2017). The figures indicate that the global crude mortality rate of CHD decreased from 7. 1 per 100000 in 1990 to 2. 8 per 100000 in 2019 (Roth et al., 2019), and the total number of global CHD deaths decreased by 43% (Su et al., 2022). It shows that the life expectancy of patients with CHD has significantly increased during the past decades and most children born with CHD can survive to adulthood. Nowadays, globally, the number of adults with CHD exceeds that of children (Bouma and Mulder, 2017) and their number continues to grow by 5% every year (Bhatt et al., 2015). Consequently, patients with adult congenital heart disease (ACHD) constitute a relatively new and growing patient population.

However, the severity of residual problems and sequelae after after surgical intervention of CHD may progress with age and induce late complications, such as arrhythmia, heart failure, thromboembolism and sudden cardiac death (Cuypers et al, 2016), which will lead to a significant increase in the risk of premature death of adults with CHD (van der Bom et al., 2015). Europe and North America have recognized the need for professional care for adults with CHD (Warnes et al., 2008) ; guidelines for the treatment of adults with CHD have also been published internationally to improve the prognosis (Baumgartner et al., 2010), which means that it is necessary to fully implement the guidelines in clinical practice and train a sufficient number of medical staff to serve in this field (Lenfant, 2003), and also represents the rapid increase of the burden on the health care system. In addition to these medical problems, adults with CHD are also confronted with psychosocial, employability, educational and behavioral challenges (Moons et al., 2002).

As a result, it is critical for nurses to learn more about the experiences of adults with CHD in order to adequately consult with and counsel patients and their families, to

provide more thorough and professional nursing care, and to assist adults with CHD in viewing CHD more objectively and striking a better balance between the disease and life in order to improve life quality.

1. 2 Definition

1. 2. 1 Life experience

There are always some subtle differences in people's understanding and perception of the word “experience”. In German, the word “Erlebnis” refers to “life experience”. The root of this word is leben, which means "life" and "live". With the prefix Er, it represents the sum of life activities and expresses the meaning of life experience. Dilthey (1921) believed that life experience refers to people's special experience form, which determines people's understanding ability, and is mastered by individuals by their unique personal feelings and experiences, and has profound significance or value to individuals. Thus, in his view, life experience appears as an individual's feelings about life (Dilthey, 1921). Heidegger (2018) emphasized another aspect of life experience, that is, life experience is not only a process, but also an life event, which needs to be reflected and observed. Zhou and Chen (2017) also pointed out that as a social and environmental circumstance, individuals' psychological and physiological adaptation to life events is carried out over time. In short, the authors thought that life experience is a complex cognitive and life event involving experience, feeling, emotion, reflection and understanding that requires physical and mental participation and it is closely related to life and live. The subject of life experience is human. Therefore, the life experience referred in this review put special emphasis on the life experience of adults with CHD, which is a personalized life activity based on this patient population, including the physiological and psychological life events they have encountered, the subjective cognition, feeling, emotion and reflective practical activities, etc.

1. 2. 2 Adult

Adult refers to a person who has attained full growth or maturity (Merriam-Webster, n. d.), but there is no unified and precise standard for the age range of adult. The research population of this review was adults aged 16-56 years old.

1. 2. 3 Congenital heart disease (CHD)

Congenital heart disease (CHD) refers to the abnormal anatomical structure caused by the formation disorder or abnormal development of the heart and great vessels during embryonic development, or the channel that should be automatically closed after birth fails to close (Mitchell et al., 1971). CHD is the most common type of major congenital anomalies, accounting for about 28% of all kinds of congenital malformations (van der Bom, et al., 2011). According to the presence or absence of shunt, CHD can be divided into three categories: no shunt (such as aortic valve stenosis), left to right shunt (such as atrial septal defect, ventricular septal defect and patent ductus arteriosus) and right to left shunt (such as Tetralogy of Fallot). The course of CHD is associated with many late sequelae, including pulmonary hypertension, arrhythmias, heart failure, etc (van der Bom, et al., 2011).

1. 2. 4 Adult congenital heart disease (ACHD)

With the rapid development of pediatric cardiac surgical diagnosis technology and surgical treatment, more and more children with congenital heart disease have improved their living conditions and grown up. Patients with adult congenital heart disease (ACHD) refers to the population who survive to adulthood and even old age with repaired or unrepaired congenital cardiovascular developmental abnormalities in the fetal period (Baumgartner et al., 2021). The new guidelines of the European Society of Cardiology (ESC) replaces the term "grown-up congenital heart disease (GUCH) " in the 2010 guideline with "adult congenital heart disease (ACHD) ", emphasizes that the growth and development of children with CHD needs lifelong monitoring, and puts forward that it is very important to pay attention to various conditions, mental and social problems in the survival of corrected or uncorrected CHD from childhood to adulthood (Baumgartner et al., 2021). 2020 ESC Guidelines stresses that managing these adults with CHD is a vital medical work and classifies mild, moderate and severe ACHD for the first time, so as to have a clear understanding of the degree of ACHD in clinic.

There is no clear age division for adults with CHD in the ESC Guidelines. Mutluer and Çeliker (2018) thought that patients with CHD older than 16 years old can be regarded as ACHD population. This review explored the life experience of adults with CHD aged 16-56 years old.

1. 3 The nurse's role

Adults with CHD is a relatively new and growing patient population and it is quite significant to provide safe and effective nursing care for these patients. However, there are challenges in providing services to these patients for nurses, including patient's emerging unique needs that have not been recognized before; and further complicated nursing care caused by the increased risk of heart disease complications and comorbidities (Anton, 2016), which calls for nurses to have appropriate training and education on how to handle such a population (Child et al., 2001), in order to advance and expand the duties of nurses now in place (Daly and Carnwell, 2003). The International Council of Nurses (ICN) (2021) emphasizes that as nursing and medicine have advanced, the role of nurses has expanded. One of the many roles that nurses can play is educator, and they are responsible for educating patients about a variety of health topics, assisting patients in understanding the factors that affect their health, and encouraging patients to actively maintain healthy behavior. The need for counseling services will increase as the average age of individuals with CHD continues to rise and as their medical problems become more complicated (Kogon et al., 2009). Self-management abilities, heart disease awareness, and self-advocacy skills can all be improved by nurse-led education (Anton, 2016). Due to the intricacy of the condition, adults with CHD typically require lifetime follow-up, and it may be necessary to offer psychosocial or behavioral support in addition to medical care (Moons et al., 2009). In conclusion, nurses are essential in the treatment of adults with CHD because they help patients transition from pediatric to adult cardiology, identify their needs, inform and consult patients and their families, screen for psychosocial issues, and appropriately refer patients to psychologists or other professionals (Canobbio and Day, 1994).

1. 4 The Uncertainty in Illness Theory

The Mishel (1990) focuses on the concept of uncertainty in the Uncertainty in Illness Theory, where one is unable to determine the meaning of a disease-related occurrence. When one is unable to identify and classify stimuli, uncertainty occurs. According to the theory of disease uncertainty (Mishel, 1990), patient sense of disease uncertainty mainly comes from the following 4 aspects: unclear symptoms of disease; ambiguous complex treatment and care; lack of information related to diagnosis and severity of disease; and the unpredictability of disease processes and prognosis (Mishel, 1988). The sense of

disease uncertainty in ACHD comes mainly from the inability to identify symptoms (such as dizziness, headache, and fatigue) with the congenital heart; A lack of knowledge about their CHD and its treatment, potential comorbidity, and preventing comorbidities; the complicacy of the health care system and the unpredictability of their disease trajectory and whether they will eventually die from CHD (Mishel, 1981). Nurses can identify feelings of illness uncertainty from patients' experience and provide nursing care for them under the guidance of Uncertainty in Illness Theory and promote care participation and intervention (Hansen, 2012).

1. 5 Previous studies

In recent decades, there are more and more studies on adults with CHD. The review written by Ntiloudi et al., (2016) analyzed the prevalence, gender, age and regional distribution of CHD. Matsuda et al., (2017) investigated the current status and future prospects of heart transplantation as a treatment for ACHD. Chubb and Motonaga (2020) studied the effect of device therapy on ACHD and the results showed that cardiac resynchronization therapy (CRT) and implantable cardioverter defibrillators (ICDs) could improve morbidity and mortality of heart failure in adults with CHD. In addition to treatment measures, the complications of ACHD are also a research hotspot in recent years. Cohen et al., (2013) 's review summarized the potential complications in five noncardiac organ systems (lung, kidney, liver, neurologic/psychiatric development, and peripheral vasculature) that effect the ACHD population. Brida et al., (2022) described the relationship between the nature of underlying CHD and the impacts on short and long-term outcomes. Additionally, some researchers had looked at how parents dealt with caring for kids who had CHD (Delaney et al., 2021; Demianczyk et al., 2022).

1. 6 Problem statement

In the past few decades, the life expectancy of patients with CHD has increased significantly (Roth et al., 2019), which makes more and more literature reviews on ACHD, mainly focusing on the investigation of epidemiological changes, the study of complications, the effect of treatment interventions and the experiences of parents taking care of children with CHD, while describing how adults experience living with CHD is very limited. It is quite beneficial for nurses to comprehend how adults with CHD live their lives. It gives nurses a foundation to offer adults with CHD more expert

advice and support, which not only helps patients better manage their condition and improve quality of life, but also gives nurses more opportunities to engage in medical practice, fully realize their comprehensive role, and advance their comprehensive ability.

1. 7 Aim and research questions

Aim: The aim of the study was to describe the life experience of adults with congenital heart disease.

Research question: How adults experience living with congenital heart disease?

2 Methods

2. 1 Design

It was a descriptive literature review (Polit and Beck, 2017).

2. 2 Search strategy

This review of the literature was undertaken in May 2022 using PubMed and Cinahl databases (Polit and Beck, 2017). English articles were retrieved from 2012 to 2022 with the search terms of " adults ", " congenital heart disease or congenital heart defect ", " life experiences or feelings or coping " and used free text to broaden various viewpoints of articles' themes, while utilized MeSH to combine articles that contained synonyms under one keyword to increase the efficiency and precision of retrieval (Polit and Beck, 2017).Boolean operator " AND " and " OR " were used in addition to search terms to identify relevant research (Polit and Beck, 2017). The initial search resulted in 287 articles and of which 49 were left for consideration. A more detailed search process was shown in Table 1.

Table 1. Results of preliminary database searches.

Database and search date	Limits	Search terms	Number of hits	Possible articles (excluding doubles)
Medline via	2012-2022,	"adults"[Mesh]	2653761	

PubMed 2022-05-06	English			
Medline via PubMed 2022-05-06	2012-2022, English	"congenital heart disease" [Mesh] OR "congenital heart defect"[Mesh]	48030	
Medline via PubMed 2022-05-06	2012-2022, English	"life experiences"[Mesh]OR "feelings" (free text) OR "coping" (free text)	276338	
Medline via PubMed 2022-05-06	2012-2022, English	"adults"[Mesh] AND ("congenital heart disease" [Mesh] OR "congenital heart defect"[Mesh]) AND ("life experiences"[Mesh] OR "feelings" (free text) OR "coping" (free text))	251	35
Cinahl Search 2022-05-06	2012-2022, English	"adults"[AB abstract]	237837	
Cinahl Search 2022-05-06	2012-2022, English	"congenital heart disease" [AB abstract] OR "congenital heart defect"[AB abstract]	5120	
Cinahl Search 2022-05-06	2012-2022, English	"life experiences"[AB abstract] OR "feelings"[AB abstract] OR "coping"[AB abstract]	74951	
Cinahl Search 2022-05-06	2012-2022, English	"adults"[AB abstract] AND ("congenital heart disease" [AB abstract] OR "congenital heart defect"[AB abstract]) AND ("life experiences"[AB abstract] OR "feelings"[AB abstract] OR "coping"[AB abstract])	34	12
Manual search	2012-2022, English	Relevance for inclusion criteria, aim and specific questions		2
				Total: 49

2. 3 Selection criteria

(1) Inclusion criteria：

~~①articles that published in English~~

①study population involved adults with CHD between 16-56years

②qualitative and mixed methods articles, which were available online

③the findings were related to the life experience of adults with CHD

④the severity, type, and whether there were complications of ACHD were unlimited

(2) Exclusion criteria：

①quantitative articles and reviews

②the findings were related to the life experience of family members or medical staff caring for adults with CHD

2. 4 Selection process

~~and outcome regarding possible articles~~

As shown in Figure 1, the databases search identified 285 articles and of which 238 were removed after screening the title and abstract. After removing the duplicate 5 articles, 42 articles remained, which were further screened. After layers of screening, 32 articles did not meet the inclusion criteria, of which 14 were quantitative articles, 4 were literature reviews, 3 participants were under the age of 16 or over 56, 5 were not about the life experiences of adults with CHD, and 6 were unable to get full text. 2 articles that met the inclusion criteria were found by manual retrieval. Finally, 12 articles were included in this review.

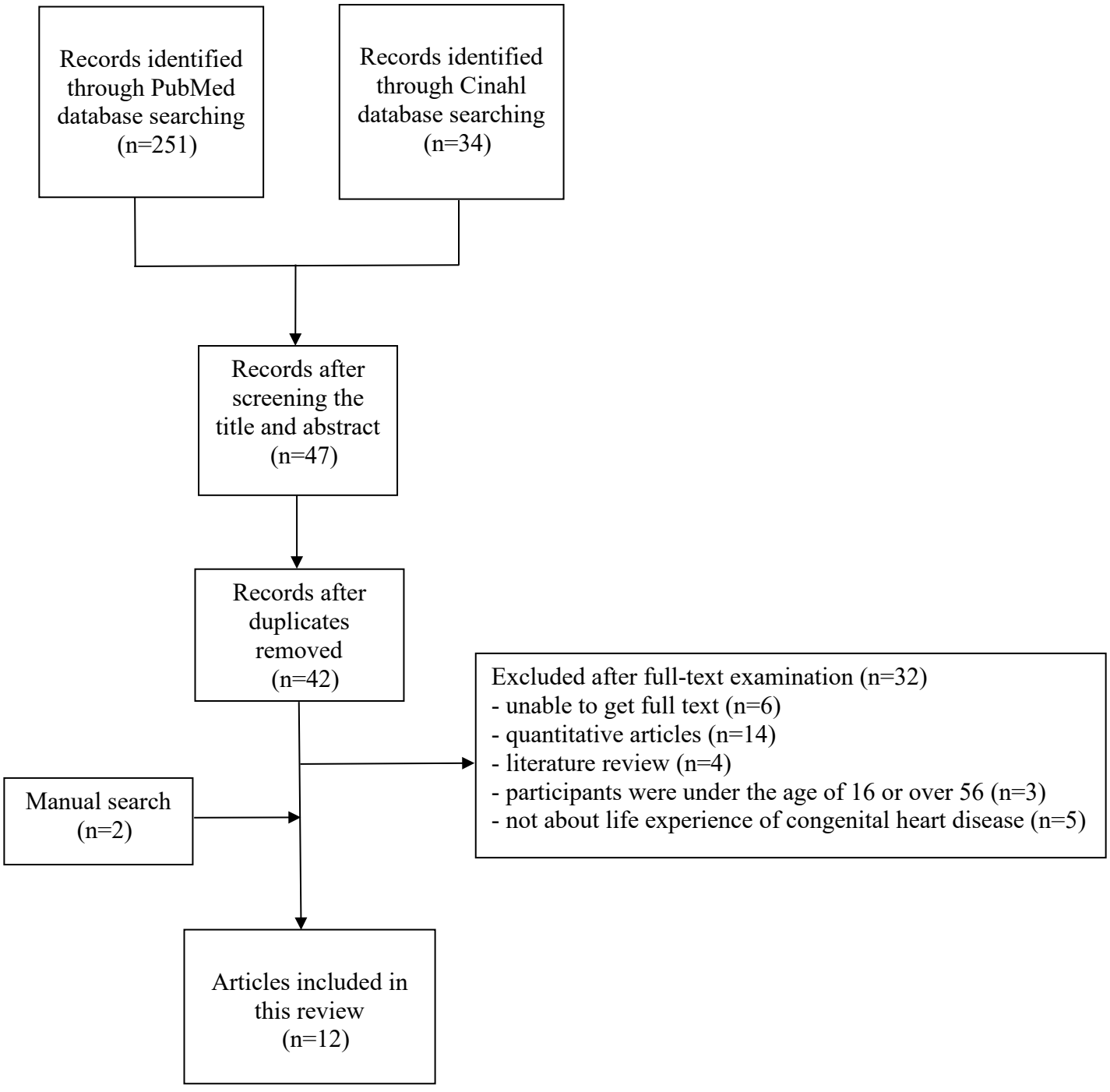

Figure1. Flow chart of the literature search

2. 5 Data analysis

Relevant data were extracted from the included research: authors, year, aim, study population and findings, etc. All articles were read (by Nicole and Sophia) and used Thomas and Harden's (2008) thematic synthesis method. This was mainly undertaken by authors in consultation with supervisor. The authors read each article independently before having a discussion about it. The stages involved in this process included: "line by line" free coding of text to identify different aspects of life experiences of adults with CHD; organized code into descriptive themes; and reviewed and interpreted these themes to generate analytical themes. Throughout the process, findings were continually discussed and reviewed by authors and supervisor to ensure agreement and that the review question was answered.

2. 6 Ethical considerations

The authors would treat this review of the literature with integrity and had read the selected articles objectively (Polit and Beck, 2017). The authors were faithful to the views and results of the selected articles, accurately understood and expressed them in own words and guaranteed that there is no plagiarism in this review of the literature (Polit and Beck, 2017).

3 Results

Three themes relating to life experience of adults with CHD were identified: (1) Personal perceptions of physical and mental activity; (2) Support from family; and, (3) Experience of social life. A more detailed description of themes and subthemes was shown in **Table 2**.

Table 2. Themes and subthemes about life experience of adults with CHD

Themes	Subthemes
(1) Personal perceptions of physical and mental activity	①Subjective cognition of the disease ②Effects of physical limitations ③Vision of the future
(2) Support from family	①Continued support from parents ②Support from other family members

(3) Experience of social life	①Accesses to health services ②School or professional life ③Interactions with other social personnel

3. 1 Personal perceptions of physical and mental activity

Adults with CHD had different perceptions of the disease (Asp et al, 2015; Gatena et al, 2018; Moreland and Santacroce, 2018; Mckillop et al, 2018; Berghammer et al, 2015; Cornett and Simms, 2014; Overgaard et al, 2013; Du Plessis et al, 2018; Flocco et al, 2020; Apers et al, 2016; Chiang et al, 2015). Although they had difficult experiences of physical limitations brought by CHD, their views on physical limitations and coping methods were mostly positive (Mckillop et al, 2018; Berghammer et al, 2015; Overgaard et al, 2013; Du Plessis et al, 2018; Apers et al, 2016). When it came to the future, most adults with CHD had some negative emotions (Berghammer et al, 2015; Cornett and Simms, 2014; Du Plessis et al, 2018; Flocco et al, 2020; Apers et al, 2016), but they still expressed their expectations for the future (Overgaard et al, 2013; Chiang et al, 2015).

3. 1. 1 Subjective cognition of the disease

When it came to CHD, many adults with CHD had a certain recognition of it, although their understanding might not be comprehensive enough (Asp et al, 2015; Gatena et al, 2018; Moreland and Santacroce, 2018; Mckillop et al, 2018; Berghammer et al, 2015; Cornett and Simms, 2014; Cornett and Simms, 2014; Overgaard et al, 2013; Du Plessis et al, 2018; Flocco et al, 2020; Apers et al, 2016; Chiang et al, 2015). They also highlighted their lack of knowledge about possible CHD problems, strategies for preventing complications, and some information about therapy, which was source of uncertainty (Asp et al, 2015; Moreland and Santacroce, 2018; Chiang et al, 2015). Adults with CHD frequently indicated fatigue, weakness, dyspnea, fainting, arrhythmias, and palpitations as symptoms. Yet, each person's symptom intensity, frequency, and duration differ widely, and the majority of them claimed they couldn't identify whether a symptom was brought on by an illness or a healthy bodily reaction (Asp et al, 2015; Moreland and Santacroce, 2018; Du Plessis et al, 2018; Chiang et al, 2015), which was another source of uncertainty. Several adults with CHD who spoke about how they perceived their CHD described it as a constant, restricting presence in their lives, as if it

were something they carried around with them, with physical restrictions serving as constant reminders. They talked about how, after a lifetime of sickness and procedures, there was a feeling of being tired of being unwell, the medical interventions, and the daily stressors the condition brings, emphasizing some negative emotions, like anxiety, sadness, despair, stress, humiliation, wrath, etc., and it even affected their sleep and mental state when these emotions were severe (Berghammer et al, 2015; Cornett and Simms, 2014; Du Plessis et al, 2018; Flocco et al, 2020; Apers et al, 2016). However, a major of adults with CHD chose to accept it and faced it positively (Berghammer et al, 2015; Cornett and Simms, 2014; Overgaard et al, 2013; Flocco et al, 2020; Apers et al, 2016). Nonetheless, rather than seeing their condition as a disease, the majority of adults with CHD regarded it as a part of their lives. They believed they were in good health and accepted their cardiac condition as a natural condition. It was just regarded as something that had always been there and not as a disease. Although the heart condition did provide some challenges, they had grown to accept it as a part of who they were, and they saw it as an opportunity to learn, develop personally, and add meaning to their lives (Berghammer et al, 2015; Cornett and Simms, 2014; Overgaard et al, 2013; Flocco et al, 2020; Apers et al, 2016).

3. 1. 2 Effects of physical limitations

The physical limitations of adults with CHD were frequently described. Although the extent of the impairments vary, a big fraction of adults with CHD were less coordinated and had less physical stamina than peers due to physical restrictions (Mckillop et al, 2018；Overgaard et al, 2013；Du Plessis et al, 2018；Apers et al, 2016). Several of them felt anxious and unhappy about this, fearing that it would interfere with their ability to communicate with people and do their jobs (Sluman et al, 2014; Mckillop et al, 2018; Du Plessis et al, 2018), but others claimed that it helped them understand the significance of health management. They deemed that despite having certain physical restrictions, they continued to engage in physical activities and overcame these difficulties either by working within their constraints or by selecting an activity that satisfied their expectations and allowed them to engage completely (Berghammer et al, 2015; Cornett and Simms, 2014; Overgaard et al, 2013; Flocco et al, 2020; Apers et al, 2016). With each new encounter, a large number of adults with CHD realized that their illnesses could not be cured and that it was better to take control of them than let them rule them. As a result, they established healthy coping mechanisms. To keep their

physical health at its best, they adopted healthy mindsets, acknowledged their limitations, and took positive measures to achieve coexistence with the disease (Mckillop et al, 2018; Berghammer et al, 2015; Cornett and Simms, 2014; Overgaard et al, 2013; Flocco et al, 2020; Apers et al, 2016).

3. 1. 3 Vision of the future

Unpredictability of disease trajectory (Moreland and Santacroce, 2018; Mckillop et al, 2018; Berghammer et al, 2015; Cornett and Simms, 2014; Du Plessis et al, 2018; Flocco et al, 2020; Chiang et al, 2015) and life expectancy (Moreland and Santacroce, 2018; Berghammer et al, 2015; Cornett and Simms, 2014; Du Plessis et al, 2018; Chiang et al, 2015) made numerous adults with CHD found it difficult to plan for the future and one feeling that had been repeatedly mentioned was the fear of death. But, despite all this, the participants highlighted the value of enjoying it to the fullest for they understood how fleeting life was. They discussed how their experiences had improved their lives and had made them more conscious of the importance of life and the need to live lives that were meaningful (Berghammer et al, 2015; Cornett and Simms, 2014; Overgaard et al, 2013; Du Plessis et al, 2018; Flocco et al, 2020; Apers et al, 2016; Chiang et al, 2015). The current existence was even more crucial because the future was uncertain. In addition, many women with ACHD who were of childbearing age had discussed having children. They concerned that if they wanted to have children, whether the pregnancy would go smoothly, whether they would pass on their disease to the child forcing them to deal with the same challenges in life due to, and whether they would be able to bring up their children. Yet, they both concurred that raising children can be one of life's most challenging yet gratifying tasks (Overgaard et al, 2013; Moreland and Santacroce, 2018; Du Plessis et al, 2018; Flocco et al, 2020).

3. 2 Support from family

Nearly every adults with CHD agreed that family support became an integral part of their life (Asp et al, 2015; Gatena et al, 2018; Mckillop et al, 2018; Cornett and Simms, 2014; Overgaard et al, 2013; Flocco et al, 2020; Apers et al, 2016). The support provided by different family members and varying degrees of support made different degrees and nature impact on them.

3. 2. 1 Continued support from parents

The continuous support of parents played a crucial role in their childhood and the transition from childhood to adulthood for during this period, parents often had a deeper understanding of their diseases, and they continued to participate in seeing doctors, communicating with doctors about illness, and intervening in decisions related to cardiac care (Asp et al, 2015; Gatena et al, 2018; Overgaard et al, 2013). In addition, parents helped them keep healthy and created sports opportunities (Gatena et al, 2018; Mckillop et al, 2018). More importantly, active companionship and spiritual comfort were significant pillars to support them to overcome difficulties (Asp et al, 2015; Gatena et al, 2018; Mckillop et al, 2018; Cornett and Simms, 2014; Overgaard et al, 2013; Flocco et al, 2020; Apers et al, 2016). After entering adulthood, adults with CHD gradually guided themselves to take responsibility and parents' immutable and frozen support tended to be regarded as an over-protection, included limiting participation in activities, strictly controlling exercise, and frequently asking about health status (Asp et al, 2015; Gatena et al, 2018; Mckillop et al, 2018; Cornett and Simms, 2014). Adults with CHD did not deny that continued parental support occupied a prominent part in their lives, and also hoped that parents to continue their involvement, but such continued support should be more relaxed in adulthood (Gatena et al, 2018; Mckillop et al, 2018; Cornett and Simms, 2014).

3. 2. 2 Support from other family members

The support from siblings and partners/in-laws was not mentioned as frequently as the support from parents, but adults with CHD pointed out that the support from these family members also had a positive impact (Mckillop et al, 2018; Flocco et al, 2020; Apers et al, 2016). Siblings would not interfere too much in their sports activities, but rather offered encouragement to make them more active, which provided a positive support system and made them confident in participating in the growing activities (Mckillop et al, 2018; Apers et al, 2016). The support from partners/in-laws was a demand for adults with CHD as well. The care given by partners was different from the care of parents and siblings, which could make them feel loved and welcomed more (Flocco et al, 2020; Apers et al, 2016).

3. 3 Experience of social life

The commonly social life experience that adults with CHD mentioned included the experience of receiving medical services (Asp et al, 2015; Gatena et al, 2018; Moreland and Santacroce, 2018; Cornett and Simms, 2014; Overgaard et al, 2013; Flocco et al, 2020; Apers et al, 2016; Chiang et al, 2015), the situation of school or professional life (Sluman et al, 2014; Mckillop et al, 2018; Apers et al, 2016; Chiang et al, 2015) and the interactions with other social personnel (Cornett and Simms, 2014; Overgaard et al, 2013; Du Plessis et al, 2018; Flocco et al, 2020; Apers et al, 2016).

3. 3. 1 Accesses to health services

Transitioning to ACHD care was an inevitable process for every adults with CHD. When it came to this process, adults with CHD emphasized the coexistence of positive and negative experiences (Asp et al, 2015; Gatena et al, 2018; Moreland and Santacroce, 2018; Chiang et al, 2015). Most of them felt attached to the comfortable and familiar pediatric cardiac care environment and thus, they needed to be prepared to adapt to the totally new environment (Asp et al, 2015; Gatena et al, 2018; Moreland and Santacroce, 2018). Continuous care was considered by adults with CHD to be the key to trust the new medical team (Asp et al, 2015; Gatena et al, 2018). Pediatric cardiologists, ACHD team and themselves should contact before transfer so that they had a comprehensive understanding and preparation of the relevant details of the transfer and ACHD team's rapid understanding of the their disease could effectively promote the transfer and establish effective personal contact with them, which was conducive to forming their trust in healthcare providers and enhancing their sense of security in the new care environment (Asp et al, 2015; Gatena et al, 2018; Overgaard et al, 2013), while the lack of such interaction was common. There were still quite a few adults with CHD complaining that incomplete or inconsistent transfer of information had caused them confusion and worry, which tended to be a negative and disappointing experience (Asp et al, 2015; Gatena et al, 2018; Moreland and Santacroce, 2018; Chiang et al, 2015). In addition, They were gradually aware of the changes in disease responsibility caused by transfer. The transition to ACHD care encouraged them to actively participate in their own diseases and improve their understanding of the disease, and they had the opportunity to participate in the discussion of topics related to adult life, and began to try to assume their own health responsibilities, during this period, guiding positive

emotions was necessary for the ACHD team, which made adults with CHD feel that they were valued and their concerns were confirmed (Asp et al, 2015; Gatena et al, 2018; Cornett and Simms, 2014; Overgaard et al, 2013; Apers et al, 2016).

3. 3. 2 School or professional life

A big fraction of adults with CHD mentioned their difficult experiences in school and in the workplace (Sluman et al, 2014; Mckillop et al, 2018; Apers et al, 2016; Chiang et al, 2015). It was not unusual to be compared with peers in school and adults with CHD admitted that they would remain active in school because of their desire to be accepted by peers, but there were difficulties in participating in team activities, especially team sports, which often made them experience interpersonal conflicts repeatedly in school (Mckillop et al, 2018; Apers et al, 2016). Besides, the physical limitations brought by CHD pose a great challenge to their employment (Sluman et al, 2014; Mckillop et al, 2018). Substantial numbers of on-the-job adults with CHD also expressed the difficulty of professional life (Sluman et al, 2014; Mckillop et al, 2018; Chiang et al, 2015), even if it was very satisfying for them to have a job (Apers et al, 2016). Symptoms of CHD like fatigue and dyspnea hindered their work progress, leading to their inability to complete the work correctly and they said that they needed to spend more time than ordinary people to recover their physical strength when completed the same workload (Sluman et al, 2014; Mckillop et al, 2018), which often made colleagues and employers doubt their ability to work and caused themselves to have some negative emotions (Sluman et al, 2014; Mckillop et al, 2018; Chiang et al, 2015).

3. 3. 3 Interactions with other social personnel

A part of adults with CHD emphasized that in the process of contact with others, they usually avoided self-disclosure and even rejected the establishment of relationships with others because of fear of being criticized and rejected (Cornett and Simms, 2014; Apers et al, 2016), while others would actively establish contact with other social personnel, for example, maintained close contact with the consultant service personnel provided by the public sector (Overgaard et al, 2013), which would helped them cope with the adverse effects of the disease on their lives (Cornett and Simms, 2014; Overgaard et al, 2013; Du Plessis et al, 2018; Flocco et al, 2020; Apers et al, 2016). Speaking of receiving psychological/psychiatric/counselling services, although many adults with CHD expressed interest and hoped to receive such services, only a small number of

them actually received such services (Du Plessis et al, 2018; Flocco et al, 2020). Whether they had enjoyed the policies and measures implemented by other social institutions except hospitals, local governments or the state had hardly been mentioned (Cornett and Simms, 2014; Overgaard et al, 2013; Du Plessis et al, 2018; Flocco et al, 2020; Apers et al, 2016), but they did had a great demand for resource platforms and welfare policies, for example, the importance of CHD survivors' group support were affirmed (Overgaard et al, 2013; Chiang et al, 2015).

4 Discussion

4. 1 Main results

The aim of this review was to describe the life experience of adults with congenital heart disease. The results of this study showed that the life experience of adults with CHD mainly included three themes, (1) Personal perceptions of physical and mental activity; (2) Support from family; and, (3) Experience of social life. The physical limitations and symptoms caused by CHD affected the life of adults with CHD and what perceptions and attitudes towards this effect and the disease itself they had determined their coping measures and views on the future. Family support was an important part of the life of adults with CHD and the support of different family members played different roles for them. The social life of adults with CHD involved accesses to medical services, school and professional life, and interactions with other social personnel. These experiences brought positive impact and negative impact on their life.

4. 2 Results discussion

The central idea running across life experiences of adults with CHD was uncertainty. Their daily activities were limited by CHD, which also had an impact on their emotions, psychological states and even the vision of their future. Their elaboration of life experiences exposed the four primary factors of illness uncertainty identified by Mishel (1990).

4.2.1 Unclear symptoms of disease

~~Initially, the symptoms of disease were unclear (Mishel, 1990).~~ The signs of CHD were not constant or homogeneous. Various heart abnormalities might have varied symptoms, and the illness might change in severity and characteristics as people age (NHS Choices, 2014). Adults with CHD found it challenging to appropriately measure their physical health due to the illness's continually shifting symptoms, which also made it more difficult to distinguish between disease symptoms and typical physical reactions. Physical limitations were one of the CHD most noticeable symptoms, and it ~~physical activity~~ was a big problem for adults with CHD. According to this study's findings, the majority of adults with CHD considerably reduce their physical activity, which was similar with Swan et al (2000) 's findings, that was, only one-third of ACHD patients consistently engaged in at least moderate exercise, and one-third of patients did not have any physical activity~~, while having an average age of 26~~. Actually, there were quite a few studies that had demonstrated that increased athletic ability would improve the quality of life of adults with CHD (Fredriksen et al., 2000; Moalla et al., 2006; Dua et al., 2010). Consequently, the management of adults with CHD must include educating patients about the immediate and long-term advantages of exercise. Early adolescence was the ideal time to start making recommendations about physical activity, sport, and training as recommended by the American Heart Association offers recommendations (Graham et al., 2005). Besides, a considerable number of adults with CHD also developed mental distress symptoms, albeit to various degrees, as a result of the long-term effects of CHD symptoms. This result was consistent with other research findings, which showed that the community of adults with CHD was experiencing an increase in emotional distress symptoms, such as anxiety and depression, and that even more of these symptoms progress to mental disease (Jackson et al., 2018; Gleason et al., 2019). Due to the overlap between mental symptoms and CHD symptoms, adults with CHD and clinical experts frequently found it difficult to evaluate these symptoms (such as fatigue, sleep disorders, palpitations, and chest pain) (Jackson et al., 2018).~~ As a result, both the care team for ACHD patients and the patients themselves must have prompt access to competent mental health support.~~ The research findings obtained by Kovacs et al. (2009) reported that more than half of adults with CHD surveyed had a strong interest in the field of psychological therapy, specifically including stress management, chronic disease response, and group therapy. This finding was consistent

with the findings of this study regarding the majority of adults with CHD who had expressed interest in mental health treatment and desire to interact with other adults with CHD. There was a growing demand for resources and strategies to improve the psychosocial health of adults with CHD through psychotherapy interventions (Callus et al., 2018).Closer collaboration between traditional members of the ACHD care team (e. g., doctors and nurses) and mental health experts (e. g., psychologists and psychiatrists) was actively encouraged given the recognized overlap between many cardiac and psychological symptoms.

~~, such as peer support, psychological education, cognitive behavioral therapy, and mindfulness training implemented by mental health professionals, including psychiatrists and psychiatric nurse practitioners, who had the capacity to supervise medication, as well as those who deliver psychotherapy (e. g., psychologists, and licensed counselors).~~

4.2.2 Complexity of the healthcare system

~~Next was about complexity of the healthcare system (Mishel, 1990).~~ One of the key unpredictability factors in adults with CHD was transition. Uncertainty resulted and even had an impact on their subsequent treatment and care because unfamiliar medical team and environment made it challenging to quickly build trust. In one study (Gurvitz et al., 2013), approximately half of the participants with ACHD had not been able to properly transition to adult care, which had resulted in treatment interruptions for their heart disease of more than three years. Also, these patients put a heavy strain on healthcare resources and were at high risk of mortality and morbidity in their early to mid-adult years (Mackie et al., 2014). Another important finding of this study was that many adults with CHD had unpleasant transfer experiences, including their own lack of understanding and incomplete or inconsistent information transfer between pediatric care and adult care, which is in line with findings from earlier research (Busse et al., 2007; Iversen et al., 2019). In this study, adults with CHD described that they needed some time to adjust to a new setting and underlined that the ACHD medical team's quick familiarity with and thorough understanding of their own disease circumstances was helpful in building confidence. Hence, the transition process for adults with CHD should start in early adolescence in order to minimize uncertainty and potential concerns regarding future healthcare and to help adults with CHD develop the necessary self-care skills and increase their sense of health responsibility, nurses should provide them with

pertinent information at an early stage and aid in creating a written medical transition plan (Reiss et al., 2005). Collaboration and positive interpersonal ties also aided in the transfer process (van Staa et al., 2011; Huang et al., 2011). Prior to the transfer, patients, parents, pediatric cardiologists, and ACHD medical teams could establish a sense of safety and trust by holding transfer meetings (Sable et al., 2011).~~, and also, to support continuity of care, the AHA Scientific Statement advised the creation of a formal transition plan that involves the involvement of a transition coordinator, who was often a clinical nurse specialist~~ It was noteworthy that this study also indicated that, with transition for adults with CHD, the level of parental support needed to shift, as prior support was frequently perceived by adults with CHD as excessive indulgence or even obstruction. This was consistent with a previous study that indicated that time around the transition zone was a critical event for the entire family, and parental involvement could become an obstacle to transition preparation (Reiss et al., 2005; Fegran et al., 2014). Transition was viewed as a process, a change in who was responsible for managing the patient's healthcare from the parents to the patients themselves, and it was a transitioning period for parents as well as for adults with CHD (Kovacs et al., 2009). Thus, the ACHD medical team's role in educating and guiding parents during the transition was equally important.

4.2.3 Lack of information related to diagnosis

~~Another primary factor of illness uncertainty was the lack of information related to diagnosis (Mishel, 1990).~~ There were numerous ways for individuals to learn about their diseases, but the most crucial sources of knowledge were seen to be medical professionals (Chalmers et al., 2001).~~ It might be challenging for some patients to locate and receive information that was helpful to them, and they may not be adept at using this information to assess the severity of their own illness for the information obtained through other platforms was widely available, on the contrary, they might be inaccurate in their assessments of the progression of their own sickness as a result of poor cognition. As a result, the importance of medical professionals had been stressed.~~ The information provided by medical professionals was usually more compelling and targeted and as information is shared, it also aided in assisting patients in understanding their various needs and handling the information in an efficient manner. ~~Providing information (all information and consultation instructions), Information seeking (all open and closed questions), Social conversations (personal conversations unrelated to~~

~~health), Positive conversation (care and comfort), and Building Partnerships (seeking the patient's opinions, thoughts, or questions) were the five categories into which Hall et al. (1988) divided the discourse of doctors.~~ According to Mishel (1990), patients with urgent medical requirements might have less disease uncertainty when medical professionals demonstrate confidence, offer a precise diagnosis, and actively participated in helping patients create a self-management plan. In addition to the uncertainty brought on by a lack of information sources, uncertainty can also be produced during the information transmission process. One point that needed to be reinforced was the use of lay terms and medical vocabulary by healthcare professionals when speaking with patients. The majority of adults with CHD, according to this study, were eager to acquire and employ theoretical and technical vocabulary in conversation, and most of them grasp some medical terminology, like "myocardial infarction" and "heart failure. "This finding stood in stark contrast to the notion that when speaking in layman's terms, patients and physicians frequently comprehend one another (Ong LM et al., 1995; Cosic et al., 2019). This difference could be explained by the fact that the majority of adults with CHD had fairly extensive medical histories, were very knowledgeable about their illnesses, and had a growing demand for medical knowledge due to the disease's ambiguity. Doctors and other healthcare professionals must take the patient's opinions and acceptance into account when deciding whether to use lay terms and medical vocabulary in an exchange. In many crucial situations, it was simpler for physicians to establish a platform for idea sharing through the use and interpretation of specific medical expressions than it was to do so by using lay terms (Nordby et al., 2008) and also, could make information transmission more efficient.

4.2.4 Unpredictability of disease processes and prognosis

~~The last one was the unpredictability of disease processes and prognosis (Mishel, 1990).~~ Despite the fact that early surgery and procedures had altered the CHD 's normal path, these treatments were palliative or corrective and cannot heal the condition. Adult effects and consequences from therapy for these ACHD patients could include arrhythmia, pulmonary hypertension, endocarditis, and heart failure (MacGillivray et al., 2019). The future plans of adults with CHD were impacted by such uncertainty, and a crucial discussion regarding role changes−specifically, whether to prepare to become parents soon−is developing. Due to their increased risk of negative cardiac results

during pregnancy, women account for almost all of the debate on this subject. This result was in line with the findings of Rao, S., et al. (2014), who pointed that substantial alterations in hemodynamics during pregnancy greatly raised the risk of cardiac complications in pregnant women with CHD and also had an effect on the development of embryos and neonates. Even among women who had a strong desire to have children, this study showed that the overwhelming majority of women with CHD exhibit some level of fear when discussing conception. They were worried about whether pregnancy was healthy, about the dangers to the heart that pregnancy entails, and about the wellbeing of their children, which was contrary to earlier research (Ngu et al., 2014; Sabanayagam et al., 2017) that suggested women with this form of heart condition did not completely comprehend the danger of pregnancy. Such distinction might be due to the growing awareness-raising and patient education initiatives in the healthcare industry, which were inspiring adults with CHD to actively research and comprehend their conditions. In order for the medical team to provide timely and thorough guidance and management to such populations, as well as provide personalized recommendations and programs based on the disease situation, such as high-risk and unsuitable for childbearing adults with CHD, it was necessary to encourage adults with CHD who were thinking about becoming pregnant or who were already pregnant to participate in medical services. To significantly lower the chance of unfavorable pregnancy outcomes in women with CHD, the medical team should talk about effective contraceptive techniques and alternative alternatives like adoption. Pregnancy termination should also be taken into consideration (Steiner et al., 2021). A study from the United Kingdom showed that ACHD patients during pregnancy had a decreased mortality rate after getting regular cardiology follow-up (Pollard, 2017), which demonstrated the significance of effective prenatal education and interdisciplinary teams in providing combined cardiac and obstetric care.

4.2.5 Professional challenges

The job dilemma was another aspect of this study that had to be emphasized individually. Zomer et al. (2012) compared a sizable number of adults with various forms of CHD with the reference group, the findings revealed that younger ACHD patients had a poorer outcome in employment. (~~those under 40 years old) fared worse than the reference group in terms of job outcomes~~. On the one hand, it was shown in the low likelihood of employment (Ladouceur et al., 2017), which might be brought on by

adults with CHD’s lower educational levels caused by absenteeism due to sickness, treatment, or rehabilitation, and learning difficulties brought on by early neurological issues. On the other hand, it was seen in the high unemployment rate (Crossland et al., 2005). Health issues was frequently cited as a cause for resignation in particular and the working hours and workload stated as the most significant particular adjustments that mentioned by adults with CHD, which were consistent with the findings of this study. For this reason, early on, governments and social institutions should offer adults with CHD active and appropriate expert consultation as well as formal occupational health guidance. This would allow them to actively pursue appropriate educational and employment opportunities, enhancing their quality of life, well-being, and societal contributions.

4.2.6 Seen uncertainty as an incentive

A good few adults with CHD adopted healthy coping strategies despite suffering the unpleasant impacts of various illnesses was an intriguing discovery worth highlighting in this study. Uncertainty was a cognitive condition of decision makers when they were unable to precisely forecast the course of an event, according to Mishel's definition of uncertainty in illness theory (Mishel, 1988). Decision-makers might encounter this cognitive state as an incentive rather than a barrier, though. In this study, the majority of adults with CHD thought that the uncertainty caused by CHD will help them reevaluate their goals in life and adopt a fresh viewpoint. There was a high degree of consistency between this finding and Mishel's theory about Reconstruction Conceptualization of the Uncertain in Disease, which contended that evaluation of uncertainty may change from posing a risk to offering a chance for personal development (Mishel, 1988). In another study (Meleis et al., 2000), patients' freedom in seeking treatment was frequently restricted by uncertainty in illness, which made it challenging to manage self-care. Unlike that study, a sizable number of adults with CHD in this study showed confidence in their ability to manage their own medical circumstances. They would create fitness regimens that were appropriate for their level of activity, actively look for information on pregnancy and contraception, and grow accustomed to observing illness signs. They portrayed the uncertainties caused by the sickness in a more optimistic light. The explanation for this discrepancy might be because these patients' conditions tend to be stable, they might be older than average, and their longer illness courses had given them more time to comprehend and control the disease situation and it was possible that they

had generally upbeat and enthusiastic personalities. In conclusion, such patient group could served as a resource for other ACHD sufferers in the areas of illness management, mental transition, and emotional processing. These empirical expressions had a lot of reference value for adults with CHD to better manage CHD in their lives, notwithstanding the possibility that there might be variations in the severity of the condition.

4. 3 Methods discussion

4. 3. 1 Advantages

This review made use of two significant databases, PubMed and Cinahl (Polit and Beck, 2017), to guarantee the thoroughness and completion of article retrieval. Using free text (Polit and Beck, 2017) to expand the different perspectives and aspects of article research topics, enhance the substance of the findings, and utilize MeSH (Polit and Beck, 2017) to group articles containing synonyms under one keyword, improving retrieval accuracy and efficiency. In addition, this review searched articles that published from 2012 to 2022. Referencing articles from the previous ten years ensured the efficacy and freshness of the study and improved the readability and scientificity of this review. This review covered qualitative literature, which had the benefit that the data source of it was the subjective materials of participants and did not attempt to generalize (Polit and Beck, 2017) and the similarities in personal experiences also showed another characteristic of qualitative research, that was, focusing on the subjective and social significance related to participants, which was particularly important for this study.

4. 3. 2 Limitations

This review accessed articles published in English from 2012 to 2022 and the search was completed in May 2022, which meant that articles after this date had not been included in this review, including some potential related articles that were identified but still unavailable through multiple attempts, all of which may lead to the omission of relevant and considerable articles. Another limitation of this review was the universality of the research question, i. e. ; the age span of the subjects was large, and there was no restriction on the type and severity of CHD. The third limitation concerned articles selected. This review included qualitative studies only, while some results may be more

convincing with reliable and universal through objective measurement, such as quality of life and psychosocial outcomes. In addition, this review was limited in its generalizability as the limited sample size and in view of the differences between health systems, the results of this review may not be extended to the entire ACHD group.

4. 4 Clinical implications

This review highlighted the importance of understanding the experience of adults with CHD. Adults with CHD is an emerging and growing patient population, thus it is essential to realize what they have experienced, what they are experiencing and what they will experience and it is the only way which must be passed for this patient population to find, analyze and solve problems in their life. The results of this review showed that adults with CHD faced challenges in physical function, psychological health, spiritual state and other aspects, which would promote the cultivation of interdisciplinary care teams in the ACHD care settings. Concurrently, transitioning to ACHD care was an inescapable experience for adults with CHD. Medical team must understand and utilise more comprehensive treatment and nursing experience to strengthen existing clinical practice, and then enhance nursing continuity and patient treatment adherence and provide reference for improving care guidelines and formulating targeted intervention strategies during the transition period of ACHD care. Furthermore, this review demonstrated that different degrees of family support had dissimilar effects on adults with CHD at all stages, which will fill a key role in providing correct and effective education and counseling for ACHD patients and their family members. Last but not least, this review is also conducive for government and relevant social institutions to establish a diversified development direction for better serving the ACHD patient population.

4. 5 Suggestions for future research

Since CHD is an innate disease and its impact on adults with CHD will be very far-reaching, it is urgent to carry out specific research on intervention measures for behavioral and psychological difficulties of ACHD patients. This review revealed the views of adults with CHD on the support provided by different family members and the influence of different degrees of support on themselves. Future research needs to correctly guide the role of family supporters on ACHD patients, hence it will be

valuable to explore the experience of different family members supporting ACHD patients. What's more, although there are guidelines on reproductive counseling for adults with CHD currently (Sable et al, 2011), the reproductive strives of such population are still one of uppermost challenges faced by experts. In the future, researchers should deepen and expand the investigation on pregnancy, focusing on further risk stratification, which will have a huge impact on the daily clinical practice of ACHD patients.

5 Conclusions

This study investigated the life experiences of adults with CHD and the results demonstrated that it involved various aspects, including personal perceptions of physical and mental activity, family support and social life.The uncertainty in illness permeated all aspect of their experiences, affecting their emotions and psychological well-being, daily activities, and future outlook.In order to improve the quality of life and even survival rate of adults with CHD, ACHD professional teams, multidisciplinary teams, governments, and social institutions must pay close attention to the problems and needs that adults with CHD faced in their lives. They must also be able to propose targeted and effective solutions.

~~(subjective cognition of the disease, effects of physical limitations and vision of the future) (medical care services and school or professional life) Several requirements and concerns were revealed by their life experiences. They elaborated on their ideas about enjoying health care services and the challenges they encountered in school and the job, expressing the varying nature of the influence of family support on themselves at different phases. To progressively attain cohabitation with disorders, they attempted to create constructive coping mechanisms. Hence, multidisciplinary teams working closely together and interact was crucial for successful transition to adult care and enhancing the continuity of chronic illness treatment, and guaranteeing the quality of ACHD care. In a timely manner, medical professionals should recognize the informational requirements of adults with CHD and their families, assumed the position of information provider, and offered sufficient psychological and physiological support and direction. In order to lessen the burden of the illness uncertainty, the ACHD medical team should give adults with CHD with pertinent treatment plans and advice at an early stage. Moreover, it was advised that social institutions and the government~~

~~develop more thorough plans and rules for the management of employment for adults with CHD, offering a platform for job advice for them.~~

References

Anton K. (2016). Challenges Caring for Adults With Congenital Heart Disease in Pediatric Settings: How Nurses Can Aid in the Transition. *Critical care nurse,* 36 (4) : e1-e8. doi: 10. 4037/ccn2016131

Apers, S., Rassart, J., Luyckx, K., Oris, L., Goossens, E., Budts, W., Moons, P., & I-DETACH Investigators (2016). Bringing Antonovsky's salutogenic theory to life: A qualitative inquiry into the experiences of young people with congenital heart disease. *International journal of qualitative studies on health and well-being*, 11, 29346. https: //doi. org/10. 3402/qhw. v11. 29346

Asp, A., Bratt, E. L., & Bramhagen, A. C. (2015). Transfer to Adult Care--Experiences of Young Adults with Congenital Heart Disease. *Journal of pediatric nursing*, 30 (5) : e3‐e10. https: //doi. org/10. 1016/j. pedn. 2015. 05. 025

Baumgartner, H., Bonhoeffer, P., De Groot, N. M., de Haan, F., Deanfield, J. E., Galie, N., Gatzoulis, M. A., Gohlke-Baerwolf, C., Kaemmerer, H., Kilner, P., Meijboom, F., Mulder, B. J., Oechslin, E., Oliver, J. M., Serraf, A., Szatmari, A., Thaulow, E., Vouhe, P. R., Walma, E., Task Force on the Management of Grown-up Congenital Heart Disease of the European Society of Cardiology (ESC), ⋯ ESC Committee for Practice Guidelines (CPG) (2010). ESC Guidelines for the management of grown-up congenital heart disease (new version 2010). *European heart journal*, 31 (23) : 2915-2957. doi: 10. 1093/eurheartj/ehq249

Baumgartner, H., De Backer, J., Babu-Narayan, S. V., Budts, W., Chessa, M., Diller, G. P., Lung, B., Kluin, J., Lang, I. M., Meijboom, F., Moons, P., Mulder, B., Oechslin, E., Roos-Hesselink, J. W., Schwerzmann, M., Sondergaard, L., Zeppenfeld, K., & ESC Scientific Document Group (2021). 2020 ESC Guidelines for the management of adult congenital heart disease. *European heart journal*, 42 (6) : 563-645. doi: 10. 1093/eurheartj/ehaa554

Berghammer, M. C., Brink, E., Rydberg, A. M., Dellborg, M., & Ekman, I. (2015). Committed to Life: Adolescents' and Young Adults' Experiences of Living with Fontan Circulation. *Congenital heart disease*, 10 (5) : 403‑412.
https: //doi. org/10. 1111/chd. 12244

Bhatt, A. B., Foster, E., Kuehl, K., Alpert, J., Brabeck, S., Crumb, S., Davidson, W. R., Jr, Earing, M. G., Ghoshhajra, B. B., Karamlou, T., Mital, S., Ting, J., Tseng, Z. H., and American Heart Association Council on Clinical Cardiology (2015). Congenital heart disease in the older adult: a scientific statement from the American Heart Association. *Circulation*, 131 (21) : 1884‑1931. doi: 10. 1161/CIR. 0000000000000204

Bouma, B. J., and Mulder, B. J. (2017). Changing Landscape of Congenital Heart Disease. *Circulation research*, 120 (6) : 908-922. doi: 10. 1161/CIRCRESAHA. 116. 309302

Brida, M., Lovrić, D., Griselli, M., Riesgo Gil, F., and Gatzoulis, M. A. (2022). Heart failure in adults with congenital heart disease. *International journal of cardiology*, 357: 39-45. doi: 10. 1016/j. ijcard. 2022. 03. 018

Busse, F. P., Hiermann, P., Galler, A., Stumvoll, M., Wiessner, T., Kiess, W., & Kapellen, T. M. (2007). Evaluation of patients' opinion and metabolic control after transfer of young adults with type 1 diabetes from a pediatric diabetes clinic to adult care. *Hormone research*, 67 (3) : 132-138. https: //doi. org/10. 1159/000096583

Callus, E., & Pravettoni, G. (2018). The Role of Clinical Psychology and Peer to Peer Support in the Management of Chronic Medical Conditions - A Practical Example With Adults With Congenital Heart Disease. *Frontiers in psychology*, 9: 731. https: //doi. org/10. 3389/fpsyg. 2018. 00731.

Canobbio, M. M., & Day, M. J. (1994). The role of the clinical specialist in an adult congenital heart disease program. *The Nursing clinics of North America*, 29 (2) : 357‑366.

Catena, G., Rempel, G. R., Kovacs, A. H., Rankin, K. N., Muhll, I. V., & Mackie, A. S. (2018). "Not such a kid thing anymore": Young adults' perspectives on transfer from paediatric to adult cardiology care. *Child: care, health and development*, 44 (4) : 592‐598. https: //doi. org/10. 1111/cch. 12564

Chalmers, K. I., Luker, K. A., Leinster, S. J., Ellis, I., & Booth, K. (2001). Information and support needs of women with primary relatives with breast cancer: development of the Information and Support Needs Questionnaire. *Journal of advanced nursing*, 35 (4) : 497-507. https: //doi. org/10. 1046/j. 1365-2648. 2001. 01866. x

Chiang, Y. T., Chen, C. W., Su, W. J., Wang, J. K., Lu, C. W., Li, Y. F., & Moons, P. (2015). Between invisible defects and visible impact: the life experiences of adolescents and young adults with congenital heart disease. *Journal of advanced nursing*, 71 (3) : 599‐608. https: //doi. org/10. 1111/jan. 12546

Child, J. S., Collins-Nakai, R. L., Alpert, J. S., Deanfield, J. E., Harris, L., McLaughlin, P., Miner, P. D., Webb, G. D., & Williams, R. G. (2001). Task force 3: workforce description and educational requirements for the care of adults with congenital heart disease. *Journal of the American College of Cardiology*, 37 (5) : 1183-1187. doi: 10. 1016/s0735-1097 (01) 01276-1

Chubb, H., and Motonaga, K. S. (2020). Cardiac resynchronization and implantable defibrillators in adults with congenital heart disease. *Heart failure reviews*, 25 (4) : 657-670. https: //doi. org/10. 1007/s10741-019-09886-y

Cohen, S. B., Ginde, S., Bartz, P. J., and Earing, M. G. (2013). Extracardiac complications in adults with congenital heart disease. *Congenital heart disease*, 8 (5) : 370-380. doi: 10. 1111/chd. 12080

Cornett, L., & Simms, J. (2014). At the 'heart' of the matter: an exploration of the psychological impact of living with congenital heart disease in adulthood. *Journal of health psychology*, 19 (3) : 393‐406. https: //doi. org/10. 1177/1359105312471569

Cosic F, Kimmel L, Edwards E. (2019). Patient Comprehension of Common Orthopedic Terminology. *Health literacy research and practice*, 3 (3) : e187-e193. doi: 10. 3928/24748307-20190624-04. PMID: 31428736.

Crossland DS, Jackson SP, Lyall R, Burn J, O'Sullivan JJ. (2005). Employment and advice regarding careers for adults with congenital heart disease. *Cardiology Young*, 15 (4) : 391-395. doi: 10. 1017/S104795110500082X

Cuypers, J. A., Utens, E. M., Roos-Hesselink, J. W. (2016). Health in adults with congenital heart disease. *Maturitas*. 91: 69-73. doi: 10. 1016/j. maturitas. 2016. 06. 005

Daly, W. M., and Carnwell, R. (2003). Nursing roles and levels of practice: a framework for differentiating between elementary, specialist and advancing nursing practice. *Journal of clinical nursing*, 12 (2) : 158-167. doi: 10. 1046/j. 1365-2702. 2003. 00690. x

Delaney, A. E., Qiu, J. M., Lee, C. S., Lyons, K. S., Vessey, J. A., & Fu, M. R. (2021). Parents' Perceptions of Emerging Adults With Congenital Heart Disease: An Integrative Review of Qualitative Studies. *Journal of pediatric health care: official publication of National Association of Pediatric Nurse Associates & Practitioners*, 35 (4): 362-376. https://doi.org/10.1016/j.pedhc.2020.11.009

Demianczyk, A. C., Bechtel Driscoll, C. F., Karpyn, A., Shillingford, A., Kazak, A. E., & Sood, E. (2022). Coping strategies used by mothers and fathers following diagnosis of congenital heart disease. *Child: care, health and development*, 48 (1): 129-138. https://doi.org/10.1111/cch.12913

Du Plessis, K., Peters, R., King, I., Robertson, K., Mackley, J., Maree, R., Stanley, T., Pickford, L., Rose, B., Orchard, M., Stewart, H., & d'Udekem, Y. (2018). "How long will I continue to be normal?" Adults with a Fontan circulation's greatest concerns. *International journal of cardiology*, 260: 54‑59.
https: //doi. org/10. 1016/j. ijcard. 2018. 01. 098

Dua J. S., Cooper A. R., Fox K. R., Graham Stuart A. (2010). Exercise training in adults with congenital heart disease: feasibility and benefits. *International journal of cardiology,* 138 (2) : 196-205. doi: 10. 1016/j. ijcard. 2009. 01. 038.

Fegran, L., Hall, E. O., Uhrenfeldt, L., Aagaard, H., & Ludvigsen, M. S. (2014). Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: a qualitative metasynthesis. *International journal of nursing studies*, 51 (1) : 123-135. https: //doi. org/10. 1016/j. ijnurstu. 2013. 02. 001

Flocco, S. F., Caruso, R., Barello, S., Nania, T., Simeone, S., & Dellafiore, F. (2020). Exploring the lived experiences of pregnancy and early motherhood in Italian women with congenital heart disease: an interpretative phenomenological analysis. *BMJ open*, 10 (1) : e034588. https: //doi. org/10. 1136/bmjopen-2019-034588

Fredriksen P. M., Kahrs N, Blaasvaer S, Sigurdsen E, Gundersen O, Roeksund O, Norgaand G, Vik JT, Soerbye O, Ingjer E, Thaulow E. (2000). Effect of physical training in children and adolescents with congenital heart disease. *Cardiol Young*, 10 (2) : 107-14. doi: 10. 1017/s1047951100006557.

Gleason, L. P., Deng, L. X., Khan, A. M., Drajpuch, D., Fuller, S., Ludmir, J., Mascio, C. E., Partington, S. L., Tobin, L., Kim, Y. Y., & Kovacs, A. H. (2019). Psychological distress in adults with congenital heart disease: focus beyond depression. *Cardiology in the young,* 29 (2) : 185‑189. https: //doi. org/10. 1017/S1047951118002068

Graham T. P. Jr, Driscoll D. J., Gersony W. M., Newburger J. W., Rocchini A, Towbin J. A. (2005). Task Force 2: congenital heart disease. *Journal of the American college of cardiology*, 45 (8) : 1326-1333. doi: 10. 1016/j. jacc. 2005. 02. 009.

Gurvitz, M., Valente, A. M., Broberg, C., Cook, S., Stout, K., Kay, J., Ting, J., Kuehl, K., Earing, M., Webb, G., Houser, L., Opotowsky, A., Harmon, A., Graham, D., Khairy, P., Gianola, A., Verstappen, A., Landzberg, M., & Alliance for Adult Research in Congenital Cardiology (AARCC) and Adult Congenital Heart Association (2013).

Prevalence and predictors of gaps in care among adult congenital heart disease patients: HEART-ACHD (The Health, Education, and Access Research Trial). *Journal of the American College of Cardiology*, 61 (21) : 2180-2184. https: //doi.org/10.1016/j.jacc.2013.02.048

Hall J. A., Roter D. L., Katz N. R. (1988). Meta-analysis of correlates of provider behavior in medical encounters. *Medical Care,* 26 (7) : 657-675. doi: 10. 1097/00005650-198807000-00002.

Heiney, S. P., Adams, S. A., Wells, L. M., Johnson, H., King, J. M. (2012). Participant evaluation of teleconference support for African American women with breast cancer. *Cancer nursing*, 35 (2) : e24-e30. doi: 10. 1097/NCC. 0b013e31821e9947

Huang, J. S., Gottschalk, M., Pian, M., Dillon, L., Barajas, D., & Bartholomew, L. K. (2011). Transition to adult care: systematic assessment of adolescents with chronic illnesses and their medical teams. *The Journal of pediatrics*, 159 (6) : 994-998. e2. https: //doi. org/10. 1016/j. jpeds. 2011. 05. 038

International Council of Nurses (ICN). (2021). Retrieved from https: //www. icn. ch/system/files/2021-10/ICN_Code-of-Ethics_EN_Web_0. pdf
Accessed on May 4th, 2022.

Iversen, E., Kolltveit, B. H., Hernar, I., Mårtensson, J., & Haugstvedt, A. (2019). Transition from paediatric to adult care: a qualitative study of the experiences of young adults with type 1 diabetes. *Scandinavian journal of caring sciences*, 33 (3) : 723-730. https: //doi. org/10. 1111/scs. 12668

Jackson, J. L., Leslie, C. E., & Hondorp, S. N. (2018). Depressive and Anxiety Symptoms in Adult Congenital Heart Disease: Prevalence, Health Impact and Treatment. *Progress in cardiovascular diseases*, 61 (3-4) : 294-299.
https: //doi. org/10. 1016/j. pcad. 2018. 07. 015

Kamphuis M, Verloove-Vanhorick S.P., Vogels T, Ottenkamp J, Vliegen H. W. (2002). Disease-related difficulties and satisfaction with level of knowledge in adults with mild or complex congenital heart disease. *Cardiology Young*, 12 (3) : 266-271. doi: 10.

1017/s1047951102000574. PMID: 12365174.

Kogon, B. E., Plattner, C., Leong, T., Kirshbom, P. M., Kanter, K. R., McConnell, M., and Book, W. (2009). Adult congenital heart surgery: adult or pediatric facility? Adult or pediatric surgeon?. *The Annals of thoracic surgery*, 87 (3) : 833-840. doi: 10. 1016/j. athoracsur. 2008. 12. 027

Kovacs, A. H., Bendell, K. L., Colman, J., Harrison, J. L., Oechslin, E., & Silversides, C. (2009). Adults with congenital heart disease: psychological needs and treatment preferences. *Congenital heart disease*, 4 (3) : 139-146.
https: //doi. org/10. 1111/j. 1747-0803. 2009. 00280. x

Kovacs, A. H., & McCrindle, B. W. (2014). So hard to say goodbye: transition from paediatric to adult cardiology care. Nature reviews. *Cardiology*, 11 (1) : 51-62. https: //doi. org/10. 1038/nrcardio. 2013. 172

Ladouceur M, Calderon J, Traore M, Cheurfi R, Pagnon C, Khraiche D, Bajolle F, Bonnet D. (2017). Educational needs of adolescents with congenital heart disease: Impact of a transition intervention programme. *Archives of Cardiovascular Diseases*, 110 (5) : 317-324. doi: 10. 1016/j. acvd. 2017. 02. 001.

Lenfant C. (2003). Shattuck lecture--clinical research to clinical practice--lost in translation?. *The New England journal of medicine*, 349 (9) : 868-874. doi: 10. 1056/NEJMsa035507

MacGillivray T. E., Lin C. H. (2019). The Growing Number of Adults Surviving with Congenital Heart Disease. *Methodist Debakey Cardiovascular Journal*, 15 (2) : 97-98. doi: 10. 14797/mdcj-15-2-97.

Mackie, A. S., Islam, S., Magill-Evans, J., Rankin, K. N., Robert, C., Schuh, M., Nicholas, D., Vonder Muhll, I., McCrindle, B. W., Yasui, Y., & Rempel, G. R. (2014). Healthcare transition for youth with heart disease: a clinical trial. *Heart (British Cardiac Society),* 100 (14) : 1113-1118. https: //doi. org/10. 1136/heartjnl-2014-305748

Martin Heidegger (2018). *Martin Heidegger Gesamtausgabe*. China: The Commercial Press. Accessed on May 11th, 2022.

Matsuda, H., Ichikawa, H., Ueno, T., and Sawa, Y. (2017). Heart transplantation for adults with congenital heart disease: current status and future prospects. *General thoracic and cardiovascular surgery*, 65 (6) : 309-320. doi: 10. 1007/s11748-017-0777-x

McKillop, A., McCrindle, B. W., Dimitropoulos, G., & Kovacs, A. H. (2018). Physical activity perceptions and behaviors among young adults with congenital heart disease: A mixed-methods study. *Congenital heart disease*, 13 (2) : 232‐240.
https: //doi. org/10. 1111/chd. 12553

Meleis, A. I., Sawyer, L. M., Im, E. O., Hilfinger Messias, D. K., & Schumacher, K. (2000). Experiencing transitions: an emerging middle-range theory. ANS. *Advances in nursing science*, 23 (1) : 12-28. https: //doi. org/10. 1097/00012272-200009000-00006

Merriam-Webster. (n. d.). Adult. In Merriam-Webster. com dictionary. Retrieved from https: //www. merriam-webster. com/dictionary/adult
Accessed on May 4th, 2022.

Mishel M. H. (1981). The measurement of uncertainty in illness. *Nursing research,* 30 (5) : 258-263.

Mishel, M. H. (1988). Uncertainty in illness. *Image--the journal of nursing scholarship*, 20 (4) : 225-232. doi: 10. 1111/j. 1547-5069. 1988. tb00082. x

Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *Image--the journal of nursing scholarship*, 22 (4) : 256-262. doi: 10. 1111/j. 1547-5069. 1990. tb00225. x

Mitchell J. H., Haskell W, Snell P, Van Camp S. P. (2005). Task Force 8: classification of sports. *Journal of the American college of cardiology*, 45 (8) : 1364-1367. doi: 10.

1016/j. jacc. 2005. 02. 015.

Mitchell, S. C., Korones, S. B., and Berendes, H. W. (1971). Congenital heart disease in 56, 109 births. Incidence and natural history. *Circulation*, 43 (3) : 323-332. doi: 10. 1161/01. cir. 43. 3. 323

Moalla W, Maingourd Y, Gauthier R, Cahalin LP, Tabka Z, Ahmaidi S. (2006). Effect of exercise training on respiratory muscle oxygenation in children with congenital heart disease. *European Journal Of Cardiovascular Prevention And Rehabilitation*, 13 (4) : 604-611. doi: 10. 1097/01. hjr. 0000201515. 59085. 69.

Moons, P., De Geest, S., and Budts, W. (2002). Comprehensive care for adults with congenital heart disease: expanding roles for nurses. *European journal of cardiovascular nursing*, 1 (1) : 23-28. doi: 10. 1016/S1474-5151 (01) 00014-7

Moons, P., Pinxten, S., Dedroog, D., Van Deyk, K., Gewillig, M., Hilderson, D., and Budts, W. (2009). Expectations and experiences of adolescents with congenital heart disease on being transferred from pediatric cardiology to an adult congenital heart disease program. *The Journal of adolescent health : official publication of the Society for Adolescent Medicine*, 44 (4) : 316-322. doi: 10. 1016/j. jadohealth. 2008. 11. 007

Moreland, P., & Santacroce, S. J. (2018). Illness Uncertainty and Posttraumatic Stress in Young Adults With Congenital Heart Disease. *The Journal of cardiovascular nursing*, 33 (4) : 356‑362. https: //doi. org/10. 1097/JCN. 0000000000000471

Mutluer, F. O., and Çeliker, A. (2018). General Concepts in Adult Congenital Heart Disease. *Balkan medical journal*, 35 (1) : 18-29. doi: 10. 4274/balkanmedj. 2017. 0910

Ngu, K., Hay, M., & Menahem, S. (2014). Perceptions and motivations of an Australian cohort of women with or without congenital heart disease proceeding to pregnancy. *International journal of gynaecology and obstetrics: the official organ of the International Federation of Gynaecology and Obstetrics*, 126 (3) : 252-255. https: //doi. org/10. 1016/j. ijgo. 2014. 03. 032

NHS Choices, UK. (2014). The symptoms of congenital heart disease. www. nhs. uk/conditions. congenital-heart-disease/pages/symptoms. aspx. Accessed on May 15th, 2022.

Ntiloudi, D., Giannakoulas, G., Parcharidou, D., Panagiotidis, T., Gatzoulis, M. A., and Karvounis, H. (2016). Adult congenital heart disease: A paradigm of epidemiological change. *International journal of cardiology*, 218: 269-274.
doi: 10. 1016/j. ijcard. 2016. 05. 046

Ong L. M., de Haes J. C., Hoos A. M., Lammes F. B. (1995). Doctor-patient communication: a review of the literature. *Social Science & Medicine*, 40 (7) : 903-918.
doi: 10. 1016/0277-9536 (94) 00155-m.

Overgaard, D., King, C., Christensen, R. F., Schrader, A. M., & Adamsen, L. (2013). Living with half a heart--experiences of young adults with single ventricle physiology: a qualitative study. *The Journal of cardiovascular nursing*, 28 (2) : 187‑196. https: //doi. org/10. 1097/JCN. 0b013e3182498677

Pagé, M. G., Kovacs, A. H., & Irvine, J. (2012). How do psychosocial challenges associated with living with congenital heart disease translate into treatment interests and preferences? A qualitative approach. *Psychology & health*, 27 (11) : 1260-1270. https: //doi. org/10. 1080/08870446. 2012. 667099

Polit, D. F., and Beck, C. T. (2017). *Nursing research: generating and assessing evidence for nursing practice.* Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins. Accessed on May 4th, 2022.

Rao, S., & Ginns, J. N. (2014). Adult congenital heart disease and pregnancy. *Seminars in perinatology*, 38 (5) : 260-272. https: //doi. org/10. 1053/j. semperi. 2014. 04. 015.

Reiss, J. G., Gibson, R. W., & Walker, L. R. (2005). Health care transition: youth, family, and provider perspectives. *Pediatrics*, 115 (1) : 112-120.
https: //doi. org/10. 1542/peds. 2004-1321

Roth, G. A., Mensah, G. A., Johnson, C. O., Addolorato, G., Ammirati, E., Baddour, L. M., Barengo, N. C., Beaton, A. Z., Benjamin, E. J., Benziger, C. P., Bonny, A., Brauer, M., Brodmann, M., Cahill, T. J., Carapetis, J., Catapano, A. L., Chugh, S. S., Cooper, L. T., Coresh, J., Criqui, M., ⋯ GBD-NHLBI-JACC Global Burden of Cardiovascular Diseases Writing Group (2020). Global Burden of Cardiovascular Diseases and Risk Factors, 1990-2019: Update From the GBD 2019 Study. *Journal of the American College of Cardiology*, 76 (25) : 2982‑3021. doi: 10. 1016/j. jacc. 2020. 11. 010

Sabanayagam, A., Briston, D., & Zaidi, A. N. (2017). Attitudes and perceptions of pregnant women with CHD: results of a single-site survey. *Cardiology in the young*, 27 (7) : 1257-1264. https: //doi. org/10. 1017/S1047951116002857

Sable, C., Foster, E., Uzark, K., Bjornsen, K., Canobbio, M. M., Connolly, H. M., Graham, T. P., Gurvitz, M. Z., Kovacs, A., Meadows, A. K., Reid, G. J., Reiss, J. G., Rosenbaum, K. N., Sagerman, P. J., Saidi, A., Schonberg, R., Shah, S., Tong, E., Williams, R. G., & American Heart Association Congenital Heart Defects Committee of the Council on Cardiovascular Disease in the Young, Council on Cardiovascular Nursing, Council on Clinical Cardiology, and Council on Peripheral Vascular Disease (2011). Best practices in managing transition to adulthood for adolescents with congenital heart disease: the transition process and medical and psychosocial issues: a scientific statement from the American Heart Association. *Circulation*, 123 (13) : 1454-1485. https: //doi. org/10. 1161/CIR. 0b013e3182107c56

Saidi, A., & Kovacs, A. H. (2009). Developing a transition program from pediatric- to adult-focused cardiology care: practical considerations. *Congenital heart disease*, 4 (4) : 204-215. https: //doi. org/10. 1111/j. 1747-0803. 2009. 00312. x

Pollard K. MBRRACE-UK Report launch December 2016. (2017). *The Practising Midwife,* 20 (2) : 30-32.

Sluman, M. A., de Man, S., Mulder, B. J., & Sluiter, J. K. (2014). Occupational challenges of young adult patients with congenital heart disease. *Netherlands heart journal : monthly journal of the Netherlands Society of Cardiology and the Netherlands Heart Foundation*, 22 (5) : 216‑224. https: //doi. org/10. 1007/s12471-014-0540-1

Steiner, J. M., Lokken, E., Bayley, E., Pechan, J., Curtin, A., Buber, J., & Albright, C. (2021). Cardiac and Pregnancy Outcomes of Pregnant Patients With Congenital Heart Disease According to Risk Classification System. *The American journal of cardiology*, 161: 95-101. https: //doi. org/10. 1016/j. amjcard. 2021. 08. 037

Su, Z., Zou, Z., Hay, S. I., Liu, Y., Li, S., Chen, H., Naghavi, M., Zimmerman, M. S., Martin, G. R., Wilner, L. B., Sable, C. A., Murray, C., Kassebaum, N. J., Patton, G. C., & Zhang, H. (2022). Global, regional, and national time trends in mortality for congenital heart disease, 1990-2019: An age-period-cohort analysis for the Global Burden of Disease 2019 study. *EClinicalMedicine*, 43: 101249. doi: 10. 1016/j. eclinm. 2021. 101249

Swan L, Hillis WS. (2000). Exercise prescription in adults with congenital heart disease: a long way to go. *Heart.* 83 (6) : 685-687. doi: 10. 1136/heart. 83. 6. 685.

Therrien J, Fredriksen P, Walker M, Granton J, Reid GJ, Webb G. (2003). A pilot study of exercise training in adult patients with repaired tetralogy of Fallot. *Canadian Journal of Cardiology*, 19 (6) : 685-689.

Thomas, J., and Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8: 45.
doi: 10. 1186/1471-2288-8-45

van der Bom, T., Zomer, A. C., Zwinderman, A. H., Meijboom, F. J., Bouma, B. J., and Mulder, B. J. (2011). The changing epidemiology of congenital heart disease. Nature reviews. *Cardiology*, 8 (1) : 50-60. doi: 10. 1038/nrcardio. 2010. 166

van der Bom, T., Mulder, B. J., Meijboom, F. J., van Dijk, A. P., Pieper, P. G., Vliegen, H. W., Konings, T. C., Zwinderman, A. H., & Bouma, B. J. (2015). Contemporary survival of adults with congenital heart disease. *Heart (British Cardiac Society),* 101 (24) : 1989‑1995. doi: 10. 1136/heartjnl-2015-308144

van Rijen E. H., Utens E. M., Roos-Hesselink J. W., Meijboom F. J., van Domburg R.

T., Roelandt J. R., Bogers A. J., Verhulst F. C. (2003). Psychosocial functioning of the adult with congenital heart disease: a 20-33 years follow-up. *European Heart Journal*, 24 (7) : 673-683. doi: 10. 1016/s0195-668x (02) 00749-2

van Staa, A. L., Jedeloo, S., van Meeteren, J., & Latour, J. M. (2011). Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers. *Child: care, health and development*, 37 (6) : 821-832. https: //doi. org/10. 1111/j. 1365-2214. 2011. 01261. x ;

Warnes, C. A., Williams, R. G., Bashore, T. M., Child, J. S., Connolly, H. M., Dearani, J. A., Del Nido, P., Fasules, J. W., Graham, T. P., Jr, Hijazi, Z. M., Hunt, S. A., King, M. E., Landzberg, M. J., Miner, P. D., Radford, M. J., Walsh, E. P., & Webb, G. D. (2008). ACC/AHA 2008 guidelines for the management of adults with congenital heart disease: a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (Writing Committee to Develop Guidelines on the Management of Adults With Congenital Heart Disease). Developed in Collaboration With the American Society of Echocardiography, Heart Rhythm Society, International Society for Adult Congenital Heart Disease, Society for Cardiovascular Angiography and Interventions, and Society of Thoracic Surgeons. *Journal of the American College of Cardiology*, 52 (23) : e143‑e263. doi: 10. 1016/j. jacc. 2008. 10. 001

Wilhelm Dilthey. (1921). *Das Erlebnis und die Dichtung*. Gottingen: Vandenhoeck & Ruprecht. Accessed on May 11th, 2022.

Winter M. M., van der Bom T, de Vries L. C., Balducci A, Bouma B. J., Pieper P. G., van Dijk A. P., van der Plas M. N., Picchio F. M., Mulder B. J. (2012). Exercise training improves exercise capacity in adult patients with a systemic right ventricle: a randomized clinical trial. *European Heart Journal*, 33 (11) : 1378-1385. doi: 10. 1093/eurheartj/ehr396.

Zhou, L., & Chen, J. (2017). Life events and hopelessness depression: The influence of affective experience. *PloS one*, 12 (11) : e0187898. doi: 10. 1371/journal. pone. 0187898.

Zomer A. C., Vaartjes I, Uiterwaal C. S., van der Velde E. T., Sieswerda G. J., Wajon E. M., Plomp K, van Bergen P. F., Verheugt C. L., Krivka E, de Vries C. J., Lok D. J., Grobbee D. E., Mulder B. J. (2012). Social burden and lifestyle in adults with congenital heart disease.
American journal of cardiology, 109 (11) : 1657-1663. doi: 10. 1016/j. amjcard. 2012. 01. 397

APPENDIX 1

Authors, year of publication and country	Title	Design (possibly approach)	Participants	Data collection method	Data analysis method	Code
Authors: Asp, A., Bratt, E. L., & Bramhagen, A. C. **Year:** 2015 **Country:** United States	Transfer to Adult Care–Experiences of Young Adults with Congenital Heart Disease.	**Design:** Descriptive design **Approach:** Qualitative approach	**Number:** 16 **Age:** 19-24 years old **Diagnosis:** Moderate or complex CHD	Interviews	Content analysis	A
Authors: Catena, G., Rempel, G. R., Kovacs, A. H., Rankin, K. N., Muhll, I. V., & Mackie, A. S. **Year:** 2018 **Country:** England	"Not such a kid thing anymore": Young adults' perspectives on transfer from paediatric to adult cardiology care.	**Design:** Explorative design **Approach:** Qualitative approach	**Number:** 21 **Age:** 18-25 years old **Diagnosis:** Moderate or complex CHD	Interviews	Content analysis & Thematic analysis	B
Authors: Sluman, M. A., de Man, S., Mulder, B. J., &	Occupational challenges of young adult patients with	**Design:** Descriptive design **Approach:**	**Number:** 15 **Age:** 20-35 years old **Diagnosis:** Mild,	Interviews	Content analysis	C

Sluiter, J. K. **Year:** 2014 **Country:** Netherlands	congenital heart disease.	Qualitative approach	moderate or complex CHD			
Authors: Moreland, P., & Santacroce, S. J. **Year:** 2018 **Country:** United States	Illness Uncertainty and Posttraumatic Stress in Young Adults With Congenital Heart Disease.	**Design:** Exploratory-descriptive design **Approach:** Mixed methods approach	**Number:** 25 **Age:** 19-35 years old **Diagnosis:** Mild, moderate or complex CHD	Interviews & Questionnaires	Constant comparative method & Descriptive statistics	D
Authors: McKillop, A., McCrindle, B. W., Dimitropoulos, G., & Kovacs, A. H. **Year:** 2018 **Country:** United States	Physical activity perceptions and behaviors among young adults with congenital heart disease: A mixed-methods study.	**Design:** Cross-sectional design **Approach:** Mixed methods approach	**Number:** 15 **Age:** 18-25 years old **Diagnosis:** Mild, moderate or complex CHD	Interviews & Questionnaires	Thematic analysis & Descriptive statistics	E
Authors:	Committed to Life:	**Design:**	**Number:** 7	Interviews	Phenomenological	F

Berghammer, M. C., Brink, E., Rydberg, A. M., Dellborg, M., & Ekman, I. **Year:** 2015 **Country:** United States	Adolescents' and Young Adults' Experiences of Living with Fontan Circulation.	Descriptive design **Approach:** Qualitative approach	**Age:** 17-32 years old **Diagnosis:** Univentricular heart defect and had undergone surgical palliation with Fontan circulation		hermeneutical method	
Authors: Cornett, L., & Simms, J. **Year:** 2014 **Country:** England	At the 'heart' of the matter: an exploration of the psychological impact of living with congenital heart disease in adulthood.	**Design:** Descriptive design **Approach:** Qualitative approach	**Number:** 7 **Age:** 21-36 years old **Diagnosis:** Mild, moderate or complex CHD and had surgery for various forms of CHD	Interviews	Interpretative phenomenological analysis	G
Authors: Overgaard, D., King, C., Christensen, R. F., Schrader, A. M., & Adamsen, L.	Living with half a heart--experiences of young adults with single ventricle physiology: a	**Design:** Descriptive design **Approach:** Qualitative approach	**Number:** 11 **Age:** 16-48 years old **Diagnosis:** Single ventricle physiology	Interviews	Phenomenological analysis	H

Year: 2013 **Country:** United States	qualitative study.					
Authors: du Plessis, K., Peters, R., King, I., Robertson, K., Mackley, J., Maree, R., Stanley, T., Pickford, L., Rose, B., Orchard, M., Stewart, H., & d'Udekem, Y. **Year:** 2018 **Country:** Netherlands	"How long will I continue to be normal?" Adults with a Fontan circulation's greatest concerns.	**Design:** Explorative design **Approach:** Qualitative approach	**Number:** 57 **Age:** 18-51 years old **Diagnosis:** Mild, moderate or complex CHD with a Fontan circulation	Questionnaires	Thematic analysis	I
Authors: Flocco, S. F., Caruso, R., Barello, S., Nania, T., Simeone, S., & Dellafiore, F. **Year:** 2020	Exploring the lived experiences of pregnancy and early motherhood in Italian women with congenital heart	**Design:** Descriptive design **Approach:** Qualitative approach	**Number:** 12 **Age:** 32-54 years old **Diagnosis:** Women with CHD during pregnancy and early motherhood	Interviews	Interpretative phenomenological analysis	J

Country: England	disease: an interpretative phenomenological analysis.					
Authors: Apers, S., Rassart, J., Luyckx, K., Oris, L., Goossens, E., Budts, W., Moons, P., & I-DETACH Investigators **Year:** 2016 **Country:** Sweden	Bringing Antonovsky's salutogenic theory to life: A qualitative inquiry into the experiences of young people with congenital heart disease.	**Design:** Explorative design **Approach:** Qualitative approach	**Number:** 12 **Age:** 18-21 years old **Diagnosis:** Mild, moderate or complex CHD	Interviews	Constant comparative method	K
Authors: Chiang, Y. T., Chen, C. W., Su, W. J., Wang, J. K., Lu, C. W., Li, Y. F., & Moons, P. **Year:** 2015 **Country:** England	Between invisible defects and visible impact: the life experiences of adolescents and young adults with congenital heart	**Design:** Descriptive design **Approach:** Qualitative approach	**Number:** 35 **Age:** 16-24 years old **Diagnosis:** Mild, moderate or complex CHD	Questionnaires	Phenomenological analysis	L

	disease.					

APPENDIX 2

Authors, year of publication and country	Title	Aim	Results
Authors: Asp, A., Bratt, E. L., & Bramhagen, A. C. **Year:** 2015 **Country:** United States	Transfer to Adult Care—Experiences of Young Adults with Congenital Heart Disease.	To explore the experiences of young adults with congenital heart disease in Sweden after transfer from the pediatric cardiac clinic to the adult congenital heart disease clinic.	**A1:** Feeling secure during the transfer process **A2:** Experiencing trust in the care **A3:** Expecting to be involved **A4:** Assuming responsibility for one's health is a process **A5:** Lack of knowledge leads to uncertainty
Authors: Catena, G., Rempel, G. R., Kovacs, A. H., Rankin, K. N., Muhll, I. V., & Mackie, A. S. **Year:** 2018 **Country:** England	"Not such a kid thing anymore": Young adults' perspectives on transfer from paediatric to adult cardiology care.	To assess perspectives on transfer in 18-25 year olds followed in paediatric versus ACHD clinics, taking advantage of a unique opportunity to study transition readiness in a setting where transition programming is in progress.	**B1:** Perspectives on paediatric settings and relationships **B2:** Perspectives on the parents' role **B3:** Perspectives on transfer

Authors: Sluman, M. A., de Man, S., Mulder, B. J., & Sluiter, J. K. **Year:** 2014 **Country:** Netherlands	Occupational challenges of young adult patients with congenital heart disease.	To gain insight into current barriers and facilitating experiences at work among young adult patients with CHD.	**C1:** Physical aspects (physical load of their work) **C2:** Lack of opportunity for recovery and processing capacity **C3:** Relationships with colleagues and employer
Authors: Moreland, P., & Santacroce, S. J. **Year:** 2018 **Country:** United States	Illness Uncertainty and Posttraumatic Stress in Young Adults With Congenital Heart Disease.	To explore how young adults with CHD appraise and experience uncertainty in the four domains described by Mishel and and to describe the relationship between posttraumatic stress symptoms and the appraisal and management process.	**D1:** Ambiguity (ambiguous, inconsistent symptoms) **D2:** Lack of information (lack of information regarding their CHD and its treatment) **D3:** Complexity of the Health Care System **D4:** Unpredictability (Unpredictability regarding the trajectory of their illness and whether they would ultimately succumb to CHD) **D5:** Appraisal and management of uncertainty
Authors: McKillop, A.,	Physical activity perceptions and	To understand perceptions of physical	**E1:** Importance of family

McCrindle, B. W., Dimitropoulos, G., & Kovacs, A. H. **Year:** 2018 **Country:** United States	behaviors among young adults with congenital heart disease: A mixed-methods study.	activity and exercise from childhood through emerging adulthood using individual semistructured qualitative interviews; and to explore psychosocial outcomes and identify potential factors for consideration in future work.	**E2:** Parental support-not overprotection **E3:** Adaptation for continued activity participation **E4:** Influence of school **E5:** Occupational activity **E6:** Activity for health
Authors: Berghammer, M. C., Brink, E., Rydberg, A. M., Dellborg, M., & Ekman, I. **Year:** 2015 **Country:** United States	Committed to Life: Adolescents' and Young Adults' Experiences of Living with Fontan Circulation.	To illuminate and gain a deeper understanding of adolescents' and young adults' experiences of living with a surgically palliated univentricular heart.	**F1:** Happiness over being me (Feeling proud and mature; Being humble and accepting other people; Feeling healthy and special; Feeling normal and the same as one's friends; Belief in oneself) **F2:** Focusing on possibilities (Dealing with physical restrictions; Mastering medical procedures; Trying to control the heart defect) **F3:** Being committed to life (Holding on to life and creating meaning; Living with uncertainty; Making the

			most out of life)
Authors: Cornett, L., & Simms, J. **Year:** 2014 **Country:** England	At the 'heart' of the matter: an exploration of the psychological impact of living with congenital heart disease in adulthood.	To gain a greater understanding of the lived experience of having CHD as an adult, in order to gain insight into the nature of the psychological and emotional distress endured, coping strategies employed and to establish what, if any, psychological support has been available and would be of benefit to them.	**G1:** A constant, limiting presence **G2:** The psychological experience **G3:** Impact on view of the self **G4:** Impact on relationships **G5:** Coping strategies **G6:** Help and support
Authors: Overgaard, D., King, C., Christensen, R. F., Schrader, A. M., & Adamsen, L. **Year:** 2013 **Country:** United States	Living with half a heart--experiences of young adults with single ventricle physiology: a qualitative study.	To investigate how young adults with an SVP diagnosis experience daily life and how they cope with the physical and emotional difficulties of the disease as they grow toward adulthood.	**H1:** Network support (The family network) **H2:** Coping with limitations **H3:** Life conditions
Authors: du Plessis, K., Peters, R., King, I., Robertson, K., Mackley, J., Maree, R., Stanley, T.,	"How long will I continue to be normal?" Adults with a Fontan circulation's greatest concerns.	To survey the greatest concerns of adults with a Fontan circulation and to use the results as a platform for developing further research agendas	**I1:** Physical concerns **I2:** Pregnancy and children **I3:** Quality of life **I4:** Fear of death/uncertainty around

Pickford, L., Rose, B., Orchard, M., Stewart, H., & d'Udekem, Y. **Year:** 2018 **Country:** Netherlands		which are closely aligned with patient needs, and informing clinical practice.	life expectancy
Authors: Flocco, S. F., Caruso, R., Barello, S., Nania, T., Simeone, S., & Dellafiore, F. **Year:** 2020 **Country:** England	Exploring the lived experiences of pregnancy and early motherhood in Italian women with congenital heart disease: an interpretative phenomenological analysis.	To explore the lived experiences of women with congenital heart disease (CHD) during pregnancy and early motherhood.	**J1:** Being a woman with CHD (Strength form disease; the difficulty of living with a heart disease) **J2:** Being a mother with CHD (Desire for maternity; victory; fears; relationship with children) **J3:** Don't be alone (Family support; social and association support; support from health personnel)
Authors: Apers, S., Rassart, J., Luyckx, K., Oris, L., Goossens, E., Budts, W., Moons, P., & I-DETACH Investigators	Bringing Antonovsky's salutogenic theory to life: A qualitative inquiry into the experiences of young people with congenital heart disease.	To gain a deeper insight into the experiences of patients with congenital heart disease (CHD) regarding resources and life events.	**K1:** Self-concept **K2:** Life environment **K3:** Daytime activities **K4:** Life events and disease-related turning points

Year: 2016 **Country:** Sweden			**K5:** Stress and coping **K6:** Illness integration
Authors: Chiang, Y. T., Chen, C. W., Su, W. J., Wang, J. K., Lu, C. W., Li, Y. F., & Moons, P. **Year:** 2015 **Country:** England	Between invisible defects and visible impact: the life experiences of adolescents and young adults with congenital heart disease.	To describe the life experiences of adolescents and young adults with congenital heart disease.	**L1:** Invisible defects: the existence of imperfect understanding **L2:** Conflict: interpersonal frustrations **L3:** Imbalance: the loss of self-balance **L4:** Suffering: increasing anxiety **L5:** Encounters: meeting needs **L6:** Coexistence: positive coping strategies

APPENDIX 3

Themes	Sub-themes	Results
Personal perceptions of physical and mental activity	①Subjective cognition of the disease	**A3:** Expecting to be involved **A4:** Assuming responsibility for one's health is a process **A5:** Lack of knowledge leads to uncertainty **D1:** Ambiguity (Ambiguous, inconsistent symptoms) **D2:** Lack of information (Lack of information regarding their CHD and its treatment) **D4:** Unpredictability (Unpredictability regarding the trajectory of their illness and whether they would ultimately succumb to CHD) **D5:** Appraisal and management of uncertainty **F1:** Happiness over being me (Feeling proud and mature; Being humble and accepting other people; Feeling healthy and special; Feeling normal and the same as one's friends; Belief in oneself) **G1:** A constant, limiting presence **G2:** The psychological experience **G3:** Impact on view of the self **I3:** Quality of life (Worries around deterioration in quality of life) **I4:** Fear of death/uncertainty around life expectancy **J1:** Being a woman with CHD (Strength form disease; the difficulty

		of living with a heart disease) **K6:** Illness integration (Outlook on life) **L3:** Imbalance: the loss of self-balance **L4:** Suffering: increasing anxiety **L1:** Invisible defects: the existence of imperfect understanding（Misperceptions of disease）
	②Effects of physical limitations	**C1:** Physical aspects (Physical load of their work) **I1:** Physical concerns **K4:** Life events and disease-related turning points（Physical problems） **K6:** Illness integration (Physical limitations)
	③Vision of the future	**E3:** Adaptation for continued activity participation **E6:** Activity for health **F2:** Focusing on possibilities (Dealing with physical restrictions; Mastering medical procedures; Trying to control the heart defect) **F3:** Being committed to life (Holding on to life and creating meaning; Living with uncertainty; Making the most out of life) **G5:** Coping strategies **H2:** Coping with limitations **H3:** Life conditions (Future goals and dreams)

		I2: Pregnancy and children **K1:** Self-concept (Identity and self-worth about future) **J2:** Being a mother with CHD (Desire for maternity; victory; fears; relationship with children) **L6:** Coexistence: positive coping strategies
Support from family	①Continued support from parents	**B2:** Perspectives on the parents' role **E2:** Parental support-not overprotection **G4:** Impact on relationships (Parents) **G6:** Help and support（From family） **H1:** Network support (The family network) **J3:** Don’t be alone (Family support) **K2:** Life environment（Parents） **K4:** Life events and disease-related turning points（Family problems） **K5:** Stress and coping (Stress from parents) **L2:** Conflict: interpersonal frustrations (Parents)
	②Support from other family members	**E1:** Importance of family **H1:** Network support (The family network) **J3:** Don’t be alone (Family support) **K2:** Life environment（Partner/in-laws）

		L2: Conflict: interpersonal frustrations (Other family members)
Experience of social life	①Accesses to health services	**A1:** Feeling secure during the transfer process **A2:** Experiencing trust in the care **B1:** Perspectives on paediatric settings and relationships **B3:** Perspectives on transfer **D3:** Complexity of the Health Care System **J3:** Don't be alone (Support from health personnel) **K5:** Stress and coping (Seek professional support) **G6:** Help and support（Professional support） **L5:** Encounters: meeting needs（healthcare needs）
	②School or professional life	**C2:** Lack of opportunity for recovery and processing capacity **C3:** Relationships with colleagues and employer **E4:** Influence of school **E5:** Occupational activity **G4:** Impact on relationships (Friends) **K2:** Life environment（Peer contacts） **K3:** Daytime activities（Study, work, and leisure activities） **K4:** Life events and disease-related turning points（School problems） **K5:** Stress and coping (Stress from school)

		L2: Conflict: interpersonal frustrations (Friends and classmates)
	③Interactions with other social personnel	**J3:** Don't be alone (Social and association support) **G6:** Help and support（From counselling） **I3:** Quality of life (Accessing psychological services/other support) **K5:** Stress and coping (Seek emotional social support) **L5:** Encounters: meeting needs（Social welfare policies）